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END-OF-LIFE DECISIONS: STUDIES OF ATTITUDES AND REASONING

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**Karolinska
Institutet**

Stockholm 2013

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ISBN 978-91-7549-182-0

In memory of Staffan Billermark

ABSTRACT

The overall aim of this thesis is to study attitudes towards and reasoning for and against end-of-life decisions among physicians and the general public in Sweden. The end-of-life decisions in focus are refraining from life-sustaining treatment, continuous deep sedation (CDS), physician-assisted suicide (PAS) and euthanasia. The thesis consists of four studies:

STUDY I: A questionnaire with the aim to study attitudes and reasoning towards PAS. **Sample** 1,206 individuals in the general public. **Results** Response rate 51%. Of these, 73%, replied in favour of PAS, 12% against and 15% were undecided. A majority believed that their trust in the medical services would either increase or not be influenced at all if PAS were to be allowed. **Conclusion** No evidence was found for the assumption that trust in the medical services would be jeopardised if physician-assisted suicide were to be legalised.

STUDY II: A vignette-based questionnaire with the aim to study attitudes and reasoning towards the withdrawal of life-sustaining treatment on a competent patient's request. **Sample** 1,200 physicians and 1,202 individuals in the general public. **Results** Response rate 57% (physicians) and 48% (general public). A majority in both groups prioritised arguments in favour of terminating life-sustaining treatment on a patient's request and classified the act as defensible in all vignettes. **Conclusion** There seems to be a widespread consensus regarding competent patients' right to refrain from life-sustaining treatment.

STUDY III: A vignette-based questionnaire with the aim to investigate attitudes towards PAS and euthanasia, and to explore whether CDS is considered an acceptable course of action. **Sample** 1,200 physicians and 1,201 individuals in the general public. **Results** Response rate 56% (physicians) and 52% (general public). Among physicians, 22% favoured granting a request for PAS expressed by a non-terminally ill patient with Huntington's disease; 21% accepted CDS as an alternative. Among the general public, 59% declared themselves in favour of PAS; 60% accepted CDS as an alternative. **Conclusion** A significant proportion of Swedish physicians and the general public seem to be more liberal in their views on CDS than current guidelines permit.

STUDY IV: A moral philosophical investigation of Daniel Sulmasy's 'reinvented' version of the rule of double effect, the aim being to determine the moral relevance of the intention/foresight distinction and this distinction's alleged implication for the moral difference between CDS and euthanasia. **Conclusion** The reinvented rule of double effect is an improvement compared to the traditional version, but it will not stand closer scrutiny. The range of proper applicability has narrowed significantly and, more importantly, Sulmasy fails to establish that there is a morally relevant distinction between intended and foreseen effects.

LIST OF PUBLICATIONS

- I. Lindblad A., Löfmark R., Lynöe N. (2009). Would physician-assisted suicide jeopardize trust in the medical services? An empirical study of attitudes among the general public in Sweden. *Scandinavian Journal of Public Health*, 37:260-264.
- II. Lindblad A., Juth N., Fürst CJ., Lynöe N. (2010). When enough is enough; terminating life-sustaining treatment at the patient's request: a survey of attitudes among Swedish physicians and the general public. *Journal of Medical Ethics*, 36:284-289.
- III. Lindblad A., Juth N., Fürst CJ., Lynöe N. (2010). Continuous deep sedation, physician-assisted suicide and euthanasia in Huntington's disorder: A study of attitudes among physicians and the general public in Sweden. *International Journal of Palliative Nursing*, 16: 527-533.
- IV. Lindblad A., Lynöe N., Juth N. (2012). End-of -life decisions and the reinvented rule of double effect: A critical analysis. *Bioethics*, 2012 Oct 1, doi: 10.1111/bioe.12001.

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LIST OF ABBREVIATIONS

| | |
|------|----------------------------------|
| CDS | Continuous deep sedation |
| HD | Huntington's disease |
| PAS | Physician-assisted suicide |
| RDE | Rule of double effect |
| RRDE | Reinvented rule of double effect |
| WHO | World Health Organization |

1 INTRODUCTION

1.1 BACKGROUND

It is almost always better to be alive than to be dead, a friend of mine once said. He was suffering from cancer and died – far too young – in September 2007. During my work on this thesis I have often come to think of those words. The continuous interest aroused by end-of-life decisions in Swedish public debate, as well as the international trend towards more permissive practices regarding physician-assisted suicide and euthanasia, indicate that many consider the word “almost” to be of the utmost importance. Or, putting it differently, there seem to be situations at the end of life where some people prefer death. At present, euthanasia and physician-assisted suicide are legally practised in the Netherlands, Belgium and Luxemburg, and physician-assisted suicide in Switzerland, Oregon, Washington and Montana (Lövrup 2009).

Historically, suicide and mercy killing have been taboo in western societies for centuries. Since its early days, the Christian Church has condemned all forms of killing and a person who committed suicide could never be given a Christian burial. In many countries, Sweden included, killing oneself was a criminal offence. Suicide was decriminalised in Sweden in 1864 (Blomquist 1964; Dowbiggin 2007; Oden 2005; Cholbi 2012).

Today, neither physician-assisted suicide nor euthanasia is allowed in Sweden, but there have been several reports of patients travelling to Switzerland in order to commit physician-assisted suicide (Haverdahl 2005; Karén 2006; Dignitas 2012). Furthermore, there seems to be an ongoing shift in attitudes. For instance, in recently published recommendations, the National Board of Health and Welfare has abandoned its earlier position and has now clearly established a competent patient’s right to refrain from life-sustaining treatment even if palliative treatment if such is needed (Blom 2006; Socialstyrelsen 2010; Socialstyrelsen 2011). This is an important shift, since there has been at least one case where a patient denied help in withdrawing respirator treatment has travelled to Switzerland to commit physician-assisted suicide instead (Haverdahl 2010).

Despite an ongoing debate about end-of-life decisions in Sweden, little empirical research had been performed before the inception of this thesis (Nilstun and Löfmark 2004). The studies that did exist were often beset with vague definitions and a failure to distinguish between physician-assisted suicide and euthanasia. Furthermore, empirical claims such as “people would feel pressured to ask for euthanasia” or “euthanasia would affect people’s trust in the medical services” had not been tested. All in all, this lack of knowledge regarding Swedish conditions became the point of departure for the whole project.

The aim of the project is to contribute to the ethical debate by studying attitudes and arguments concerning end-of-life decisions among physicians and the general public in Sweden. In this context, end-of-life decisions means questions about refraining from life-sustaining treatment, palliative sedation, physician-assisted suicide and euthanasia. The terminology will be further introduced below. The following important proviso should be kept in mind throughout this text: the fact that some of the most important arguments in the debate are analysed and, to some extent a stand taken on them, does

not mean that a final standpoint will be reached on all these issues. This is but a contribution to an ongoing discussion.

1.2 WHAT IS MEDICAL ETHICS?

Since medical ethics is a multidisciplinary field typically attracting people from different backgrounds, a few words of introduction may be appropriate. Briefly, medical ethics may be described as the “critical, analytical, historical and empirical study of ethical and moral aspects of healthcare” (Lynøe and Juth 2009a:234). Basically, ethics is about judgments concerning what is right and wrong, good and bad and the reasons underlying these judgments. In *normative ethics*, questions about acts, virtues and values are investigated, or more specifically, what (if anything) makes an act right or wrong, what makes a person morally admirable or blameworthy and what (if anything) is good (Lynøe and Juth 2009a:268-269). *Descriptive ethics* on the other hand is the study of people’s actual moral conducts, attitudes and beliefs (Lynøe and Juth 2009a: 268; Beauchamp and Childress 2001:2).¹ Medical ethics is a form of *applied ethics*, and as such may include normative as well as descriptive studies. Much medical ethics is about identifying and investigating moral conflicts in the field of clinical medicine and medical research. This sometimes involves empirical investigations, whereas deciding which side of the conflict has the strongest arguments sometimes involves normative studies. Accordingly, medical ethics harbours both kinds of studies, as does this thesis.

In order to conduct studies in medical ethics, not only moral theories but relevant facts are needed; through the reciprocity between the factual situation and the moral theories a normative conclusion regarding what to do – and why – may be argued (Tännsjö 2008:4-7). As in all philosophy, medical ethicists should strive to be argumentative, precise and open to criticism (Hansson 1998:48). Hence, the core of the philosophical discussion is constituted by the critical analysis of arguments. Arguments may be purely normative, but they may also involve factual claims. In the ethical debate concerning end-of-life decision-making, both kinds appear. Normative arguments, such as “Euthanasia is wrong since the intention of the act is to kill the patient, and intentionally killing humans is wrong” may be investigated through philosophical analysis of the premises of the argument. The discussion presented in Study IV exemplifies this. Arguments containing empirical claims, such as “If euthanasia is allowed, people’s trust in the medical services will decline” may be empirically tested, which is also one of the reasons why empirical research may be useful for the ethical discussion.

Finally, the structure of philosophical texts is worth commenting on. In empirical science, e.g. medicine, we are used to texts being divided into introduction/background, method, results, discussion and conclusion. Results are often presented in tables and figures. A philosophical text, however, is somewhat different. Here the discussion, i.e. the analysis of arguments, constitutes the core result. The reader of this compilation thesis will soon enough become aware of the difference, since Studies I-III are based on empirical data and study IV is a purely philosophical investigation.

¹ In this thesis the terms ‘descriptive ethics’ and ‘empirical ethics’ will be used synonymously.

1.3 TERMINOLOGY

In discussions about end-of-life decision-making, it is important to define the terms involved, since the same term may be used to describe different practices, thus causing confusion. As there are no unanimously accepted definitions to hold onto, those presented here are stipulated for the purpose of clarity throughout the thesis. When other definitions are used, this will be explicitly stated.

The terms are presented in alphabetical order:

1.3.1 Euthanasia

Euthanasia is defined as the administration of drugs with the intention of ending life at the explicit and voluntary request of a patient.²

1.3.2 Palliative care

According to the World Health Organization (WHO), palliative care is:

“[...] an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
(Sepúlveda et al 2002:94; WHO)

This is a widely accepted definition and will therefore be adopted here, with two exceptions. First, palliative measures may not always succeed. According to the WHO definition, they are not palliative at all, since the definition says that it is an approach that actually improves quality of life that is palliative. However, it must be conceptually possible to administer palliative measures that fail. Second, it seems to be too strict a condition to say that an intervention is not palliative unless it is subject to ‘impeccable’ assessment. So, a less persuasive definition would be: Palliative care is “an approach that *intends to* improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” This is what is meant by palliative care throughout this text, unless explicitly stated otherwise.

1.3.3 Palliative sedation

In palliative care at the end of life, sedation therapy is sometimes used in order to control suffering that cannot otherwise be treated. Although frequently applied, there has been no consensus regarding indications or even naming of the procedure.³

² This definition is in line with the one used in the Netherlands, which is the country with the longest history of legal practice of euthanasia. According to the Dutch definition, which has been in use since 1985, euthanasia means: “Intentionally taking the life of another person on his or her explicit request” (Rietjens et al 2009; Thomasma et al 1998:3) The Dutch criteria of due care euthanasia state that: “1. The patient’s request is voluntary and well-considered; 2. The patient’s suffering is unbearable and hopeless; 3. The patient is informed about his situation and prospects; 4. There are no reasonable alternatives. Further, 5. Another independent physician should be consulted; and 6. The termination of life should be performed with due medical care and attention.” (Rietjens et al 2009:273-274)

Here, palliative sedation will be regarded as “[t]he monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness)” (Cherny and Radbruch 2009:581).⁴

Palliative sedation may be described and classified in terms of *level of sedation* and *duration*. The *level of sedation* can be mild, intermediate or deep. In mild sedation, consciousness is lowered but the patient is still awake and can communicate. In intermediate sedation the patient is asleep but can be woken and may communicate briefly. In deep sedation consciousness is lost and the patient is unable to communicate (de Graeff and Dean 2007; Morita et al 2001; Morita et al 2002). The *duration of sedation* can be either intermittent (the patient will be woken for intermittent periods of alertness) or continuous (the patient is sedated until death occurs) (de Graeff and Dean 2007; Morita et al 2001; Morita et al 2002).

Depending on type of sedation used, e.g. mild intermittent sedation or deep continuous sedation, different ethical problems arise (Cherny and Radbruch 2009). However, continuous deep sedation, i.e. when the patient is sedated to a point where consciousness is lost and where there is no intent to discontinue sedation, is the ethically most controversial type. The practice has even been called “slow euthanasia” since it causes the patient’s social death (Billings and Bloch 1996; Cherny and Radbruch 2009; Materstvedt 2012). Furthermore, continuous deep sedation is often combined with refraining from nutrition and hydration. The sedation in itself is not supposed to hasten death, but refraining from nutrition/hydration might, if occurring before the patient is imminently dying (Miccinesi et al 2006). Due to its controversial nature, it is this type of sedation therapy that will be in focus for the thesis.

1.3.4 Physician-assisted suicide

Physician-assisted suicide is defined as the administration, supply or prescription of drugs with the explicit intention of enabling the patient to end his or her life, on that patient’s explicit and voluntary request (Rietjens et al 2009).

1.3.5 Suffering

Here, suffering is understood as a mental state that is negative for the individual experiencing it.⁵

³ In one literature review, as many as nine different terms were found: sedation, terminal sedation, sedation for intractable distress in the imminently dying, end-of-life sedation, total sedation, sedation in the terminal or final stages of life, controlled sedation, palliative sedation and palliative sedation therapy (de Graeff and Dean 2007). Here the term palliative sedation has been chosen since it is descriptive without being persuasive, and furthermore, because of its widespread use.

⁴ This definition is in line with the one stipulated by the European Association of Palliative Care (EAPC). However, the EAPC also adds the following: “[...] in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers” (Cherny and Radbruch 2009:581). This part has deliberately been left out here, since it builds in a proviso for when palliative sedation is justifiable and when it is not.

⁵ The focus here is on human suffering, which may be divided into at least two different types: 1) Taking a negative attitude to one’s life or current situation and 2) a subjective experience of discomfort or distress, for example due to physical sensations, emotions or moods (Brülde 2007:41-43; Lynøe and Juth 2009a:217-218).

1.3.6 Treatment-refractory suffering

Treatment-refractory suffering is suffering due to symptoms “[...] for which all possible treatment has failed, or it is estimated that no methods are available for palliation within the time frame and risk-benefit ratio that the patient can tolerate” (de Graeff and Dean 2007:68-69). Reasonably, it is a physician’s role to determine which treatment options there are left, and the patient’s what he/she can tolerate.

1.3.7 Withholding and withdrawing life-sustaining treatment

To withhold life-sustaining treatment means that a specific potentially life-saving medical treatment is not initialised at all, as, for example, when refraining from cardiopulmonary resuscitation in a case of cardiac arrest.

Withdrawal of life-sustaining treatment means that an ongoing life-saving treatment is stopped, for example dialysis or ventilator treatment.⁶

1.4 END-OF-LIFE LAW

In order to investigate a moral question, one must describe its context. When it comes to end-of-life decisions, the legal situation is an important part of the context, since it tends to influence not only practices but also people’s views. The aim of this chapter is to offer an overview of the legal status of different end-of-life decisions in Sweden, followed by a brief look at the international situation regarding laws regulating euthanasia and physician-assisted suicide.

1.4.1 Sweden

1.4.1.1 *Withholding/withdrawing life-sustaining treatment*

The Swedish Health and Medical Services Act lays down that all healthcare should be founded on respect for patient autonomy and personal integrity (SFS 1982:763). The National Board of Health and Welfare has recently made clear that the right to refrain from life-sustaining treatment applies to *all* competent patients, i.e. not only at the end of life, a right considered to be an implication of respecting patient autonomy. Furthermore, palliative care should be given if needed. If the patient is incompetent and continued life-sustaining treatment is considered contrary to evidenced-based medicine and good clinical practice,⁷ the physician treating the patient may decide to withdraw treatment (SOSFS 2011:7 (M); Socialstyrelsen 2011).

1.4.1.2 *Palliative sedation*

In a Swedish context, palliative sedation is considered an intervention to be used at the end of life when no other acceptable treatment options remain (Läkemedelsverket 2010; Socialstyrelsen 2011). In the guidelines on life-sustaining treatment, the National Board of Health and Welfare states that palliative sedation may be continuous or

⁶ Typically, life-sustaining treatments are withheld or withdrawn since they are considered medically futile, i.e. not to the benefit of the patient, or on the patient’s request.

