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**END-OF-LIFE CARE AND EUTHANASIA: ATTITUDES OF  
MEDICAL STUDENTS AND DYING CANCER PATIENTS**

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*To Daniel, Hilma and Britta*



## ABSTRACT

**Introduction:** In end-of-life care, supporting the factors required for a good death is a goal. Core concepts in a good death are dignity, autonomy, and the relief of suffering. Paradoxically, these concepts are used both in palliative care and to promote euthanasia, which are traditionally seen as conflicting alternatives. In this thesis, attitudes towards end-of-life care and especially euthanasia were explored in medical students and dying cancer patients.

**Material and methods:** Two separate studies were performed: in the first study, data were collected from 165 medical students using a questionnaire (Papers I and II) and, in the second study, 66 dying cancer patients were interviewed on their attitudes to euthanasia (Papers III and IV). The data were analyzed by inductive qualitative content analysis without predetermined categories.

**Results:** Heterogeneous attitudes to euthanasia were identified in the studies, where the medical students more frequently had a fixed opinion of opposition to or support of euthanasia, while the dying cancer patients were more often undecided. None of the dying cancer patients wanted euthanasia for themselves at the time of the interview. The medical students described a dignified death as involving relief of suffering, respect for autonomy, being nursed professionally in a secure environment, acceptance of impending death, and with limited medical-technical interventions. The students criticized the medicalization of death and preferred a “natural death”. The medical students’ attitudes toward euthanasia were explained using well-known arguments as supporting euthanasia due to respect for autonomy and the relief of suffering, and opposing euthanasia due to the sanctity of life, the fear of unwanted gradual changes in society’s norms (the slippery slope argument), doubts about the true meaning of euthanasia requests, and because of the strain put on medical staff. In contrast to the medical students’ perspectives on euthanasia, the dying cancer patients reasoning on euthanasia was more complex and involved more consideration of practical problems. The patients’ perspectives on autonomy in relation to euthanasia focused on medical decision-making, where aspects of trust and power were important. Euthanasia was not solely seen as a means to increase patient empowerment, but also, in contrast, as a means to decrease patient influence. Patients expressed various levels of trust in healthcare, ranging from complete trust to mistrust, which affected their attitudes toward euthanasia. Dying cancer patients draw varying conclusions from suffering: suffering can, but does not necessarily, lead them to advocate euthanasia. Patients experiencing continued meaning in their existence and feelings of trust, and who find strategies to handle suffering opposed euthanasia. In contrast, patients with anticipatory fears of multi-dimensional meaningless suffering and with lack of belief in the continuing availability of help advocated euthanasia.

**Conclusion:** These results have possible implications for the education of medical students and the understanding of patients’ situations in end of life. The findings indicate a need for healthcare staff to address issues of trust, meaning, and anticipatory fears in patients. The results also serve as a background to the current debate on euthanasia in end-of-life care.



## LIST OF PUBLICATIONS

- I. **Karlsson M, Milberg A, Strang P.** Dying with dignity according to Swedish medical students. *Support Care Cancer* 2006; 14: 334-339.
- II. **Karlsson M, Strang P, Milberg A.** Attitudes toward euthanasia among Swedish medical students. *Palliative Medicine* 2007; 21; 615-622.
- III. **Karlsson M, Milberg A, Strang P.** Dying cancer patients' own opinions on euthanasia: an expression of autonomy? [In press 2011, *Palliative Medicine*]
- IV. **Karlsson M, Milberg A, Strang P.** Suffering and euthanasia: a qualitative study of dying patients' perspectives. [submitted, 2011]

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## **LIST OF ABBREVIATIONS**

WHD	Wish to hasten death
PAS	Physician-assisted suicide

# 1 FOREWORD

Death has fascinated and frightened man throughout the ages. The inevitability and mystery of death puzzles us, and has been contemplated on and dealt with in most of man's creative fields such as in religion, culture, science and art, maybe in an attempt to find a way to handle the deep fears evoked. These are fears of the unknown, of the unavoidable future of our own impending death somewhere in the future, and the cruelty of death forcing us to separate from our loved ones.

You, as a reader of this thesis, might ask yourself why someone would want to spend their working days facing death and its ripping and destroying effects? To have to encounter suffering and sadness everyday, without any possibility to change the fact that death is approaching, and to face those who will be left behind with a void in their lives?

Well, I find many reasons: because of the complex medical problems, of the multi-faceted human problems, all often challenging me personally to the furthest of my abilities to handle well. And because there is more to dying than suffering: demonstrations of happiness, love and friendship. Also, I find that the constant reminder of life's finiteness and unpredictability helps put my own life into perspective a bit.

*Death destroys a man, but the idea of death saves him.* E.M. Forster (64)

When my daughter Hilma, at the age of five, was given an awarded children's book about the death of a guinea pig (149), she listened patiently to the whole story, and then said: Why did they have to write a book about this? They could have written a book about the guinea pig when he was young and healthy instead; that would have been more fun to read.

This is one of those not-so-fun books about death and dying. If you find this less appealing maybe you should, already at this point, consider changing to more cheerful literature.

## 2 