⁷ For the Swedish-speaking reader it might be worth noting that the original expression used in the recommendations is “beprövad erfarenhet”. This expression lacks an English equivalent; here, it has been translated into the somewhat wider “good clinical practice”.

intermittent, and that the degree of sedation may be varied according to the patient's needs. Furthermore, the doses of sedatives and/or analgesics may be increased in order to achieve relief of suffering, even if this could possibly have the effect of hastening death. However, the intention of the treatment should be symptom relief (Socialstyrelsen 2011).

1.4.1.3 Physician-assisted suicide

Suicide is not a crime in Sweden, nor is assisting a person to commit suicide. However, a physician doing so would risk losing his/her licence to practise. Physician-assisted suicide is a matter of health law and does not come under the Penal Code (Nilstun 1996; Aspelin 2005; Förde et al 2008).

1.4.1.4 Euthanasia

Unlike the penal codes of some other Scandinavian countries, Sweden's does not contain any special section about killing on request. Therefore, euthanasia would probably be considered as either manslaughter or murder, though in the presence of extenuating circumstances a milder sentence may be allowed, or charges may even be dropped (Materstvedt and Kaasa 2002; Förde et al 2008).

1.4.2 International outlook

While work on this thesis has been in progress, the number of countries and states around the world where physician-assisted suicide and/or euthanasia is legally allowed has increased. Today, both practices are allowed in the Netherlands, Belgium and Luxemburg, whereas physician-assisted suicide is allowed in Switzerland and in the US states of Oregon, Montana and Washington (Lövtrup 2009). Furthermore, legalisation of euthanasia and/or physician-assisted suicide is being discussed in other places, e.g. the UK, France and several US states, to mention but a few (Morris 2012; BBC; Sumner 2012:328-337).

The Netherlands is the country with the longest history of legal euthanasia practice. Here, public discussions regarding euthanasia began already in the 1970s, and intensified during the 1980s. In 1985, a State Commission presented a report where euthanasia was defined as “intentionally terminating another person's life at the person's request”; a definition that is still in use. Also, the Royal Dutch Medical Association took an official position in favour of societal control of euthanasia. However, only a few physicians reported their euthanasia cases, and in the 1990s a formalised notification procedure was established in order to increase the number of reports. Furthermore, physicians who had followed the criteria for due care would not be prosecuted. A few years later, a shift in the governing coalition made possible the legalisation of euthanasia and physician-assisted suicide. The Euthanasia Act, which regulates euthanasia performed by a physician, came into force in 2002 (Legemaate 1998:19-31; Griffiths et al 2008:29-50; Rietjens et al 2009). Soon thereafter, Belgium adopted a similar law,⁸ followed by Luxemburg a few years later (Griffiths et al 2008: 275-294; Lövtrup 2009). At present, euthanasia accounts for approximately 2.8% of all

⁸ It should be noted that the Belgian law does not expressly apply to physician-assisted suicide. However, as long as the provisions of the Law on Euthanasia are followed, physician-assisted suicide and euthanasia have been regarded as equivalent by the Belgian Order of Physicians as well as by the

deaths in the Netherlands, and assisted suicide for 0.1% (Onwuteaka-Philipsen et al 2012).

In some parts of the world, physician-assisted suicide is allowed whereas euthanasia is forbidden. This can be instanced with Switzerland and Oregon, where physician-assisted suicide has been practised openly for a number of years.

Under Swiss legalisation, assisted suicide is only punishable if performed out of self-interest and this applies to any person, i.e. not only physicians. The development of an open practice has been promoted since the 1980s by right-to-die organisations such as EXIT. The Swiss model for physician-assisted suicide includes the involvement of a physician at some stage in the decision-making process,⁹ but is not limited to physicians (Hurst and Mauron 2003). A majority of all cases of physician-assisted suicide in Switzerland are performed by right-to die societies, which nowadays are also allowed to work in nursing homes and hospitals. Approximately 0.3-0.4% of all Swiss deaths are assisted deaths (Griffiths et al 2008:470-481).

In Oregon on the other hand, there is no room for lay people to be involved in the practice of physician-assisted suicide. The Death with Dignity Act allows a terminally ill patient to end his/her life "[...]through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose" (Oregon Health Authority).¹⁰ Since the enactment of the law in 1997, the number of prescriptions as well as completed assisted suicides has increased. In 2012, 115 prescriptions were issued and 77 assisted deaths were reported (Oregon Public Health Division 2013).

1.5 PREVIOUS RESEARCH

In recent years, numerous studies of end-of-life decisions have been conducted throughout the world. However, results are often difficult to compare, since not only do methods differ, but measures are defined in different ways. In this section an attempt is made to present an overview of some of the previous research on attitudes towards end-of-life decisions conducted in Sweden, as well as comparisons to the international situation. Furthermore, a brief conspectus will be offered of current practices. Since literature searches have generated a great many results, the data presented here are far from representing the full picture.¹¹ The studies referred to have been included because of their publication date (mainly the last ten years) and methodology (e.g. use of clear terminology, quantitative studies with large samples, reviews on previous

Federal Control and Evaluation Commission which reviews and evaluates the practice of euthanasia in Belgium (Griffiths et al 2008:310-311).

⁹ A physician must at least be involved in the prescription of sodium pentobarbital, which is the drug used for assisted suicide. However, Swiss courts have held that it is a prerequisite for the prescription of a lethal drug to be used in assisted suicide that a) the patient's competence is assessed, and b) the patient is suffering from a condition that will lead to death (Griffiths et al 2008:470-481)

¹⁰ The following criteria must be fulfilled in order for physician-assisted suicide to be carried out in Oregon: "The patient must make a voluntary, informed and well-considered request. The patient must be facing unbearable and hopeless suffering, either currently or in the immediate future and with no outlook for improvement. The physician must agree with the patient that no reasonable alternative treatment that might reduce the suffering is available. The physician must consult with another, independent physician. The action must be performed with due care. The action must be reported to the appropriate authorities." (Battin et al 2007:593)

¹¹ Searches have mainly been conducted using the PubMed and Scopus data bases, and to some extent Web of Science.

research). Where possible, multinational studies have been preferred, since the use of a similar methodology allows for a fairer comparison of results. However, since there are only a limited number of Swedish studies, some of these have been added even though not all of the above criteria are fulfilled.

Generally speaking, end-of-life decisions precede many deaths, at least in western European countries.¹² According to studies conducted by the EURELD consortium,¹³ there is a widespread acceptance among physicians of refraining from life-sustaining treatment at a patient's request, and also of the alleviation of symptoms with the foreseen effect of hastening death (Miccinesi et al 2005). Unsurprisingly, non-treatment decisions and symptom alleviation with possible hastening of death also constitute the most common types of end-of-life decisions in the countries investigated (van der Heide et al 2003). However, physicians in all of the participating countries reported having administered medication with the explicit intention of hastening death, with incidences varying from 1% or less of all deaths in Sweden, Italy, Denmark and Switzerland to 1.82% in Belgium and 3.40% in The Netherlands (van der Heide et al 2003; Bosshard et al 2005).

1.5.1 Continuous deep sedation

In palliative care, palliative sedation is sometimes used as a means of alleviating suffering that cannot be otherwise treated. Continuous deep sedation is a type of palliative sedation that involves sedation to a point where consciousness is lost and where there is no intention of discontinuing sedation before death occurs. Previous studies have shown that the incidence of continuous deep sedation varies between different countries, ranging between about 15% of all deaths in Flanders, Belgium, 12% in the Netherlands, to a mere 3% or so in Sweden and Denmark (Miccinesi et al 2006; Chambaere et al 2010; Anquinet et al 2012; Onwuteaka-Philipsen et al 2012). A cross-sectional Swedish study indicates that continuous deep sedation may be even rarer than that; out of approximately 2000 patients treated in palliative care settings, 22 (1%) had an ongoing sedating treatment and only one patient was deeply and continuously sedated (Eckerdal et al 2009).

Not only practices, but also physicians' attitudes towards continuous deep sedation, vary between different countries. In countries with a higher incidence of continuous deep sedation, attitudes are more approbatory than in countries with a lower incidence. Accordingly, 83% of the physicians surveyed in Belgium declared themselves willing to provide continuous deep sedation at the request of a terminally ill competent patient with a life expectancy of no more than 2 weeks, compared to 52% in Denmark and 55% in Sweden. In the same scenario, but with a life expectancy of at least 3 months, those willing to provide continuous deep sedation dropped to 22% in Denmark, followed by 34% in Sweden, ranging to 52% in Belgium (Onwuteaka-Philipsen et al 2006). All in all, it seems that physicians in Sweden have more restrictive views on continuous deep sedation than colleagues in other countries, and that these views are reflected in the lower incidence of treatment. However, research on the reasons for these differences in physicians' attitudes between countries is lacking.

¹² End-of-life decisions have been reported to precede deaths in a range from 23% in Italy to 51% in Belgium (van der Heide et al 2003).

¹³ EURELD=European End-of-Life Decisions. A European collaborative research project.

1.5.2 Physician-assisted suicide

1.5.2.1 Sweden

Although physician-assisted suicide is not a criminal offence in Sweden, it is still considered a controversial action ethically, and the legal consequences for a physician conducting physician-assisted suicide are not known, since no such cases have come to court in recent years. The legal situation is likely to be reflected in people's attitudes. However, at the starting point of this thesis there was no research available on current attitudes towards physician-assisted suicide in Sweden, since all previous studies had failed to distinguish between physician-assisted suicide and euthanasia.

It was not until 2007 that the Swedish Society of Medicine commissioned a survey on physicians' attitudes towards physician-assisted suicide. The study included 1,200 physicians and was based on a questionnaire containing three different parts: first, a main question about attitude towards physician-assisted suicide, thereafter a list of arguments for/against which participants were asked to prioritise and finally, questions about the possible influence on trust in the healthcare system would physician-assisted suicide be allowed. In short, 34 % of the respondents were in favour of physician-assisted suicide, 39% against and 25% doubtful. Also, older physicians (>50 years) were more in favour than younger ones, and psychiatrists were more in favour than oncologists (Lindblad et al 2008). Shortly thereafter, a similar questionnaire was used to explore the general public's attitudes. This study has been included in the thesis; see Study I.

Both physicians and the general public were given the opportunity to make comments in connection with each question in the questionnaires. These were then investigated further through content analysis in order to find out more about the underlying moral reasoning. Briefly, this analysis confirmed the quantitative results in terms of physicians being more restrictive in their views concerning physician-assisted suicide than the general public. Furthermore, proponents and opponents in both groups seemed to agree on the importance of several conditions being fulfilled for physician-assisted suicide to be justifiable. However, physicians appeared more prone to believe that these conditions cannot be met in practice and that physician-assisted suicide would jeopardise the public's trust in the healthcare system (Helgesson et al 2009).

The studies on physicians and the general public's views were also extended to include veterinary surgeons (Lerner et al 2011). There are many similarities between veterinary surgeons and physicians, even if the type of patient differs. For example, the basic education for both professions includes physiology, pharmacology and pathology, and there is a common goal of preventing disease, promoting health and providing necessary treatment for patients. When no treatment options remain, suffering should be alleviated. However, here practices differ: physicians may provide advanced palliative care, whereas veterinary surgeons usually put animals to death in such situations (Lerner et al 2011).

There is practically no research on veterinary surgeons' attitudes towards physician-assisted suicide or (human) euthanasia to be found in databases like Scopus or PubMed. In the Swedish study, veterinary surgeons' attitudes towards physician-assisted suicide were explored using a questionnaire similar to the ones used in the previous studies on physicians' and the general public's attitudes. It was delivered by email to 2,421 members of the Swedish Veterinary Association, with a response rate of 47%. Briefly, a majority of the veterinary surgeons declared approbatory views of physician-assisted

suicide: 75 % stated in favour of physician-assisted suicide, 10% against, and 15% were doubtful. These results tally with those from the general public, where 73% declared themselves in favour, 12% against and 15% were doubtful (see Key results, Study I). Thus the response patterns of both veterinary surgeons and the general public differed significantly from that of the physicians surveyed previously (Lerner et al 2011). However, the data do not provide any explanations as to wherein these differences in attitudes lie; in order to understand this, further research is needed.

1.5.2.2 International comparisons

There are numerous studies on attitudes towards end-of-life decisions, but the majority fail to distinguish between physician-assisted suicide and euthanasia. In particular, there is a lack of larger, multinational studies. However, there are one or two exceptions. For example, a review of the American public's attitudes led to the conclusion that in the studies investigated approximately 1/3 of the population seems to be against physician-assisted suicide, whereas the proportion in favour varies (Emanuel 2002). In Europe, a Finnish study revealed that 49% of the participants from the general public accepted physician-assisted suicide in the case of a patient with incurable cancer (Ryynänen et al 2002). Also, data from Britain suggest that the public's attitudes have grown more supportive (O'Neill et al 2003). Nevertheless, the obvious lack of studies focusing on the public's attitudes towards physician-assisted suicide exclusively calls for further research to be conducted.

A similar situation prevails when it comes to studies on physicians' opinions. According to a relatively recent review, physicians' attitudes towards physician-assisted suicide were discussed in 22 different articles. All in all, the studies differed in a number of ways, thus making it hard to compare the results. In short, attitudes varied between countries. For example, among general practitioners in Germany, 80% declared approbatory views towards physician-assisted suicide, whereas 73% of Irish general practitioners found it unacceptable. A minority of the physicians studied were willing to perform physician-assisted suicide (McGlade et al 2000; Maitra et al 2005; Gielen et al 2008). Restrictive attitudes towards the acceptability of physician-assisted suicide (ethically and/or legally) were also found in a recent review of British studies of physicians' attitudes (McCormack et al 2012).

Unfortunately, the EURELD studies do not clearly distinguish physician-assisted suicide from euthanasia, and no other larger European study investigating this has yet been conducted (Miccinesi et al 2005). A reasonable hypothesis is that physicians' attitudes are more approbatory in countries where physician-assisted suicide is allowed, but this remains to be confirmed by future research.

1.5.3 Euthanasia

1.5.3.1 Sweden

Previous research on attitudes towards euthanasia in Sweden is rare and existing results difficult to interpret, due to the use of unclear terminology. For example, the public's attitudes towards active euthanasia were briefly surveyed in an opinion poll in 2001. 68% of the 1,000 participants opined that active euthanasia should be allowed if a person requests it (Sifos telefonbuss 2001). However, the concept of "active euthanasia" was not further specified, thus leaving it open to interpretation. The same

problem troubles a study of physicians' attitudes from 1996, where 39 % of the respondents declared that active euthanasia can sometimes be justifiable, whereas 47% declared that it cannot. Furthermore, legalisation of active euthanasia was favoured by 25% and opposed by 51% of the respondents (Nilstun et al 1996; Materstvedt and Kaasa 2002).

A few years later, a questionnaire study explored Swedish physicians' experiences of themes and desires expressed by patients at the end of life and the physicians' actions in response to these conversations. Here, one-third of the responding physicians had given drugs in such doses that the patient's death might have been hastened, one-third had been asked to perform euthanasia and 10% had been asked to perform assisted suicide. None of the participants reported ever having performed euthanasia, but a few cases of assisted suicide were mentioned (Valverius et al 2000). Similarly, restrictive attitudes towards the deliberate hastening of death were reported by Swedish physicians participating in a large European study in 2003. The study, which was published in 2008, indicated that 24 % of the Swedish participants had at some time been asked by a patient to administer, supply or prescribe drugs hastening death. A majority, 84%, declared that they would never accede to such a request (Löfmark et al 2008). However, in this study physician-assisted suicide was not distinguished from euthanasia, again making the results difficult to interpret.

Later studies have used clearer definitions, one such example being a qualitative study, published in 2007, of medical students' attitudes towards euthanasia. Here a definition of the term "euthanasia" was provided. One-third of the respondents declared in favour of legalising euthanasia, half were against and the rest undecided. The authors discussed that the results may not be generalisable for the entire student population, but still have some bearing (Karlsson et al 2007).

The same researchers have also published another qualitative study focusing on terminal cancer patients' views on suffering as justification for euthanasia. None of the 66 participants requested euthanasia at the time of the study, but 29% were in favour of it, 20% against and the rest undecided. Those reasoning that suffering can justify euthanasia used arguments involving the meaningless of suffering, fear of future suffering and distrust regarding the provision of help. Those arguing that suffering cannot justify euthanasia employed a variety of arguments, such as life always having or containing meaning, trust in adaptation to the illness and trust in the provision of help (Karlsson et al 2012). Although providing some in-depth information on an interesting subject, the study is too small for its results to be generalised.

In short, previous research has shown that Swedish physicians hold restrictive views concerning euthanasia. These views are reflected in their declared practices; according to data from one of the EURELD studies, none of the participating physicians reported having ever performed euthanasia or physician-assisted suicide (Cohen et al 2007). The public, on the other hand, seems to hold more permissive views, but there is a lack of major studies using clear terminology to confirm this.

1.5.3.2 International comparisons

Attitudes towards euthanasia among the general public in West European countries as well as in the United States have changed in a more approbatory direction during recent decades (Emanuel 2002; Cohen et al 2006a; Cohen et al 2006b). A large study based on

data from 1999-2000 explored attitudes towards euthanasia among the general public in 33 European countries.¹⁴ Acceptance of euthanasia was highest in the Netherlands, Denmark, France and Sweden, and lowest in Romania, Malta and Turkey. The most important factor associated with an approbatory attitude was weak religious beliefs. However, socioeconomic factors and moral beliefs were also discussed as possible explanations for the differences between countries (Cohen et al 2006a).

The Netherlands is the first country in the world to have legalised euthanasia, a process preceded by decades of debate. Hence, it should not come as a surprise that people's attitudes towards euthanasia have been more investigated here than in other countries. In the first poll, conducted in 1950, 54% of the participants declared against euthanasia.¹⁵ Between 1966 and 2004, the Social and Cultural Planning Bureau conducted public surveys asking "Should a doctor give a lethal injection at the request of a patient to put an end to his suffering?" Here, the proportion answering "No" fell from 49% in 1966 to 12% in 1975, and has steadied at about 9% since 1991 (van der Maas et al 1995; Griffiths et al 2008:25). The proportion answering "Yes" has varied between 50-58% since 1975. It has been speculated why the change in opinion occurred between 1966 and 1975. Possibly, it has been argued, the change is related to the shift in public attitudes towards a more liberal view on morality, sex, religion and individual responsibility that occurred during the same period. Also, the first case of euthanasia was tried in a Dutch court in 1973, which started a public debate and resulted in a legal opening for euthanasia.¹⁶

Several studies have indicated that many physicians distinguish between physician-assisted suicide and euthanasia (Emanuel 2002; Gielen et al 2008). In general, physicians' attitudes towards euthanasia are more restrictive, but they vary significantly between countries (Clark et al 2001; Materstvedt and Kaasa 2002; Miccinesi et al 2005). Unsurprisingly, the most approbatory views have been reported in Belgium and the Netherlands, where euthanasia has been practised openly for many years. Here, more than 75% of the physicians surveyed declared themselves in favour of euthanasia. The most restrictive attitudes were declared by physicians in Sweden and Italy, where about 35% held approbatory views. The study concluded that attitudes were mainly determined by country of residence, but also by individual characteristics such as religious beliefs. Religiously committed physicians were more opposed to euthanasia than non-religiously committed physicians (Miccinesi et al 2005). Interestingly, physicians and the general public declared concurrent attitudes in the Netherlands, Belgium, and Italy, whereas there is a significant difference between the rather restrictive Swedish physicians, and the more approbatory Swedish general public

¹⁴ Euthanasia was here defined as "terminating the life of the incurably sick". (Cohen et al 2006)

¹⁵ The question was formulated: "If a person is suffering from a painful and incurable disease and the patient and the family request it, should a doctor be allowed painlessly to hasten the moment of death?" (Griffiths et al 2008:24)

¹⁶ The so-called Postma case. A physician had administered a deadly dose of morphine to her terminally ill mother at the mother's persistent request. The Regional Court of Leeuwarden concluded that "the average Dutch physician no longer considered it his or her duty to prolong a patient's life under all circumstances" (Legemaate 1998:20). Also, a physician may prevent suffering even if this may shorten the patient's life, a statement that created a legal opening for euthanasia. In the Postma case the physician was found guilty, and was given a suspended sentence of one week's imprisonment (Legemaate 1998:20, van der Maas et al 1995; Griffiths et al 2008:112; Rietjens et al 2009).

(Miccinesi et al 2005; Cohen et al 2006). This discrepancy calls for exploration through further research.

2 AIMS OF THE THESIS

The overall aim of this thesis is to study attitudes towards and reasoning for and against end-of-life decisions among physicians and the general public in Sweden. The end-of-life decisions in focus are refraining from life-sustaining treatment, continuous deep sedation, physician-assisted suicide and euthanasia. The thesis consists of four different studies, each with its specific aim:

Study I: A questionnaire aimed at canvassing attitudes and reasoning among the general public towards physician-assisted suicide and comparing the results with a previous study of physicians' attitudes.

Study II: A questionnaire aimed at canvassing attitudes and reasoning among Swedish physicians and the general public towards the withdrawal of life-sustaining treatment at a competent patient's request.

Study III: A questionnaire aimed at canvassing attitudes among Swedish physicians and the general public towards physician-assisted suicide and euthanasia, as well as enquiring whether continuous deep sedation may be accepted as an alternative course of action in the case of a non-terminally ill patient with Huntington's disease.

Study IV: A moral philosophical investigation of the rule of double effect, aimed at determining the moral relevance of the intention/foresight distinction and this distinction's alleged implication for the moral difference between continuous deep sedation and euthanasia.

3 METHODOLOGY

In the original research plan, the thesis was planned to consist of the three surveys and a qualitative interview study of physicians' attitudes and reasoning. The combination of quantitative and qualitative methods would not only offer good training in different techniques, but also increase the validity of the results through triangulation (i.e. the exploration of a certain topic using different study techniques). However, the surveys generated far more data than expected. These have mainly been analysed by quantitative methods, but due to the great amount of free-text comments, content analysis has also been carried out in some parts (Helgesson et al 2009). More comments remain to be examined, but even a superficial glance at the data indicates an interesting difference between physicians and the general public, namely that physicians tend to regard intentions as morally relevant to a higher degree than the public does. This kind of thinking is central to the rule of double effect, which is often used in end-of-life ethical reasoning. The finding therefore led to a change of plan: Instead of conducting another empirical study, it was decided that the fourth part of the thesis would consist of an essay discussing the rule of double effect (RDE). Although frequently used in medical ethical reasoning, the RDE's soundness and applicability has been much debated. We chose to focus on the intention/foresight distinction, since it is considered a weak link, and is one to which the proponents have devoted much effort in order to "save" the RDE from criticism. Study IV differs significantly from Studies I-III and will be presented separately further below.

3.1 STUDY DESIGN: STUDIES I-III

In the three empirical studies presented in this thesis, the same methodological approach was used, namely that of a postal questionnaire. However, each study was based on its own questionnaire, developed by the research group in order to investigate attitudes and reasoning with regard to different end-of-life decisions. The process of developing the questionnaires (three in total) involved discussions with other researchers, colleagues and experts, literature searches and pilot studies at the institution and in clinical settings. Apart from the questionnaires themselves, two letters were formulated for each study. The first was a covering letter to be distributed together with the questionnaire and containing brief information about study background and aim, study procedure (such as voluntary and confidential participation) and researcher contact particulars. The second letter was a reminder to be distributed without a questionnaire. All covering letters and questionnaires (in Swedish) are reproduced in the Appendix.

The questionnaires were distributed to approximately 1,200 physicians with different specialities and 1,200 individuals in the general public aged 18-85 years and living in the County of Stockholm (more detailed information for each study separately follows below). The distribution process took several weeks and involved three steps, as illustrated in Figure 1. After distribution and registration of responses, data analysis followed. In all studies, Epi 6 and Epi Info 3.3.2 software were used for data registration and analysis. An overview of Studies I-III is presented in Table 1 at the end of this chapter.

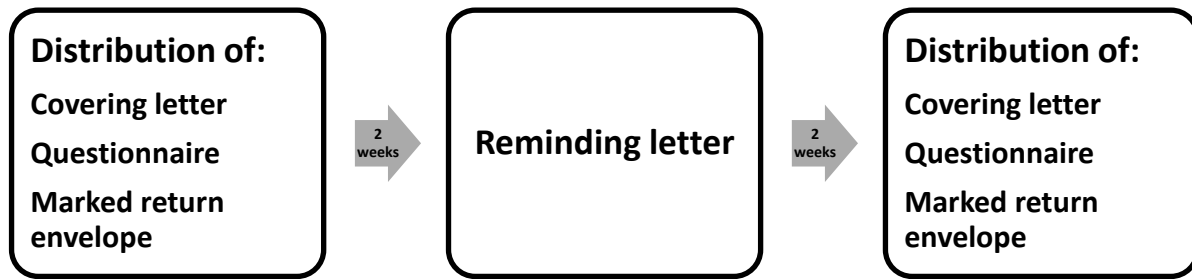


Figure 1. An illustration of the process of distribution of questionnaires. Each return envelope was marked with a unique identifying number, making it possible for the researchers to connect an incoming envelope with a specific participant. This was done during the data-collecting process in order to prevent reminders from being delivered to respondents. After data registration, all envelopes were destroyed and the possibility of linking a certain questionnaire to a specific person thus eliminated.

3.1.1 Study I: Physician-assisted suicide

3.1.1.1 Instrument

The questionnaire in this study was almost identical to the one used in a previous study of physicians' attitudes towards physician-assisted suicide (which has not been included in the thesis) (Lindblad et al 2008). It consisted of four parts:

1. The main question regarding attitude towards physician-assisted suicide, given that certain criteria were met.¹⁷ These criteria were based on the backdrop of those already valid in the Netherlands and Oregon, where physician-assisted suicide is legally practised (Oregon Death with Dignity Act; Rietjens et al 2009).
2. A list of fixed arguments for/against physician-assisted suicide. Participants were asked to prioritise one argument they considered most important, or to formulate an argument or arguments of their own. The fixed arguments were selected due to their common occurrence in the literature on euthanasia and physician-assisted suicide and are presented in Box 1 (Beauchamp and Childress 2001:144-146; Tännsjö 2009:127-142; Blomquist 1964:27-65; Hendry et al 2013).
3. Questions regarding the respondent's current trust in the medical service, and the possible influence on this trust of physician-assisted suicide being allowed.
4. Background factors: age and sex.

¹⁷ The criteria listed were: 1) The patient is at the end of life and his/her suffering is unbearable; 2) The patient must be decision-competent and well informed about alternative palliative measures; 3) The patient must be asking for physician-assisted suicide of his/her own accord, without being influenced by others; 4) The patient must be capable of administering the drug by him/herself; 5) The patient must not be suffering from any treatable psychiatric disorder; 6) The treating physician must have known the patient for a considerable length of time; 7) A second physician must verify that the listed criteria are fulfilled.

In order to examine whether the order of the response options (yes/ no/ in doubt) and arguments (for and against) determined responses, two versions of the questionnaire were constructed and randomly distributed. In one version, the response option to the main question was yes/in doubt/no, followed by a list of arguments in favour of physician-assisted suicide and thereafter a list of arguments against physician-assisted suicide. In the other version the response option to the main question was no/ in doubt/yes, followed by a list of arguments against physician-assisted suicide and thereafter a list of arguments in favour of physician-assisted suicide; see Appendix. Furthermore, a short version of the questionnaire, containing only the main question and background information, was constructed in order to serve as a final reminder; see Appendix.

3.1.1.2 Sample and setting

The questionnaire was distributed in spring 2007 to 1,206 randomly selected individuals aged 18-85 years and living in the County of Stockholm; see Table 1.

3.1.1.3 Distribution

The process of distribution has been described in Fig 1. However, in this study the second reminder, which was a full version of the questionnaire, was followed by a third reminder comprising an abridged version of the questionnaire.

Box 1. The fixed arguments for/against physician-assisted suicide in Study I.

Fixed arguments

Pro:

1. Respect for patient autonomy
2. The aim is to minimise suffering, not to shorten the patient's life
3. The principle of autonomy should override the principle of doing no harm
4. The patient might resort to other, more painful methods of suicide

Contra:

1. The principle of non-maleficence should override the principle of autonomy
2. Patients who perceive themselves as burdens may experience pressure to ask for physician-assisted suicide
3. Patients in these situations do not know what is best for them
4. Patients' trust in physicians may be put at risk

3.1.2 Study II: Life-sustaining treatment

3.1.2.1 Instrument

This questionnaire consisted of three vignettes about patients asking to terminate their life-sustaining treatment. Each vignette was followed by two statements in favour of terminating treatment and two against.¹⁸ Participants were asked to prioritise the statement they regarded most important, or to formulate own arguments. The last question in each section regarded how respondents would classify the act of terminating the life-sustaining treatment in the given vignette. At the end of the questionnaire, background information on sex, age and current trust in the medical services was asked for. The physicians' version of the questionnaire differed from the general public's in one respect: physicians were also asked to add information on speciality and years in practice since becoming licensed to practice. The vignettes are presented in Box 2. For a full version of the questionnaire; see Appendix.

The vignettes shared a common theme, *viz* a decision-competent patient's wish for the withdrawal of a life-sustaining treatment, whereas other variables differed between the scenarios. In the first two vignettes, the patients suffered from the same diagnosis, namely kidney failure with dialysis dependency, but the cause of the disease as well as sex, age and treatment options varied. The reason for choosing withdrawal of dialysis as an example was that this is a common cause of death within this group of patients (Cohen et al 1995; Hackett and Watnick 2007; Fassett et al 2011). The reason for choosing withdrawal of ventilator treatment at a patient's competent request was that it at the time of the study was unclear whether this was a legal practice at all, which made it interesting to explore the current attitudes.

3.1.2.2 Sample and setting

The questionnaire was distributed to two groups:

1. 1,202 randomly selected individuals aged 18+ years and living in the County of Stockholm.
2. 1,200 randomly selected Swedish physicians in the following six specialities (200 in each): internal medicine, surgery, anaesthesiology, sub-specialities of internal medicine, general practice and psychiatry.

The choice of medical specialities was based on the assumption that these groups of physicians had some experience of end-of life decision-making, and/or experience in assessing decision capacity and suicide risk. For a summary of sample and participants, see Table 1 below.

3.1.2.3 Distribution

The questionnaire was mailed in the autumn of 2007. The process of distribution has already been described; see Fig 1.

¹⁸ The pro arguments were: "The patient has the right to decide" and "A mentally sound patient should not be coerced". The contra arguments were: "The physician's task is to preserve and protect life" and "To end treatment could be understood as a kind of euthanasia".

Box 2. A display of the vignettes as formulated in the original article (*Journal of Medical Ethics* 2010;36:284-289).

| Vignette I | Vignette II | Vignette III |
|--|--|--|
| <p>A 77-year-old woman, who as a result of type 2 diabetes and chronic renal insufficiency is dependent on dialysis three times a week. In recent months she has repeatedly expressed a wish to terminate the dialysis treatment. The woman is tired of life, but cognitively clear and not suffering from any mental illness.</p> | <p>A 36-year-old man who 5 years earlier attempted to commit suicide. He was saved without brain injuries, but as a result of a persistent chronic kidney disorder he is still dialysis dependent. Initially he also received psychiatric treatment. The patient is in line for a kidney transplant. During the past 6 months he has repeatedly expressed a wish to decline the kidney transplant and to terminate the dialysis treatment. A psychiatric examination does not reveal any mental illness.</p> | <p>A 34-year-old competent man who is tetraplegic and ventilator dependent as the result of a car accident 5 years ago. There is no chance of improvement, but the patient may live for many years in his current state. During the past 6 months, the patient has repeatedly asked for the ventilator treatment to be discontinued. Neither the physician, who knows the patient well, nor a consulting psychiatrist regards the patient as clinically depressed.</p> |

3.1.3 Study III: Huntington's disease

3.1.3.1 Instrument

The questionnaire contained three parts: 1) a vignette about a patient with Huntington's disease, asking for different end-of-life decisions, 2) general questions about attitude towards physician-assisted suicide and euthanasia and 3) background information on age, sex, current trust in the medical services and possible effects on the respondent's own trust in the medical services, should physician-assisted suicide /euthanasia be allowed. The physicians' version of the questionnaire differed from the general public's in one respect, since physicians were also asked to add information on speciality and years in practice since becoming licensed to practise. A summary of the vignette is presented in Box 3. For a full version of the questionnaire; see Appendix.

Huntington's disease (HD) is an autosomal dominantly inherited neurodegenerative disorder with late onset (Almqvist et al 1999; Hubers et al 2012). Symptoms, which are progressive, may involve motor disorders, cognitive impairment, behavioural problems and psychiatric problems. Typically, the palliative phase is long. The suicide risk, which is increased compared to the general population, is especially elevated in the prodromal phase before receiving diagnosis, and later when symptoms start limiting independency (Almqvist et al 1999; Baliko et al 2004; Paulsen et al 2005; Hubers et al 2012). Patients carrying the HD gene are likely to have seen their relatives suffer from the disease and thus know what to expect for themselves. At present, there is no cure

for HD. Accordingly, a competent person carrying the HD gene (with or without current symptoms) may consider asking for measures that may prevent future suffering, such as physician-assisted suicide or euthanasia (Christie 1996; Adema et al 2010; Cribb 2012).

The reason for choosing HD in the vignette was to explore attitudes towards continuous deep sedation, physician-assisted suicide and euthanasia in a situation where a non-terminal patient prefers death to prevent future suffering, and how these attitudes may be affected by the patient's gradual deterioration.

3.1.3.2 *Sample and Setting*

The questionnaire was distributed to two groups:

1. 1,201 randomly selected individuals aged 18-85 years and living in the County of Stockholm.
2. 1,200 randomly selected Swedish physicians in the following six specialities (200 in each): internal medicine, surgery, anaesthesiology, sub-specialities of internal medicine, general practice and psychiatry.

The choice of medical specialities was based on the assumption that these groups of physicians had some experience of end-of life decision-making, and/or experience of assessing decision capacity and suicide risk. For a summary of sample and participants; see Table 1 below.

3.1.3.3 *Distribution*

The questionnaire was mailed in the autumn of 2007. The process of distribution has been described above; see Fig 1.

Box 3. A summary of the vignette about end-of-life decisions in the case of Huntington's disease as presented in the original publication in the *International Journal of Palliative Nursing* 2010;16:527-533.

Vignette

The vignette describes a hypothetical case of a competent patient with Huntington's disease who at an early stage of the disease asks for physician-assisted suicide in order to prevent future suffering. The physician refuses the patient's request, but instead offers her continuous deep sedation, which the patient rejects. As her condition declines the patient asks for euthanasia, but the request is refused. Eventually the disease reaches an advanced stage and the patient is physically and cognitively impaired. The family now asks for euthanasia on behalf of the patient. Again, continuous deep sedation is offered and finally accepted by the family.

Table 1. An overview of Studies I-III.

| Study | Sample | Data collection | Response rate | Publication |
|--------------|--------------------------------------|---|--|--|
| I | Public n=1,206 | Postal questionnaire + short version of the questionnaire | Full version n=612 Short version n=86 | Would physician-assisted suicide jeopardize trust in the medical services? An empirical study of attitudes among the general public in Sweden <i>Scandinavian Journal of Public Health</i> 2009;37:260-264 |
| II | Public n=1,202 Physicians n=1,200 | Vignette-based postal questionnaire | Public n=572 Physicians n=687 | When enough is enough; terminating life-sustaining treatment at the patient's request: a survey of attitudes among Swedish physicians and the general public <i>Journal of Medical Ethics</i> 2010;36:284-289 |
| III | Public n=1,201 Physicians n=1,200 | Vignette-based postal questionnaire | Public n=625 Physicians n=669 | Continuous deep sedation, physician-assisted suicide and euthanasia in Huntington's disorder <i>International Journal of Palliative Nursing</i> 2010;16:527-533 |

3.2 STATISTICAL ANALYSIS: STUDIES I-III

The choice of statistical method depends on the research question. In Studies I-III, the main research question could be formulated like this: “To what extent can physicians and the general public accept the termination of life-sustaining treatment/continuous deep sedation/physician-assisted suicide/euthanasia?” The studies were descriptive, with the primary aim of increasing knowledge regarding current attitudes (i.e. basic research). The data consisted of nominal and ordinal data. The use of ordinal scale response options was aimed at minimising the internal dropout rate. However, during analysis the ordinal data were recoded to dichotomous nominal data in order to allow for non-parametric testing. No zero-hypotheses were generated, and thus no hypothesis testing was conducted. Proportions were calculated with 95% confidence intervals in order to gauge the precision of each value, as well as the magnitude of the differences between the groups (Machine et al 2007). 95% confidence intervals of proportions that do not overlap indicate that if a hypothesis test had been conducted, the zero-hypothesis would have been rejected at 0.01 significance level (Lynöe and Stenlund 1998). Furthermore, in order to estimate the strength of certain correlations, Odds’ ratios were calculated with 95% confidence intervals (Study III). In all three studies, the respondent’s mean age and median age were either identical or differed by one year. In the articles, mean age was reported. Data were registered and analysed using Epi 6 and Epi Info 3.3.2 software.

3.3 ETHICAL APPROVAL: STUDIES I-III

According to Swedish law, surveys of the kind included in this thesis may be conducted without an ethical permit. However, due to the sensitive nature of the topic, an ethical application regarding Study I (Dnr 2007/310-31) and Study II-III (Dnr 2007/650-31/3) was nevertheless submitted to the Regional Research Committee in Stockholm, which approved the studies planned.¹⁹ No ethical approval was applied for in Study IV, since this project did not involve any live subjects.

3.4 STUDY DESIGN: STUDY IV

As mentioned in the introduction, medical ethics is a discipline identifying and investigating moral conflicts in the field of clinical medicine and medical research. In the case of investigating moral conflicts, the ‘result’ of the study is the discussion itself, i.e. the reasoned defence of a thesis (Horban 1993).

A common structure shared by many philosophical essays includes a short *introduction* to the topic. Here, the main argument is outlined and sometimes even the conclusion is presented. Thereafter follows the *background*, where the relevant literature on the topic is introduced or at least referred to. The next part – which is also the main part – is the *discussion*. Here the author(s) present their own reasoning, i.e. their contribution to the discussion of the particular topic. Finally, the discussion is summarised and *conclusions* are drawn (Hansson 1998:108-110).

¹⁹ The vignette based surveys were applied for in the same application, hence the identical Dnr.

In Study IV, we decided to follow the structure sketched above. The choice of topic was based on an observation from Study III. Here many physicians expressed the view that the intention of an act is morally relevant.²⁰ This can be compared to comments made by respondents from the general public, where discussions of the moral relevance of intentions were absent.

Ascribing moral relevance to the intention of an act is the heart of the rule of double effect (RDE). More precisely, the RDE holds that it may be permissible to harm an individual while acting for the sake of a proportionate good, given that the harm is not an *intended means* to the good but merely a *foreseen side-effect*. The RDE has a long tradition in medical ethics and is often applied in cases concerning palliative medicine at the end of life. Its main role then is to provide those against euthanasia and physician-assisted suicide but in favour of, e.g. continuous deep sedation with a moral justification (Sulmasy 2007).

The RDE has its historical roots in Thomas Aquinas' discussions about killing in self-defence. However, Aquinas did not articulate the RDE, which over the centuries has developed into its modern form (Sulmasy 2007; Mangan 1949). In literature, different versions of the RDE can be found. The traditional formulation as presented by Mangan reads as follows:

“A person may licitly perform an action that he foresees will produce a good and a bad effect provided that four conditions are verified at one and the same time: that the action in itself from its very object be good or at least indifferent; that the good effect and not the evil effect be intended; that the good effect be not produced by means of the evil effect; that there be a proportionately grave reason for permitting the evil effect.” (Mangan 1949:43)

Despite the RDE being frequently used in medical ethical reasoning, its soundness and applicability have been much debated. Nevertheless, the comments made in Study III, as well as formulations in ethical guidelines such as those from the Swedish Medical Association, bear witness to the influence the RDE has on contemporary ethical reasoning (Materstvedt et al 2003; Läkarförbundet 2009; Svenska läkaresällskapet 2010; Socialstyrelsen 2011). It was from this starting point that we decided to conduct a philosophical analysis of the RDE, with special regard to the moral relevance of the intention/foresight distinction and its alleged implication for the moral difference between continuous deep sedation and euthanasia. More precisely, we decided to evaluate a contemporary, reformulated version of the RDE, namely the ‘reinvented’ RDE by Daniel Sulmasy, which to this day represents the most ambitious attempt to formulate the rule in order for it to meet some of its main problems. The reinvented RDE (from now on abbreviated RRDE) was published in *The Oxford Handbook of Bioethics* in 2007 (Sulmasy 2007). The RRDE is significantly more precise than the traditional version and thus makes it more clear in which situations the rule is applicable. By being more precise in this respect, it also excludes some of the paradigm

²⁰ In the minds of many respondents the intended/foreseen distinction seems to be intermingled with the active/passive distinction. A brief analysis of the comments indicates that at least 30 physicians (out of 203) have written comments which discuss either the moral relevance of intentions, or the difference between active/passive euthanasia, or both.

cases which have been problematic for the traditional RDE. As a result, the RRDE avoids problems that plagued the traditional version and is therefore more plausible. The investigation began with extensive literature searches on the RDE, with special regard to the intention/foresight distinction and the RDE's applicability in end-of-life decision-making. After that, we chose to focus on Sulmasy, for reasons mentioned above. Then, Sulmasy's previous work on the topic was reviewed. While working on the first drafts, the main argument was outlined, namely: even if one accepts that intentions are morally relevant, their relevance *in the way proposed by the RRDE* must be justified. Since Sulmasy fails to deliver such a justification, we turned to the work of other philosophers, finding the most promising attempt in Shelly Kagan's "The limits of morality" (1989:128-182). After a process of mutual discussions between the authors – and several rewritten drafts – the final version was achieved as presented in Study IV.

4 KEY RESULTS

4.1 STUDY I: PHYSICIAN-ASSISTED SUICIDE

The aim of this study was to explore attitudes and reasoning among the general public with regard to physician-assisted suicide among the general public, as well as the possible influence on trust in the medical services if physician-assisted suicide were to be allowed.

The response rate was 51%, but the final reminder, containing only the main question about attitude towards physician-assisted suicide, added another 7%. On the main question regarding the acceptability of physician-assisted suicide, 72% declared themselves in favour, 12% against, and 15% were undecided. Ten participants did not answer the question at all. Respondents to the final, short version of the questionnaire tended to be more in doubt compared to early respondents. There were no differences in response pattern between older/younger respondents and men/women. The most prioritised arguments in favour of physician-assisted suicide were “respect for patient autonomy” (56%), followed by “the purpose is to alleviate the suffering of a human being, not primarily to hasten death (32%)”. The most prioritised arguments against physician-assisted suicide were “the non-maleficence principle should take precedence over the autonomy principle” (34%), followed by “risk of pressure from relatives” (30%).

A majority of participants, 83%, declared a high or fairly high trust in the medical services. A similar proportion believed that their trust would not be influenced (45%) or would even increase (38%) if physician-assisted suicide were to be allowed. Furthermore, there was a correlation between attitude towards physician-assisted suicide and the influence on trust; see Table 2. Among those declaring low current trust in medical services (n=97), 49% (95% CI=39-59%) believed that their trust would increase. This is significantly more than in the proportion declaring high current trust in the medical services, where 36% (95% CI=35-37%) believed that their trust would increase.

In conclusion, a majority of the participants declared an approbatory view of physician-assisted suicide, provided certain criteria were met. Furthermore, we found no support for the assumption that the general public’s trust in the medical services would be jeopardised if physician-assisted suicide were to be allowed.

Title: Would physician-assisted suicide jeopardise trust in the medical services? An empirical study of attitudes among the general public in Sweden.

Authors: Lindblad A., Löfmark R., Lynöe N.

Published in: *Scandinavian Journal of Public Health* 2009;37:260-264

Table 2. A correlation was found between attitude towards physician-assisted suicide and possible influence on trust. Proportions are presented with a 95% confidence interval (CI); non-overlapping CI's indicate that if a hypotheses test had been conducted, p-values would have been <0.001. The internal drop-out was n=25. A similar table was presented in the original paper (*Scandinavian Journal of Public Health* 2009;37:260-264).

| Attitudes towards physician-assisted suicide (n=583) | Trust would | | |
|--|-----------------|--------------------------|-----------------|
| | Decrease % (CI) | Not be influenced % (CI) | Increase % (CI) |
| In favour (n=437) | 3 (1-5) | 50 (45-55) | 47 (42-52) |
| Doubtful (n=82) | 46 (35-57) | 37 (27-47) | 17 (9-25) |
| Against (n=64) | 75 (64-86) | 17 (8-26) | 8 (1-15) |

4.2 STUDY II: LIFE-SUSTAINING TREATMENT

The aim of this vignette-based questionnaire was to explore attitudes and reasoning concerning the withdrawal of life-sustaining treatment at a competent patient's request. The vignettes described: (1) a 77-year-old woman on dialysis; (2) a 36-year-old man on dialysis; (3) a 34-year-old ventilator-dependent tetraplegic man. Respondents were asked to classify the act of terminating treatment and to prioritise arguments for/against.

Summary of results: The response rate was 57% among physicians and 48% among the general public. A majority in both groups prioritised arguments in favour of terminating treatment and classified the act as defensible in all three vignettes. However, approximately 16% of the general public perceived the act to be a type of euthanasia in all the vignettes. Among physicians, this was especially the case in vignette 3 regarding ventilator treatment (26%). Generally, respondents classifying the act as euthanasia also prioritised a contra argument; however, there was also a proportion in both groups who classified the act as euthanasia but nevertheless prioritised a pro argument. This was especially the case in vignette 3; see Table 3. Respondents' own pro-arguments (from both groups) mainly concerned the right to autonomy in all three scenarios, but in vignette 3 there were also arguments expressing empathy for the patient's situation and quality of life. The contra arguments regarding vignettes 1 and 2 concerned decision-competence, the possibility of patients changing their minds and alternative medical treatments. Furthermore, in vignette 2, the patient's age was mentioned. In vignette 3, some physicians stressed the possibility of the patient changing his mind, whereas there were comments from the general public regarding the possibility of future development of medical treatment.

Summing up, there seems to be a widespread consensus regarding competent patients' right to refrain from life-sustaining treatment. An association is proposed between the hastening of death, caused by the withdrawal of life-sustaining treatment, and the concept of euthanasia. The results also suggest that classifying the withdrawal of life-sustaining treatment as 'euthanasia' does not necessarily mean that the act is interpreted as ethically unacceptable.

Title: When enough is enough; terminating life-sustaining treatment at the patient's request: a survey of attitudes among Swedish physicians and the general public

Authors: Lindblad A., Juth N., Fürst C.J., Lynöe N.

Published in: *Journal of Medical Ethics* 2010;36:284-289

Table 3. A display of the proportion of physicians and the general public who classified the withdrawal of life-sustaining treatment as euthanasia, and the type of arguments they prioritised as the most important. A similar table was presented in the original paper (*Journal of Medical Ethics* 2010;36:284-289).

| | Vignette 1 77-yr-old woman, Dialysis | | Vignette 2 36-yr-old man, Dialysis | | Vignette 3 34-yr-old man, Ventilator | |
|------------------------|---|--------------------------------|---|--------------------------------|---|--------------------------------|
| | Phys n=49 (%) | Public n=78 (%) | Phys n=85 (%) | Public n=90 (%) | Phys n=158 (%) | Public n=84 (%) |
| Pro argument | 18 | 35 | 19 | 20 | 34 | 48 |
| Contra argument | 82 | 65 | 81 | 80 | 68 | 52 |

4.3 STUDY III: HUNTINGTON'S DISEASE

The aim of this vignette-based questionnaire was to investigate attitudes among Swedish physicians and the general public towards physician-assisted suicide and euthanasia, and to enquire whether continuous deep sedation may be accepted as an alternative course of action in the case of a non-terminally ill patient with Huntington's disease.

The response rate was 56% among physicians and 52% among the general public. Among physicians, 22% were pro granting the request for physician-assisted suicide and 21% accepted continuous deep sedation as an alternative. Among the general public, 59% declared themselves pro physician-assisted suicide and 60% accepted continuous deep sedation as an alternative. When the family asked for euthanasia on the patient's behalf, 13% of the physicians declared themselves pro euthanasia and 43% accepted continuous deep sedation as an alternative. In the general public 65% declared themselves pro euthanasia and 61% accepted continuous deep sedation as an alternative.

The respondents were also asked about their general attitudes regarding physician-assisted suicide and euthanasia, see Table 4.

In conclusion, according to these results quite a large proportion of the participants are more liberal in their views on continuous deep sedation than current guidelines permit. Furthermore, there seems to be a fairly widespread acceptance of physician-assisted suicide and euthanasia among the participants from general public compared to physicians.

Title: Continuous deep sedation, physician-assisted suicide and euthanasia in Huntington's disorder

Authors: Lindblad A., Juth N., Fürst C.J., Lynöe N.

Published in: *International Journal of Palliative Nursing* 2010;16:527-533

Table 4. A display of the general questions about physician-assisted suicide and euthanasia and the proportion who answered "Yes", with a 95% confidence interval (CI). A similar table was presented in the original paper (*International Journal of Palliative Nursing* 2010;16:527-533).

| When a competent patient is severely suffering incurably ill, physicians should be allowed to: | Physicians % (CI) | Gen public % (CI) |
|---|--------------------------|--------------------------|
| Prescribe medication which the patient can take to end his/her life, assuming that the patient is competent and asks for it. | 31 (CI: 27-35) | 58 (CI: 54-62) |
| Give lethal injections to the patient if he/she cannot do it on his/her own, assuming that the patient is competent and asks for it. | 18 (CI: 15-21) | 69 (CI: 65-73) |
| Give lethal injections to the patient even if he/she is no longer competent, but has asked for it previously. | 15 (CI: 12-18) | 60 (CI: 56-64) |
| Give lethal injections to the patient even if he/she is no longer competent and has not expressed such a wish earlier, but the family demands it. | 3 (CI: 2-4) | 30 (CI: 26-34) |

4.4 STUDY IV: RULE OF DOUBLE EFFECT

According to the rule of double effect (RDE) it may be permissible to harm an individual while acting for the sake of a proportionate good, given that the harm is not an intended means to the good but merely a foreseen side-effect. In medical ethics, the RDE is often applied in cases concerning palliative medicine at the end of life. Its main role then is to provide those who are against euthanasia and physician-assisted suicide with a moral justification for performing acts which potentially may hasten death.

During the past decades, the RDE has been repeatedly questioned. However, recently one of its contemporary proponents, Daniel Sulmasy, has presented a reformulated and more detailed version of the rule. Thanks to its greater precision, this reinvented RDE avoids several problems thought to plague the traditional RDE. But although it is an improvement compared to the traditional RDE, we argue that Sulmasy's version is not flawless. Not only has the range of applicability narrowed significantly; the distinction between intended and foreseen effects still lacks a moral justification. In particular, Sulmasy fails to establish that there is any distinction that can account for the alleged moral difference between palliative sedation and euthanasia.

Title: End-of-life decisions and the reinvented rule of double effect: A critical analysis

Authors: Lindblad A., Lynöe N., Juth N.

Published in: *Bioethics* 2012 Oct 1. doi: 10.1111/bioe.12001.

5 DISCUSSION

5.1 PART I: STUDIES I-III

5.1.1 Methodological considerations

Surveys are convenient study tools, since large amounts of data may be collected in a fairly short time and results may be generalisable to a larger population (Kelley et al 2003). However, difficulties regarding validity and reliability may cast a shadow on this approach. Below follows a critical discussion of some of the methodological ‘downsides’ in relation to Studies I-III.

5.1.1.1 *Internal validity*

In this context, the term ‘internal validity’ refers to whether a certain study has measured what it intended to measure, or, in other words, whether the *measured property* is the same as (or at least a good indicator of) the *target property* (Feldman 1999:242). In surveys based on written questionnaires, several factors may cause a discrepancy between the measured property and the target property. For example, the instrument itself may contain complicated, unclear or even dubious terminology. Furthermore, if the topic is of a sensitive nature, respondents may give dishonest answers or may adjust their answers to what is considered legally or politically correct (Feldman 1999:248).

For the researcher, there are methods for validating the instrument. A common strategy is to conduct pilot studies in order to test whether questions and instructions can be understood, whether questions are interpreted similarly by all respondents and whether response categories are sufficient (Kelley et al 2003; Jakobsson and Westergren 2005).

As previously described in the chapter on Methodology, the process of developing the questionnaires used in Studies I-III included several steps: literature studies, discussions of preliminary drafts and pilot studies followed by further discussions and revisions of the instruments. Much effort was put into the wording of the questionnaires and the covering letters in order to make the language understandable also for people without medical knowledge. Generally, value-laden terms such as ‘physician-assisted suicide’ and ‘euthanasia’ were avoided in order to prevent bias. However, a few exceptions were made: In Study I, the term ‘physician-assisted suicide’ was explained in the covering letter. In the questionnaire, the practice was first described in plain words, but later the term ‘physician-assisted suicide’ was also used. The lack of comments from the respondents regarding this terminology indicates that it did not cause any considerable trouble in terms of understanding, but of course, this cannot be ruled out.

Furthermore, Study II contained a question regarding the classification of the act of withdrawing life-sustaining treatment. Six response options were given, grouped 3+3. The first three were arguments in favour of terminating treatment, and the last three were arguments against. One of the options against was “To withdraw the treatment could be regarded as a form of euthanasia”. However, the term euthanasia was not further explained. This is problematic, since we do not know what the respondents understood by ‘euthanasia’. What we do know is that some of those choosing this option had prioritised arguments in favour of withdrawing life-sustaining treatment.

This may possibly indicate that classifying a term as ‘euthanasia’ does not necessarily mean that the act is considered ethically unacceptable. Nevertheless, avoiding the term or at least explaining it in plain words would have benefited the questionnaire and the interpretation of the results, since it is known that attitudes towards euthanasia may vary, depending on the wording of questions and on the respondents’ own understanding of the concept (Parkinson et al 2005; Marcoux et al 2007).

In Study III, the practices of continuous deep sedation, physician-assisted suicide and euthanasia were described in plain words without ever mentioning these terms. Here, however, another factor may have biased the responses: in the introduction to the questionnaire, it was specified that a physician in Sweden may risk losing his/her licence to practise if assisting a patient in dying. This information may have induced respondents to give answers in line with the current legal situation, rather than state their own beliefs. Of course, the risk of respondents providing ‘correct’ answers may also be the case in Study I and II, but the presence of introductory information about the current law probably increases such bias.

Finally, further terminological ambiguity can be found in the questions about trust in the medical services in Study I and III. Here, neither the term “trust” nor the term “the medical services” was further specified. What we had in mind while constructing these questions was trust in the sense described by Ahnquist et al, namely an “[...] expectation that an individual or institution will act competently, fairly, openly and with concern” (Ahnquist et al 2010:251). With the term “medical services” we included healthcare provided at all levels, i.e. in hospitals as well as in outpatient clinics. A consequence of this lack of specification is that we do not know how respondents interpreted the terms, and therefore the results must be interpreted with caution. Not only the terms, e.g. “trust”, but also their objects may be understood in many different ways: trust in the medical services as a whole, trust in the medical services in a specific county, in “my” hospital/general practitioner etc (Hall et al 2001). However, since neither results from the pilot studies nor from the actual surveys have indicated that respondents had any difficulties answering these questions, it seems reasonable to believe that the concepts are understandable at face value. Even if we do not know exactly how respondents interpreted the terms and their objects, it still seems reasonable that the data can be used as a rough indicator, as has been done in the articles.

Not only the terminology, but the order of questions and response options could influence the response pattern (Trost 1994:71-72, 85-86). In order to determine this, two versions of the questionnaire in Study I were constructed. In the first one, the main question about attitude towards physician-assisted suicide was followed by the response options Yes – In doubt – No. Thereafter followed a list of fixed arguments, where pro arguments came first and contra arguments last. In the second version, the order of response options and arguments was reversed, i.e. No – In doubt – Yes and contra arguments before pro arguments. However, the analysis revealed no differences in response pattern between the two versions.

In conclusion, although the instruments had gone through a process of validation, some ambiguities remained. This prompts the question whether a written questionnaire may ever be fully validated, i.e. whether it is ever possible for the measured property to be identical with the target property. A more modest goal – and, I believe, an attainable

one – is that the collected data should be a good indicator of the target property. In the case of Studies I-III, a majority of the questionnaires were completed, the answers were consistent and the comments relevant to the context, thus indicating an acceptable level of internal validity.

5.1.1.2 External validity

Are the results from Studies I-III generalisable? Whether this is the case depends on the representativeness of the sample, i.e. if the sample is similar to the target population in a relevant way (Feldman 1999:252). One way of achieving representativeness is by using random samples of an appropriate size, meaning that every member of the target population has the same chance to be selected to the study. But response rate and analysis of non-respondents is also of importance when considering the risk of bias.

5.1.1.2.1 Sample

In Studies I-III, a random sample was selected from the population aged 18-85 years and living in the County of Stockholm (where Karolinska Institutet is located). The age group was defined as 18-85 years in order to include a broad spectrum of people. Individuals aged over 85 were excluded, since a higher proportion of the senior elderly may have difficulties filling out an extensive questionnaire, e.g. due to visual or other physical or cognitive impairment.

Generally speaking, the population of Stockholm has a level of education above the national average and is therefore not entirely representative. However, in previous studies loyalty from participants to the hospital or institute in their own region has been experienced and, accordingly, resulted in a higher response rate. It could be argued that people in major cities such as Stockholm are generally more liberal in their moral views; possibly, including representatives of the general public from a broader section of Sweden would have generated more restrictive results. However, no data exist at present to either support or refute such an argument.

Study II-III also included a random sample of physicians from medical specialities likely to have some experience of end-of-life decision-making. In order to achieve representativeness – and thus enhance generalisability – Sweden as a whole was chosen as the setting.

5.1.1.2.2 Sample size

The sample size in Studies I-III was set to 1,200 individuals in each group (general public and physicians), and 200 physicians from each medical specialty. Given a response rate of 50%, these numbers would enable statistical subgroup analysis even of the medical specialities.

5.1.1.2.3 Response rate and non-respondents

Response rates may be calculated in various ways. In Studies I-III the following strategy was used:

$$\frac{\text{Number of responses}}{(\text{Number of surveys sent} - \text{Number of undeliverable surveys})}$$

If the number of undeliverable surveys is high, this way of calculating may be problematic, since one may suspect that the targets of the undeliverable surveys are different from the others (Asch et al 1997). However, in Studies I-III the number of undeliverable surveys was small, varying between 2-8 (out of 1,200) among physicians and 13-17 (out of roughly 1,200) among the general public. Even assuming some of the targets of the undeliverable surveys to be unrepresentative, the small number reduces the risk of significant bias.

In the current surveys, response rates among physicians were 57% (Study II) and 56 % (Study III). The general public response rates were 51% (Study I),²¹ 48% (Study II) and 52% (Study III). This corresponds well with other studies; the mean response rate among mail surveys published in medical journals is about 60%. In surveys of physicians the mean response rate is 54% (Asch et al 1997). In general, response rates to surveys seem to vary between 50-75% (Trost 1994:113).

The response rate is often used for evaluating the risk of respondent bias. However, bias is only introduced if non-respondents differ in a meaningful way from respondents, or, put otherwise, even a low response rate may constitute a representative sample of the study population (Asch et al 1997). An analysis of non-respondents may add information on respondent bias. However, in the current studies, analysis of non-respondents was difficult, due partly to lack of background information. In Study I it could be concluded that the male/female ratio among non-respondents correlated well the overall male/female ratio in the County of Stockholm. There was no information on other aspects such as age, education level etc.

In Study II-III the difficulties were even worse, since the only information available on the recipients of the questionnaires was name and address. This was insufficient in order to conduct a reliable non-respondent analysis, since many names did not reveal the person's sex.

Another way of approaching the question of respondent bias is by looking at the response pattern. If there are no significant differences between early and late respondents, there is no reason to believe that there are any significant differences between respondents and non-respondents. A discussion of the response pattern for each study follows below.

²¹ In Study I, two different response rates were calculated: 51% of the respondents returned the full questionnaire, whereas 7% returned a short-version reminder of the questionnaire. Thus the response rate of 58% only refers to the main question, i.e. the question about attitude to physician-assisted suicide.

5.1.1.2.4 Response pattern

5.1.1.2.4.1 STUDY I

There was a slight majority of women among respondents (male/female 46%: 54%), but this was also the case in the original sample of randomly selected individuals (male/female 47%: 53%). The overall male/female ratio in the County of Stockholm at the time was 49%: 51%. No age- or gender-related differences were found in the response pattern for the main question regarding attitude towards physician-assisted suicide. There was a tendency for those answering the last version of the questionnaire to be more in doubt. Therefore, being undecided might have been a possible reason for not participating in the study, suggesting that a higher response rate could have influenced the response pattern somewhat.

5.1.1.2.4.2 STUDY II

In the sample from the general public, the gender balance among respondents matched the demographic data of the average male/female ratio in the population in the County of Stockholm as well as in Sweden as a whole (Statistiska Centralbyrån). Among the participating physicians, men were over-represented when compared with the demographic data of the average male/female ratio of the specialities included, as well as with the group of Swedish physicians as a whole (specialists <65 years) (Läkarförbundet 2007). There were no significant differences in attitudes, age or sex between early and late respondents in either group, suggesting that a higher response rate would not have significantly influenced the response pattern – at least, not among the general public. However, a more representative male/female ratio among physicians might possibly have generated somewhat different results.

5.1.1.2.4.3 STUDY III

Among respondents from the general public, the gender balance matched the demographic data of the average male/female ratio in the population of the County of Stockholm as well as in that of Sweden as a whole (Statistiska centralbyrån). There was no difference in male/female ratio between early and late respondents. However, younger respondents (<50 years) tended to answer later and opted for ‘don’t know’ more often than older ones, which indicates that if the response rate had been higher the results among the general public might have been slightly different.

Among the participating physicians, men were over-represented when compared with the demographic data of the average male/female ratio of the specialities included, as well as with the group of Swedish physicians as a whole (specialists <65 years) (Läkarförbundet 2007). As gender was associated with attitudes to physician-assisted suicide and euthanasia in the vignette part of the questionnaire, it is possible that a more representative male/female ratio would have generated slightly different results.

Thus neither the respondents from the general public nor physicians were entirely representative of the target group. It is therefore reasonable to believe that if attitudes among non-respondents had been obtainable, these would have been more uncertain or more restrictive. However, the study results tally with previous research on end-of-life decisions (see the chapter on Previous research) and it is therefore unlikely that a higher response rate would have generated entirely different results.

5.1.1.2.5 Other factors influencing external validity

Studies II and III were administered simultaneously, i.e. 4,800 questionnaires were distributed at the same time, in order to make the process more efficient. There were two lists of addresses: one for the general public and one for physicians. The participants were randomised to belong either to Study II or Study III. However, managing this amount of questionnaires, envelopes, labels etc. was both time-consuming and complicated, and it is possible that some individuals who were randomised to belong to Study II actually received the questionnaire from Study III, and vice versa. The exact number of mistakes is unknown, but has been estimated at +/- 10 questionnaires.

Although this is a minor problem, it may also be worth noticing that in all of the three studies some occasional questionnaires were returned in private envelopes. Since the identity number of each participant was written on the envelope attached to the questionnaire, this made it impossible to register the person as respondent/non-respondent. Also, a few participants had used the attached envelopes but erased their identity numbers.

5.1.1.3 *Reliability*

After this discussion on validity, it is time to turn to the question of reliability. Reliability concerns the repeatability of a measurement, that is, whether a new measurement would generate the same result. This presupposes that conditions are static (Troost 1994:57). However, people's attitudes may change due to a variety of factors, such as personal experiences, public discussions etc. Attitudes towards end-of-life decisions are no exception.

Since 2007, when the data gathering for Studies I-III took place, patients' rights at the end of life have continued to raise debate in Swedish media. In 2009, a physician was arrested on a charge of mercy-killing a severely brain-damaged baby. The case drew a lot of attention in the years that followed, until the physician was acquitted in 2011.²² Furthermore, new guidelines on palliative sedation have been published (Svenska läkaresällskapet 2010) and the National Board of Health and Welfare has stated a competent patient's right to refrain from life-sustaining treatment.²³ Due to this ongoing debate and the new clarifying guidelines, it is possible that the surveys would generate somewhat different results if conducted again today.

5.1.1.4 *Selecting method or Quantitative vs. Qualitative*

As we have just seen, the use of a survey approach in order to gain information on a specific matter has advantages as well as disadvantages. The fact that a large amount of data may be obtained in a short time, and that results may be generalisable to a larger population, argues in favour of this approach. However, due to the methodological

²² For a summary of the trial see Lynöe and Leijonhufvud 2012

²³ The clarification regarding competent patients' right to refrain from life-sustaining treatment came in 2010, and also stated that if palliative measures are needed (e.g. to terminate ventilator treatment) they should be given. This was preceded by a letter to the National Board of Health and Welfare from a ventilator-dependent woman who wanted to terminate her ventilator treatment. For more information, see Socialstyrelsen 2010.

problems discussed above, it may be difficult to ascertain unexceptionable validity. Furthermore, the results are presented in numbers and do not provide much in-depth information on the beliefs behind the declared attitudes. In Studies I-III, the questionnaires allowed participants to add free-text comments which could be analysed using qualitative methods such as content analysis; however, up till now this has only been done in Study I (Helgesson et al 2009). Even if content analysis of the comments could add further aspects to the quantitative results, this probably cannot be compared to the richer and more complex information that a purely qualitative study (e.g. interviews or focus groups) most probably could achieve. In addition to providing a deeper understanding of the area of interest, a qualitative study may sometimes support and thus validate quantitative results. These are two important arguments in favour of using a so-called mixed method approach, that is using quantitative and qualitative study design to explore the same issue, and it is reasonable for the reader to ask why this has not been done within the framework of this thesis.

As already mentioned, when this project began there was a considerable lack of knowledge regarding attitudes towards end-of-life decisions in Sweden. A survey approach seemed reasonable in order to gain an overview of the present situation, and in addition to this an interview study was planned. However, the surveys generated more data than expected. Among the comments expressing views against physician-assisted suicide and euthanasia, double effect reasoning as well as the active/passive distinction was often invoked.²⁴ The same types of arguments occur frequently in the ethical debate on end-of-life decisions; however, the moral assumptions underlying these arguments are seldom illuminated. Since moral reasoning in terms of intentions appeared to be widespread in literature as well as in the survey responses, this caused a change of plans. Instead of pursuing the exploration of attitudes in a qualitative study, it was decided to widen the approach by adding a philosophical investigation of the rule of double effect (Study IV). The decision to refrain from a qualitative study does not mean that such an approach was regarded as unnecessary, on the contrary, but to include both a philosophical and a qualitative study to the already existing empirical investigations would have been beyond the scope of this thesis.

5.1.2 Interpretation of results

5.1.2.1 On attitudes

The empirical studies included in this thesis were aimed at exploring attitudes towards different end-of-life decisions. The methodology has been described and discussed above, but so far little has been said about the results. But before taking a closer look at the empirical findings, a few general words are needed concerning attitudes.

According to the Oxford Dictionary of Philosophy, an attitude is:

“An evaluative response, usually contrasted with simple belief by its more direct connection with motivation and behaviour. An attitude is a state whose essence is contentment or active discontent with some way the world is, rather than a simple cognition of the way the world is.” (Blackburn 1996:28-29)

²⁴ There is no complete analysis of the comments from Study III, but a brief look suggests that double effect reasoning and the active/passive distinction are especially frequent in physicians' responses.

Thus, when a person has formed a specific view, for instance that a certain course of action is either right or wrong, this may (or may not) motivate the person to act in line with the particular view; to make it come true. This is different from merely holding a certain belief; beliefs aim at the truth, and when they turn out to be false, we usually let go of them (Blackburn 1994:111-116).

Philosophers disagree as to whether normative or evaluative statements should be analysed as attitudes or beliefs. No stand will be taken here in this discussion, though everything said is compatible with either view. But even those who deny that moral judgements are attitudes would agree that they are strongly connected to attitudes (Miller 2003:217-227). It therefore seems appropriate to say that we have primarily been investigating attitudes.

5.1.2.2 Experts and lay men

Studies I-III involve two different populations: representatives of the general public in the County of Stockholm and a sample of physicians from certain specialities. The reason for choosing these groups was a wish to explore – and compare – the attitudes of people who may have been professionally involved in end-of-life decision-making, and people who are representatives of society as a whole and who may or may not have some medical knowledge, experience of healthcare, first-hand experience of severe illness etc.

The results reveal significant differences in attitudes between the groups when it comes to continuous deep sedation, physician-assisted suicide and euthanasia, results which tally with the international findings presented earlier.

However, one may ask how the results should be interpreted, since the different starting points may have affected the respondents' understanding of the questions. For instance, it is likely that the physicians' reading of the vignettes in Studies II-III was coloured by their medical knowledge, raising questions regarding the likeliness of these situations occurring, differential diagnosis, possible treatments, prognosis etc.

Furthermore, in all of the studies some physicians may have answered the questions from the very personal standpoint "can you imagine doing this?" instead of the more general "do you find this ethically acceptable?" Thus, they may have opined against physician-assisted suicide or euthanasia, not because they are against it in general, but because they do not wish to perform the acts themselves. The qualitative analysis of the survey on physicians' and the general public's attitudes towards physician-assisted suicide reveals that this may indeed be the case:

“[...] It is clear from the many comments that a considerable number of physicians do not want this kind of duty; some because they think it should not be handled by physicians in the regular health-care system and others because they do not want to do it themselves. Some of those expressing these views state that they are not generally opposed to assisted suicide.” (Helgesson et al 2009:23)

Another problem is that some physicians may have replied in line with current rules and regulation rather than presenting a considered opinion of their own. The fact of both physician-assisted suicide and euthanasia being forbidden in Sweden at present may to some extent explain the restrictive views expressed. Also, having knowledge about the organisation of the healthcare system may affect one's confidence in the

possibility of permitting physician-assisted suicide and euthanasia in a manner involving minimal risks of misuse.

There are of course many other factors that may influence attitudes – views on physicians’ role vs. patients’ roles in healthcare, first-hand experiences of end-of-life decision-making, religious views etc. However, the surveys conducted did not reveal anything about such reasons. In order to gain a deeper understanding of physicians’ attitudes, further research is recommended.

The respondents from the general public were more in favour of physician-assisted suicide and euthanasia than physicians were – results that agree with international research. Here again, however, we cannot be sure how the questionnaires have been understood. For example, the question on the acceptability of physician-assisted suicide in Study I may have been interpreted in terms of “is this something you believe should be offered within the Swedish healthcare system?” or “is this something you think you would ask for yourself if you were seriously ill?” Furthermore, we do not have much in-depth information about the reasons underlying the attitudes. In a recent review of international qualitative research on the general public’s attitudes towards assisted dying,²⁵ four main themes could be identified: concerns about poor quality of life, the desire for a good quality of death, concerns about abuse if assisted dying was legalised, and the importance of an individual stance related to assisted dying (Hendry et al 2013). It is likely that similar reasoning underlies the attitudes declared in the current surveys, but this has yet to be confirmed.

Exploring the attitudes of experts and laymen also begs the question of whether or not the responses should be valued equally. If we assume that the participating physicians have a deeper understanding of end-of-life decision-making in practice and thus express more considered opinions, whereas the respondents from the general public more often report pre-reflective views, does this imply that we should pay more attention to the physicians’ attitudes than to the general public’s? The question has no straightforward answer, since it depends on what we intend to do with the results. If we have pursued an opinion poll in order to run a campaign, e.g. for the legalisation of physician-assisted suicide, we might not care very much whether the respondents have reflected upon their answers or not; what we are looking for is numbers speaking in favour of our case. However, the aim of the current studies was not to campaign, but to investigate and explore attitudes and reasoning. Therefore, the questionnaires were designed to engage the participants in ethical thinking, so that even those who had never reflected on these questions before would be constrained to do so while filling out the form. Thus, we not only hoped to gain numbers, but also to get some insight into the reasoning behind the numbers, to be able to generate new hypotheses and perhaps even formulate new arguments. In order to do so, there is no need to value the responses from one group more or less than the responses from another group. The question of how responses should be valued is an instance of a broader issue, namely whether empirical research is at all relevant to normative medical ethics. This topic will be further discussed below; see Significance.

²⁵ Here, the term assisted dying refers to both euthanasia and physician-assisted suicide.

5.1.2.3 Using vignettes

The questionnaires in Studies II and III were based on vignettes in order to encourage participants to engage in ethical reasoning. The method is by no means new; ethics has a long tradition of using imaginary cases for the exploration and testing of general beliefs (Glover 1977:34). However, one may object that the results from the vignette-based questionnaires may be difficult to interpret and the generalisability limited. Furthermore, to take a stance in an isolated case of, say, physician-assisted suicide is a different matter from taking a stance on the more general question of the permissibility of the same measure. For example, I may believe that there are certain situations in which physician-assisted suicide is the right thing to do, but still be against legalising the procedure. Therefore, the attitudes declared in Studies II and III should be handled with some care, and generalisation to other than relevantly similar cases avoided. However, they may still be useful as indicators regarding the general opinion on the different end-of-life decisions and their relation to existing guidelines and regulations. Furthermore, the results may also be hypothesis-generating and thus useful for the design of future research in the field.

Let us take a look at some of the results more specifically. Study II contained three vignettes based on the same theme, i.e. a patient's request to terminate life-sustaining treatment. Factors usually considered ethically relevant, such as type of treatment, prognosis, competence²⁶ and age,²⁷ were varied between the cases in order to explore their influence on attitudes and to increase the generalisability of the results. Accordingly, attitudes differed somewhat between the scenarios, but since several factors were varied it is impossible to tell which one was considered the most important, or why. We may only conclude that a majority of physicians and the general public declared approbatory views concerning a (presumably) decision-competent patient's right to refrain from life-sustaining treatment – views in line with current guidelines and regulations (Socialstyrelsen 2011; SOSFS 2011:7 (M)).

Study III had a different design, since it was based on just one vignette, followed by a few general questions regarding the permissibility of physician-assisted suicide and euthanasia. The attitudes declared in the vignette-based part may by no means be generalised to all kinds of situations where physician-assisted suicide, continuous deep sedation or euthanasia may be discussed. However, they do offer a snapshot of the attitudes towards a less often discussed theme in palliative medicine, namely the case of a progressive degenerative neurological disease with a long palliative phase. Also, the results generate new questions. For example, 43% of the physicians declared an approbatory view of continuous deep sedation when the patient was incompetent, but not yet imminently dying.²⁸ How should these results be interpreted? Do physicians consider it acceptable to disregard the recommendations in this particular case, or do they perceive the recommendations as too narrow and in need of revision in general, i.e. is it a more normative statement? The results do not offer any clues, but call for further exploration.

²⁶ In all vignettes the patients were said to be decision-competent. However, in vignette 2 the patient had a previous history of a suicide attempt, which may have caused some participants to believe that the patient had a reduced capacity.

²⁷ Here age is interesting in terms of being an indicator of remaining life expectancy.

²⁸ According to Swedish guidelines, continuous deep sedation should only be considered in cases where the patient has less than 2 weeks' life expectancy (Svenska läkaresällskapet 2010).

5.1.2.4 *Autonomy*

Arguments referring to autonomy are frequently used in ethical discussions about end-of-life decision-making. Personal autonomy is often understood as “self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (Beauchamp and Childress 2001:58). In order to be an autonomous person, one must not only consider oneself an agent, but must also display decision-competency,²⁹ capacity to exercise one’s decision-making powers (i.e. at least to say yes or no), as well as capacity to revise one’s decisions in the light of new information or experiences (Lynöe and Juth 2009a:36-37).

There are different theories regarding the normative relevance of autonomy. Briefly, its relevance may be understood as a *right* to be respected or as a *value* to be preserved or strengthened. When understood as a right to be respected by others, it may be used as an argument in favour of physician-assisted suicide (Sjöstrand et al 2013). If instead understood as a value, autonomy could be seen as something that should be preserved or even strengthened; a view that has been advocated by representatives from the European Association of Palliative Care (EAPC) and others (Eckerdal 2004:37–41; Materstvedt et al 2003). This standpoint has been used to argue that end-of-life decisions such as euthanasia and physician-assisted suicide (and continuous deep sedation some argue) are impermissible since they extinguish the patient’s capacity to act autonomously (Lynöe et al 2009b; Sjöstrand et al 2013).

When designing the instruments used in Studies I-III, autonomy was generally understood as a right, and thus the arguments referring to patient autonomy were treated as pro-arguments. However, Studies I and III differed from Study II in at least one respect: In Study II we investigated attitudes towards the termination of life-sustaining treatment. The general right to refrain from treatment is a so-called negative right and widely accepted, and the aim was to explore whether this acceptance also included life-sustaining treatment. Studies I and III on the other hand, concerned requests for particular measures. The right to receive a certain treatment or service from someone else is called a positive right (Beauchamp and Childress 2001:358). In Sweden, there is only a limited range of treatments within the healthcare system that patients may claim, i.e. positive rights.³⁰

It may also be worth noting that the pro-arguments in Study II actually contained two aspects of autonomy: autonomous choice as a moral right and autonomous choice (or decision competency) in relation to current law. The participants were asked whether the physician in each vignette should terminate the life-sustaining treatment since a) the patient has a right to decide whether to continue the treatment or not and b) prolonging it would mean coercive treatment of a mentally sound patient. Although these questions are similar, they are not identical. The first one clearly focuses on the patient’s right to decide, to make an autonomous choice regarding abstention from treatment (i.e. a negative right). The second one, however, may be perceived by

²⁹ Decision-competency involves having the capacity to understand information, make a judgement based on the information, to intend a specific outcome and to communicate one’s intention. Beauchamp and Childress 2001:71

³⁰ These include abortion, sterilisation and to some extent the right to information about one’s condition (Lynöe and Juth 2009a:303).

respondents as referring to current Swedish law on involuntary psychiatric treatment. According to this law, a patient with a severe mental disorder, an imperative need of full-time psychiatric care, who is refusing (or unable to consent to) voluntary care may be subjected to involuntary psychiatric care (SFS 1991:1128). In practice, a patient fulfilling these criteria may also be subjected to involuntary *somatic* care, given that the condition is fatal and the patient's refusal of treatment is due to her severe mental disorder (which has prompted the compulsory care in the first place) (Fridén and Silfverhjelm 2010). Respondents who prioritised the second argument may have done so due to being aware of current regulations.

Looking back at the results from Study I and III, it is obvious that physicians and the general public report diametrically different views concerning physician-assisted suicide and euthanasia. There are many possible explanations for this pattern, different understandings of the concept autonomy being one of them. In Study I, as well as in the previous investigation of physicians' attitudes towards physician-assisted suicide (Lindblad et al 2008), the main argument for accepting physician-assisted suicide was respect for patient autonomy, i.e. a view that presupposes that autonomy is understood as a right. However, the physicians presented more restrictive views than the general public, and objection to physician-assisted suicide was frequently associated with the argument that the "non-maleficence principle should override respect for patients' autonomy" (Lindblad et al 2008:725). Prioritising this argument may very well be in line with an understanding of autonomy as a value that should be preserved or strengthened. Since granting the patient's request for physician-assisted suicide would lead to the extinction of the patient's autonomy (given that the patient would actually choose to commit suicide), this act is regarded as wrong. However, other interpretations are also possible. For instance, it has been suggested that physicians' prioritising of non-maleficence over patient autonomy could be a cloak for paternalism (Lynöe et al 2010).

In summary, many participants in Studies I-III have given respect for patient autonomy as the main argument in favour of the end-of-life decisions discussed here; views that agree with results from other studies (Hendry et al 2013). It seems reasonable to believe that these attitudes are a reflection of the shift towards a more patient-centred view within healthcare and ethics which has taken place over the past few decades (Lynöe et al 2009b). The well-known ethicist Raanan Gillon has even stated that among the four primary principles in medical ethics,³¹ respect for patient autonomy should be "first among equals" (Gillon 2003:307).

5.1.2.5 *Non-maleficence*

The obligation to do no harm as formulated in the principle of non-maleficence is often used as an argument against end-of-life decisions which potentially may hasten death (Beauchamp and Childress 2001:117). This was also the case in our studies; in Studies I-II, it was one of the most prioritised contra arguments. However, in Study II the argument was formulated: "The physician's task is to preserve and protect life". This could be interpreted as non-maleficence, i.e. to refrain from harm, but also as

³¹ The four principles are Respect for Autonomy, Non-maleficence, Beneficence and Justice (Beauchamp and Childress 2001).

beneficence, i.e. not only to refrain from harm but to contribute to welfare. However, as Beauchamp and Childress have noted, there is no sharp boundary between the two principles (Beauchamp and Childress 2001:165). Furthermore, the qualitative analysis of free-text comments from Study I and from the previous investigation of physicians' attitudes towards physician-assisted suicide resulted in a list of arguments where non-maleficence was mentioned, for example "Not to harm is more important than patient autonomy". The argument was also formulated in specific relation to physicians, for instance as "It is unacceptable that physicians participate in suicide and euthanasia", "It is unacceptable that physicians actively contribute to a patient's death" and "It is not the task of physicians to assist suicides" (Helgesson et al 2009:22).

However, in order to use the principle of non-maleficence as an argument against end-of-life decisions which may hasten death, one must presuppose that these actions actually inflict harm upon the patient. Let us consider the case of euthanasia. As stipulated already at the beginning of this thesis, euthanasia involves the administration of drugs with the intention to end life at the explicit and voluntary request of a patient. Thus successful euthanasia means the shortening of life/hastening of death. However, whether shortening of life constitutes harm is a further question. A minimal requirement for something to constitute harm is that it is bad for someone. However, it could be argued that in order for death to be bad, it must involve deprivation of a future *good* life.³² However, in the case of euthanasia, death is a way out of ongoing unbearable suffering and, furthermore, inevitable future suffering.³³ At least, many who defend euthanasia hold that it is only defensible under such circumstances. Under such conditions it could then be questioned whether the hastening of death is really an infliction of harm upon the patient.

The principle of non-maleficence is also typically used to support moral rules which may be used as arguments against euthanasia, such as "Do not kill" (Beauchamp and Childress 2001:117). However, like all moral rules, the statement that it is wrong to kill calls for justification. A common view is that the wrongness of killing has to do with the intrinsic value of life, i.e. the sanctity of life. This was inter alia expressed in the free text comments analysed in the qualitative study mentioned above, for instance "Life is holy/It is wrong to play God" and "Human life is so valuable that no one must end it" (Helgesson et al 2009:22). The sanctity-of-life view is by no means uncomplicated, neither regarding the concept in itself nor its implications.³⁴ For example, on some versions of the view, acts that many would consider to be ethically defensible in an end-of-life setting would be forbidden, e.g. the termination of life-sustaining treatment or the administration of adequate pain relief with the possible consequence of hastening death. In order to handle these complications, proponents have traditionally turned to the active/passive distinction as well as the rule of double effect, which will be further discussed in relation to Study IV.

In summary, although the principle of non-maleficence was listed as a contra argument in Studies I-II, it may in fact also be used as an argument in favour of end-of-life decisions which may hasten death.

³² That is, the so called deprivation approach; see Johansson 2005.

³³ For a deeper discussion of harm in relation to death, see Sumner 2012: chapter 1

³⁴ For more on the Sanctity of life-view, see Glover 1977:39-59; Sumner 2012:125-141

5.1.2.6 *Physician-assisted suicide and euthanasia*

The results from Studies I and III indicate that the general public holds more approbatory views concerning physician-assisted suicide and euthanasia than physicians do – results tallying with previous research.³⁵ Interestingly, physicians seem to prefer physician-assisted suicide to euthanasia, a view that is in line with the recommendations of the Royal Dutch Medical Association. The general public on the other hand declare themselves more in favour of euthanasia than of physician-assisted suicide, a view tallying with Dutch practice (Rietjens et al 2009).

But wherein lies the perceived difference between these measures? In Study III, we proposed that it may have to do with the degree of activity: in physician-assisted suicide the physician prescribes the medication for the patient to take, whereas in euthanasia the physician administers the medication. Possibly, some may interpret physician involvement in physician-assisted suicide as a passive act, and thus acceptable. In ethical reasoning regarding end-of-life decisions, the passive/active distinction has traditionally been invoked in order to draw a line between acts (or rather, omissions) that hasten death but are still considered permissible, e.g. withholding life-sustaining treatment, and acts that hasten death but are considered impermissible, e.g. euthanasia. However, even if one manages to construe the act of physician-assisted suicide as passive (at least regarding the physician's involvement) the distinction's moral relevance is still in need of justification.³⁶

Another factor which may be of importance is the degree of responsibility and control; physicians especially may perceive physician-assisted suicide as a safer way to go, since it is the patient who must take the decisive step, thus minimising doubts as to whether it is really the patient's autonomous choice to die. On the other hand, one may question whether this difference between physician-assisted suicide and euthanasia really is so great: in practice, the patient has the same opportunity to say no in both scenarios, except for the very final moment. Some authors have therefore suggested that the difference lies on a symbolic (rather than moral) plane, “[...] in that the patient who is willing to be the direct agent of her own death gives a more unambiguous demonstration of her desire to die” (Dixon 1998).

However, control may also be an explanatory factor in the general public's preference of euthanasia: having a physician present may be perceived as a guarantee of the measure succeeding without complications, as well as minimising the risk of misuse (for example through lethal drugs adrift). This is reflected in statements from the qualitative study partly based on Study I, e.g. “There is a risk that patients will be harmed (without succeeding to commit suicide) if they have to handle lethal drugs without physician supervision”, “Physicians should be present at the occasion of the suicide in order to guarantee that nothing goes wrong, such as wrong dosage or the patient being harmed but not dying” and “Control is required to ensure that the patient does not use the prescribed drugs to harm others” (Helgesson et al 2009:24).

Yet another explanation for the differences in at least physicians' attitudes may have to do with the current legal situation in Sweden, where health-care professionals involved in physician-assisted suicide “only” risk losing their license to practice, whereas euthanasia is a criminal offence.

³⁵ See the chapter on Previous research.

³⁶ For a discussion of the active/passive-distinction, see for instance Sumner 2012:152-164.

Of course, these are but a few factors possibly influencing the response pattern and other aspects not mentioned here may also be involved.

5.1.2.7 Trust

In the previous methodological discussion, it was noted that the results regarding trust in the medical services obtained in Studies I and III may be tricky to interpret, since the questionnaires contained no definition of ‘trust’. However, since no difficulties in answering the questions were reported, it was suggested that the concept may be understandable at face value. Furthermore, the aim was not to explore what trust is constituted by, or how people interpret the concept, but to get a brief account regarding the level of trusting *attitudes* towards the medical services in general, and how these might change if physician-assisted suicide or euthanasia were to be allowed.³⁷ Measurements of trust are conducted on a yearly basis in Sweden, through a national population survey of attitudes towards the medical services. Due to different response options, only the proportion of respondents declaring low/very low trust may be compared to the results from our studies. The proportions displayed in Table 5 indicate that the attitudes from Studies I and III are at least partly in line with those obtained in the national population survey from the same year (2007), as well as a few years later (2010) (Vårdbarometern 2007; Vårdbarometern 2010).

Table 5. Percentages declaring low/very low trust in medical services in Studies I, III and the national population study from 2007 and 2010. The 2007 national population survey, contained two questions on trust, the first regarding trust in hospitals and the second regarding trust in primary care. In 2010, there was also a question regarding trust in the medical services in each county. Since the response options differed somewhat between the studies, only the proportion declaring low/very low current trust can be compared.

| | Proportion declaring low/very low trust (%) |
|----------------------------------|---|
| Study I | 16 |
| Study III | 12 |
| National pop. survey 2007 | 6 (hospitals), 14 (primary care) |
| National pop. survey 2010 | 9 (medical services in resp. county) |

The yearly population survey may also give us some clues regarding factors influencing trust. When comparing results from different Swedish counties, there was a correlation between a higher level of agreement with the statement “The healthcare services I need are available to me” and a larger proportion declaring a high level of trust/satisfaction and primary care availability (Vårdbarometern 2007). Furthermore, in data from later years, common reasons for distrust in primary care and hospitals have

³⁷ Here the difference should be noted between a trusting *behaviour* and a trusting *attitude*. For example, a person who seeks care may display trusting behaviour, but need not necessarily have a trusting attitude. Hence it has been argued that a trusting attitude is a necessary part of trust (Hall et al 2001).

been the following: you do not get the help you need; physicians are not competent enough; malpractice; too little dialogue (Vårdbarometern 2010).

According to these results, the level of trust seems to be connected with previous experiences of care, i.e. satisfaction.³⁸ This relation has been noted by other authors as well. For instance, van der Schee et al discuss the complex relationship between interpersonal trust and public trust, suggesting that public trust in healthcare is influenced by previous experiences of healthcare as well as media images.

Furthermore, public trust is also said to influence how people enter contacts with healthcare providers (van der Schee et al 2007). Although we cannot know for sure, it seems reasonable to believe that similar factors would be considered important by the respondents in Studies I and III.

A common argument against allowing euthanasia and physician-assisted suicide is that it would jeopardise trust in medical services (Beauchamp and Childress 2001:146; Snyder and Sulmasy 2001; Watkins 2005). Evidently, the argument is based on the value premise that trust is a good thing. Furthermore, it seems to presuppose that less trusting attitudes are attended by consequences in terms of less trusting behaviour from patients, e.g., by a weaker propensity to pursue healthcare when experiencing health problems.³⁹ It is this *instrumental* value of trust that is in focus here (McLeod 2011). But then one needs to specify *why* allowing euthanasia and physician-assisted suicide would jeopardise trust. Some authors have suggested that the patient-physician relationship would be endangered, and that it would “undermine the integrity of the profession” (Snyder and Sulmasy 2001:212), but perhaps there are other possible explanations as well.

The purpose of including questions about trust in Studies I and III was to test the argument empirically. The results did not provide any support for the statement that trust in the healthcare system would decrease if physician-assisted suicide or euthanasia were to be allowed; respondents from the general public declared a high level of trust in medical services, along with a conviction that their trust in medical services would be increased or unaffected by the sanctioning of physician-assisted suicide. Furthermore, in Study I, 49% of those declaring low trust stated that their trust would increase if physician-assisted suicide was allowed. The results agree with previous research presented by Hall et al (2005).

However, both our studies as well as Hall’s have the same weakness, namely that respondents have stated what they *believe* would happen to their trust, and not the actual effect of legalisation. Also, the results only tell us what respondents believe would happen to their trust in general, but not more specifically; i.e. would a change in level of trust result in the public being more/less inclined to seek healthcare, would it influence the relationship to healthcare providers etc.? These questions remain unanswered. However, data on trust in the medical services in the Netherlands have shown that trust in medical specialists actually increased between 1997 and 2004

³⁸ According to Hall et al, satisfaction has to do with the assessment of past events, whereas trust is “a forward-looking evaluation of an ongoing relationship” (2001:617). The two concepts are closely related; a trusting patient is more likely to be satisfied, and satisfaction is likely to promote trust.

³⁹ This opens up for questions regarding what constitutes a trusting behaviour towards health care. Previous studies have suggested that trust in physicians is correlated with a range of positive behaviours, for instance adherence to treatment recommendations, perceived effectiveness of care and improvement in self-reported health (Hall et al 2001).

(euthanasia was legalised in 2002), whereas trust in hospitals did not show any significant trend (van der Schee et al 2006). The empirical data thus weaken the argument that legalisation of physician-assisted suicide or euthanasia would have a negative impact on trust in the medical services.

In previous studies, the most common reasons for requesting euthanasia or physician-assisted suicide have been current – and/or fear of future – pointless suffering, deterioration or loss of dignity, loss of autonomy, weakness/tiredness and pain (Chin et al 1999; Haverkate et al 2000; Jansen-van der Weide et al 2005; van Wesemael et al 2011). In the light of this, one may speculate whether a legalisation of physician-assisted suicide or euthanasia may even have a positive impact on public trust in the healthcare, since it could open up for clearer communication about issues surrounding death and dying in the patient-physician relationship, and offer patients under the threat of severe illness a sense of control. Thus it seems as though the trust argument can be used by opponents as well as proponents, and further research is needed in order to explore the suggested connection between public trust and legalisation of physician-assisted suicide/euthanasia.

5.1.2.8 *Vulnerable groups*

The history of suicide in Sweden is also associated with the legend of the so-called *ättestupa*. The story goes that the *ättestupa* is a precipice over which old people or those considered a burden to society were thrown – or threw themselves – in ancient times. Although there is no historical evidence for this legend, it has survived to the present day and is often mentioned in connection with end-of-life decisions (Odén 2005).

Hence, the *ättestupa* is more than just a tale; it is a vivid illustration of a common fear, namely that legalisation of physician-assisted suicide and/or euthanasia would lead to illicit performance of these acts, i.e. the development of a so-called slippery slope, and put vulnerable groups in society at risk. For instance, older people or patients with chronic diseases may start to feel they are a burden to their families and to society, and therefore choose to end their lives.

In Study I, 21% of those in doubt and 30% of those reporting against physician-assisted suicide prioritised the argument “Patients who perceive themselves as burdens may experience pressure to ask for physician-assisted suicide”. However, this argument is based on at least two implicit premises: 1) that such a request for physician-assisted suicide/euthanasia would be granted, and 2) that there is no way of preventing such a request being granted, i.e. no matter how the regulating guidelines are formulated. Just as with the argument about trust in healthcare discussed previously, the argument about risk of illicit use if physician-assisted suicide or euthanasia in vulnerable groups were to be allowed can be tested empirically, i.e. it is a so-called factual argument. In data from the Netherlands and Oregon, no evidence for a heightened risk has been found for the elderly, women or uninsured people. Neither is there support for a heightened risk among poor people, people with low educational status, racial and ethnic minorities or people with non-terminal physical disabilities or chronic non-terminal disease. The only group where a heightened risk was found was people with AIDS (Battin et al 2007). A current review and meta-analysis also concluded that “the administration of medication with a potential or certain life-shortening effect seemed generally to be practiced less often among the elderly, females and less well-educated

patients compared with younger, male or more educated patients” (Rietjens et al 2012:1282). These data seem reassuring, but may also be interpreted in the opposite way; i.e. that euthanasia requests from patients belonging to vulnerable groups in society are rejected to a greater extent. This line of reasoning has been highlighted by feminist ethicist Jennifer Parks, who has argued that feminist arguments “can support conclusions either that gendered perceptions of women as self-sacrificing predispose physicians to accede to women’s requests to die — or that cultural understandings of women as not fully rational agents lead physicians to reject their requests as irrational” (Parks 2000).

On the other hand, the higher prevalence of physician-assisted suicide/euthanasia among men may also be discussed from another perspective, namely suicide risk; it is well-known that although women make more suicide attempts, men more often succeed in committing suicide (Socialstyrelsen 2003). Data from the Netherlands (1993-1999) have indicated that although the combined rate of suicide and euthanasia among people aged 55+ has been stable, the suicide rate has decreased and the euthanasia rate increased (Schudel and Vroom-Jorgerden 2001). Hence it may be argued that when it comes to end-of-life decisions, men are a vulnerable group at risk for illicit physician-assisted suicide/euthanasia. On the other hand, it is also arguable that euthanasia may prevent suicide, since a request for euthanasia is usually followed by a medical examination, offering time for further reflection. Furthermore, euthanasia offers a “safe” death in contrast to a suicide attempt which may be violent or even put other people at risk.

However thought-provoking this may be, it is beyond the scope of this thesis to pursue the discussion further. In summary, the cited studies do not present any data corroborating the development of a slippery slope in the Netherlands or in Oregon. But, numbers are on group level and cannot exclude individual cases of illicit use of physician-assisted suicide and euthanasia.

5.1.3 Significance

5.1.3.1 Empirical research in medical ethics

Why is it interesting to know what Swedish physicians and the general public think about end-of-life decision-making? Or, putting it otherwise, can investigations like these provide anything of relevance to ethical discussions and decision-making? This is a fundamental issue which opens up for questions about methods of moral justification and, more specifically, the role of empirical research in medical ethics.

As mentioned in the introduction, medical ethics involves the identification and investigation of moral conflicts in the field of clinical medicine and medical research. The process of justification is usually initiated by describing the context of the moral question, and here empirical research may be needed in order to answer questions regarding:

- what, why, how, who, where, when,
- the possible alternatives,
- the foreseeable effects (Borry et al 2004).

However, one should not expect empirical research results to be justificatory in themselves; the normative question whether, for example, euthanasia is acceptable also needs a normative justification, i.e. normative arguments or premises. No matter how many people declare themselves in favour of euthanasia, this is not enough to justify

the act (Düwell 2009). It may give us reason to believe that euthanasia is acceptable to common morality, but it does not provide us with sufficient reason to conclude that euthanasia is ethically right – at least not without further argument establishing the idea that whatever is acceptable to common morality is thereby also right. However, such an argument has yet to be formulated and is unlikely ever to be formulated, since the idea seems inherently implausible. But although empirical findings alone cannot determine what is right or wrong, good or evil, they may very well affect the evaluation of an argumentation about what is right or wrong regarding a specific issue. For instance, empirical data contradicting a normative analysis cannot be ignored, but must be taken into consideration. It is simply that one incurs a greater burden of proof when faced with explaining why most people are wrong.

Moreover, in arguments regarding a specific issue, e.g. euthanasia, both normative and empirical premises appear. The practical normative conclusion (e.g. “Euthanasia should (not) be legally allowed”) thus hinges on the empirical premises being correct as well (e.g. “Allowing euthanasia will decrease trust in healthcare”). Hence, empirical investigations can be of great relevance to a specific normative discussion.

Regarding Studies I-III, the results can be categorised into at least three groups: 1) attitudes towards a particular end-of-life decision 2) prioritisation of arguments pro/contra a particular end-of-life decision and 3) influence on trust.

It seems fairly clear that all these categories add information which may contribute to the first, descriptive phase of the justificatory process; by highlighting the attitudes and reasoning at a specific point in time, the data say something about the context surrounding end-of-life questions. Although the data cannot be used as a guide regarding whether the different end-of-life decisions are morally justifiable, they do, for example, provide us with some information as to whether public attitudes are in harmony with current law. They also indicate what kind of challenges policy-makers may encounter when suggesting changes to current guidelines, regulations etc. (Salloch et al 2012). Furthermore, as Loughlin puts it “[...] we need to know what people think, not as logical *basis* for conclusions but as a necessary starting point for our thinking” (Loughlin 2011:972).

However, some of the results may also contribute to a normative discussion. For example, one common argument against physician-assisted suicide says that allowing this measure would have a negative impact on people’s trust in the medical services. This statement finds no support in the results from Study I, where a majority of participants from the general public believed that their trust would either increase or remain unchanged. If the above mentioned argument is to be pursued further, these findings will have to be taken into consideration and discussed.

To conclude, empirical research has an important role to play in the process of ethical reflection, but empirical findings alone are not enough to determine whether a certain action is right or wrong; the moral justification must also contain an analysis of normative arguments.

5.1.3.2 *What’s new?*

What makes the results from Studies I-III interesting? The most obvious reason is that they add information to a field where only a little was known before, that is, about Swedish attitudes towards end-of-life decisions. This snapshot of current views is not

only interesting in itself, but may also generate ideas from which further research may take off (as was the case with Study IV) and be of importance for public debate. Furthermore, some of the data may also affect our evaluation of some of the factual arguments that are a part of normative discussions, as in the case of how a sanctioning of physician-assisted suicide would impact on trust in medical services.

The results regarding continuous deep sedation in Study III raise questions as to whether there is a gulf between current attitudes among physicians/the general public and the existing recommendations. This is something that should be taken into consideration, and further research is needed in order to explore these attitudes further. Also, by including a neurodegenerative disorder such as Huntington's in Study III, we have tried to widen the discussion to include not only cancer, but also chronic disorders with a long palliative phase.

In conclusion, Studies I-III amount to an attempt at exploring attitudes and reasoning in Sweden on the subject of end-of-life decisions more systematically than before. The results provide us with a base for further discussion, and numerous ideas for future research.

5.2 PART II: STUDY IV

Since Study IV is a purely normative philosophical investigation, there will be no discussion here of validity and reliability in the traditional sense. Neither are there any results to examine, since it is the discussion itself that is the 'result'. However, a few words regarding the study's significance may be appropriate. What is the point of conducting yet another investigation of an ancient rule such as the RDE? Well, the most evident answer is that although the RDE has a long history, it is 'still going strong' in the contemporary medical ethical debate. The physicians' comments in Study III⁴⁰ – as well as current guidelines (Läkarförbundet 2009; Svenska läkaresällskapet 2010; Socialstyrelsen 2011) – illustrate how widespread the view actually is that intentions are germane to morality. It is no overstatement to claim that for those against euthanasia and physician-assisted suicide, but in favour of continuous deep sedation and/or adequate symptom relief with the risk of hastening death at the end of life, the RDE – or aspects of it – is the standard kind of justification.

Therefore, the result from our investigation is troublesome, since it leaves the proponents of the RDE with the burden of proof, namely that of composing a justification for intentions having a moral import in the way proposed. Until then, the RDE cannot be used to justify a morally relevant difference between continuous deep sedation and euthanasia.

⁴⁰ See chapter 3.4 Study design: Study IV for more on this.

6 CONCLUDING REMARKS AND FUTURE RESEARCH

At the commencement of work on this thesis, little was known about attitudes towards end-of-life decisions among physicians and the general public in Sweden. In particular, there was a lack of previous research distinguishing physician-assisted suicide from euthanasia, and of research focusing on continuous deep sedation. The empirical studies included here have contributed a snapshot of current opinions on these issues, but also with some insights into the reasoning underlying the declared attitudes. Furthermore, the results have generated new questions and hypotheses which call for further exploration.

One observation has already encouraged further investigations, namely that many physicians ascribe moral relevance to the intention of an act. This finding inspired to the critical analysis of the rule of double effect conducted in Study IV.

Other questions remain to be explored. For instance, the differences in attitudes to end-of-life decisions between physicians and the general public call for further research regarding the underlying moral reasoning. Furthermore, the implications of these attitudes on the clinical end-of-life decision-making process need to be addressed. In particular, the question of continuous deep sedation calls for further investigation, since the results suggest that many physicians hold more liberal views concerning continuous deep sedation than are compatible with present guidelines. At present, only little is known about current practices of continuous deep sedation in Sweden. Questions to be investigated involve frequency, patient involvement in decision-making, physicians' moral justification of the treatment and its distinction from euthanasia.

Furthermore, exploring people's views on what constitutes a good death is also of importance. According to recent empirical data, being diagnosed with cancer is associated with a significantly elevated relative risk of suicide within the first weeks (Fang et al 2012). Many other severe somatic diseases are also associated with an elevated risk for suicide (Fang et al 2008; Haw C et al 2009; Hubers et al 2012). The reasons underlying these results have yet to be explored. However, in the light of data from the Netherlands, which indicate that suicide rate and euthanasia rate may be connected (Schudel and Vroom-Jorgerden 2001) one may speculate that more knowledge about common hopes, apprehensions and fears regarding death and dying could contribute to more personalised care at the end of life.

Not only people's views on these matters need to be explored further, but so does the normative basis of good dying and death,⁴¹ questions which have been only touched on. For instance, as indicated, if wellbeing in life is the only thing of intrinsic value, then death is less likely to be a bad occurrence than if life itself has intrinsic value. As has already been said, matters such as these cannot be settled by empirical investigations, but must be resolved by normative argument.

These are but a few suggestions regarding future research on end-of-life decisions; for sure, the field may be approached from numerous other angles, with the aim of elucidating other aspects.

⁴¹ For more about these kinds of questions, see Sandman 2005

7 SAMMANFATTNING PÅ SVENSKA

7.1 BAKGRUND

Under de senaste decennierna har den beslutkapabla patientens ställning i sjukvården stärkts. Tidigare antogs läkaren i kraft av sitt ämbete veta vad som är bäst för patienten; idag beaktas och respekteras patientens egna värderingar, åsikter och önsknings i allt högre grad. Detta kommer till uttryck i svensk hälso- och sjukvårdslagstiftning, liksom i nationella och internationella konventioner och riktlinjer.

Respekten för patientens rätt till självbestämmande gäller också i frågor som rör livets slutskede. Exempelvis har en beslutskapabel patient rätt att på begäran avsluta sin livsuppehållande behandling, trots att det innebär att patienten avlider som följd av detta. Om beslutet att avstå från den livsuppehållande behandlingen kan ge upphov till förutsebart lidande ska symtomlindrande behandling erbjudas.

Att avbryta eller avstå från att inleda livsuppehållande behandling är alltså tillåtet i Sverige. Det är också tillåtet att ge symtomlindrande behandling i sådana doser att det är en förutsedd effekt av behandlingen att döden påskyndas, samt att söva patienter i livets slutskede, s.k. palliativ sedering. Även självmord och medhjälp till självmord är tillåtet, dock undantaget sjukvårdspersonal. Eftersom sjukvårdspersonal har speciella skyldigheter och förväntas rädda liv samt förebygga självmord, skulle medverkan vid en patients självmord betraktas som underlåtenhet och eventuellt kunna leda till åtal. Det som i dagligt tal kallas för aktiv dödshjälp är inte tillåtet i Sverige idag. Med aktiv dödshjälp avses vanligen antingen läkarassisterat självmord eller dödshjälp. I denna avhandling har läkarassisterat självmord specificerats som att en läkare på en patients uttryckliga och frivilliga begäran förser patienten med en dödlig dos läkemedel i syfte att möjliggöra för patienten att avsluta sitt liv. Dödshjälp har specificerats som att en läkare administrerar en dödlig dos läkemedel till en patient på patientens uttryckliga och frivilliga begäran.

Huvudsyftet med det aktuella doktorandprojektet är att undersöka attityder och resonemang rörande patienters rätt till självbestämmande i livets slutskede. I fokus står åtgärder som att avsluta livsuppehållande behandling, palliativ sedering, läkarassisterat självmord och dödshjälp. Utöver detta ingår en filosofisk utredning av den s.k. doktrinen om dubbel effekt. Denna doktrin säger i korthet att en handling som har både bra och dåliga effekter kan rättfärdigas om syftet med handlingen är att uppnå de bra effekterna, medan de dåliga effekterna enbart är förutsedda men inte avsedda. Den används ofta av motståndare till dödshjälp för att motivera varför behandlingar som ges i syfte att lindra lidande, men med den förutsedda effekten att döden kan påskyndas, bör accepteras.

7.2 ÖVERGRIPANDE FRÅGESTÄLLNINGAR

Vilka argument finns det för att respektera, alternativt inte respektera, en patients önskemål om avslutande av livsuppehållande behandling/palliativ sedering/läkarassisterat självmord/dödshjälp?

Finns det skillnader i hur olika grupper resonerar och vilka skäl de anger för/mot att respektera en patients önskemål i dessa frågor?

7.3 METOD

Doktorandprojektet utgörs av fyra delstudier. Delstudie I-III är enkätstudier som vardera inkluderar ca 1,200 slumpmässigt utvalda individer ur befolkningen i Stockholms län, samt ca 1,200 slumpmässigt utvalda läkare ur olika specialiteter. Syftet är att utforska gruppernas attityder och resonemang samt att jämföra dessa. Delstudie I fokuserar på läkarassisterat självmord, delstudie II på avslutande av livsuppehållande behandling och delstudie III på palliativ sedering, läkarassisterat självmord och dödshjälp.

Delstudie IV utgörs av en filosofisk undersökning av den s.k. doktrinen om dubbel effekt, med särskilt fokus på distinktionen mellan avsedda och förutsedda effekter.

7.4 RESULTAT

7.4.1 Delstudie I

Enkäten syftar till att undersöka befolkningens attityder och argument för/mot läkarassisterat självmord, samt huruvida förtroendet för sjukvården skulle påverkas om läkarassisterat självmord skulle tillåtas, givet ett antal kriterier.

En majoritet av deltagarna rapporterade en tillåtande attityd till läkarassisterat självmord: 73% för, 12% mot, 15% osäkra. Resultaten kan jämföras med läkares attityder, som undersökts tidigare med en liknande enkät (dock ingår den studien ej i avhandlingen). Läkarna rapporterade en betydligt mer restriktiv hållning: 34% för, 39% mot, 25% osäkra. Bland läkarna uttrycktes även farhågor om att ett accepterande av läkarassisterade självmord skulle kunna minska förtroendet för sjukvården; dessa farhågor delades ej av de tillfrågade i befolkningen.

7.4.2 Delstudie II

Fallbaserad enkät med tre olika vinjetter om beslutskapabla patienter som önskar avsluta sin livsuppehållande behandling: 1) en 77-årig dialysbehandlad kvinna 2) en 36-årig dialysbehandlad man 3) en 34-årig man, förlamad i både armar och ben, med respiratorbehandling. De svarande ombads klassificera åtgärden att avsluta behandlingen samt att prioritera argument för/emot.

En majoritet ibland såväl läkare som befolkning rapporterade att beslutskapabla patienter bör ha rätt att avstå från livsuppehållande behandling. Bland befolkningen klassificerade 16% åtgärden som dödshjälp i samtliga tre fall. Bland läkare framfördes denna syn framför när det gällde att avsluta respiratorbehandling; detta klassificerades som dödshjälp av 26% av läkarna. En del av dem som klassificerade handlingen som dödshjälp valde att prioritera argument för att avsluta den livsuppehållande behandlingen: bland läkare var det 18% i fall 1), 19% i fall 2) samt 34% i fall 3). Bland befolkningen var det 35% i fall 1), 20% i fall 2) samt 48% i fall 3).

7.4.3 Delstudie III

Fallbaserad enkät om en beslutskapabel patient med Huntingtons sjukdom som i ett tidigt skede av sjukdomen efterfrågar läkarassisterat självmord, men erbjuds palliativ sedering istället. Patienten avböjer. När patienten är svårt sjuk och inte längre

beslutskapabel efterfrågar anhöriga dödshjälp å patientens vägnar. Läkaren nekar ånyo, men erbjuder palliativ sedering som ett alternativ.

Bland läkarna rapporterade 22% för att patienten skulle få läkarassisterat självmord och 21% accepterade palliativ sedering som ett alternativ till detta. Bland befolkningen rapporterade 59% för att patienten skulle få läkarassisterat självmord och 60% accepterade palliativ sedering som ett alternativ. När anhöriga efterfrågade dödshjälp å patientens vägnar rapporterade 13% av läkarna för dödshjälp och 43% accepterade palliativ sedering som ett alternativ. Bland befolkningen rapporterade 65% för dödshjälp och 61% accepterade palliativ sedering som ett alternativ.

Sammanfattningsvis rapporterade såväl läkare som befolkningen mer liberala attityder i synen på palliativ sedering än vad gällande riktlinjer medger.

7.4.4 Delstudie IV

En moralfilosofisk undersökning av doktrinen om dubbel effekt, med särskilt fokus på avsedd/förutsedd distinktionen. Diskussionen utgår från Daniel Sulmasy omformulerade version av doktrinen, den s.k. ”reinvented rule of double effect”. Denna omformulerade version är tydligare än den traditionella versionen och undviker därmed en del av den kritik som vanligen riktas mot doktrinen. Diskussionen som förs i Delstudie IV syftar dock till att visa att den moraliska relevansen av avsedd/förutsedd distinktionen fortfarande saknar ett rättfärdigande, och att doktrinen därför inte är användbar för att motivera den anförda moraliska skillnaden mellan palliativ sedering och dödshjälp.

7.5 BETYDELSE

Patienters rättigheter inom sjukvården har under senaste decennierna stärkts. Särskilt har respekten för beslutkapabla patienters rätt att vara med att bestämma angående beslut som berör patienten betonats. När det handlar om patienter som befinner sig i livets slutskede och/eller patienter som är beroende av livsuppehållande behandlingar ställs frågan om rätten till självbestämmande på sin spets. I Sverige präglas diskussionen om åtgärder i livets slutskede ofta av begreppsförvirring och individuella ställningstaganden som saknar förankring i den vetenskapliga litteraturen. Behovet av klargöranden av de aktuella begreppen är stort både bland allmänhet och professionella. Undersökningarna förväntas kunna bidra med ett empiriskt underlag för den fortsatta diskussionen, liksom för utvecklingen av framtida riktlinjer.

8 ACKNOWLEDGEMENTS

I wish to express my gratitude to all of you who have supported me during the years of work with this thesis. Without your help, advice and encouragement this book would never have been completed.

In particular, I would like to thank all the participants in Studies I-III for filling out the rather extensive questionnaires, and for sharing thoughts and experiences in your writing. Your contribution made this thesis come true, and hopefully the results of the studies will add some important aspects to the ongoing debate about end-of-life decisions.

Furthermore, I wish to thank all my supervisors. My first main supervisor, Niels Lynøe, I would like to thank for giving me the chance to pursue doctoral studies in medical ethics. This has been no less than a dream come true. Thank you for being present and enthusiastic and for introducing me to the inscrutable world of questionnaire-based research. My second main supervisor, Niklas Juth, I wish to thank for firm support and encouragement in times of despondency and for invaluable comments on texts, no matter whether unfinished sketches or final-phase manuscripts. Niels and Niklas, you have both been truly reassuring and ever-believing and for this I am deeply grateful. To my co-supervisors, Rurik Löfmark and Carl Johan Fürst I wish to say thank you for valuable advice and practical help in the process of designing the questionnaires and for never being more than an email away.

I have also been blessed with a supportive and empathic mentor, Frank Lindblad, who encouraged me to apply for a doctoral position at the ethics unit back in 2006. Thank you for listening to me at moments of both joy and tribulation, and for a very great deal of sensible advice.

At the Centre for Healthcare Ethics I especially wish to thank Torbjörn Tännsjö for invaluable comments and criticism and Gert Helgesson for encouragement and linguistic discussions. To my fellow doctoral students, Manne Sjöstrand and Maja Wessel, I wish to say that it has been a pleasure to undertake this journey towards a completed thesis in your company. Thank you for laughter, good advice, thought-provoking discussions, easy-going lunches, loads of *kexchoklad* and – at last! – sharing a room with a view. Furthermore, to all participants in the seminars at the Centre for Healthcare Ethics I wish to say, thank you for invaluable comments and for contributing to a supportive atmosphere where ideas may grow.

Of course, many other people have in different ways contributed to this thesis. Friends, family and clinical colleagues, not all mentioned but none forgotten, have supported and encouraged me, cheered me up and diverted me. Thank you, all!

Last, but by no means least, I am forever grateful to my love and life companion Wolfram Johnen, for your seemingly endless trust in my ability to accomplish this project and for your patience and support during the last months of intense work. You and Anton make life both meaningful and joyful.

Financial support:

This project was made possible by financial support from the National Board of Health and Welfare, Centrum för Psykiatrforskning Stockholm and the Swedish Medical Association.

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10 APPENDIX

STUDY I

Covering letters and questionnaires

STUDY II

Covering letter and questionnaires

STUDY III

Covering letter and questionnaires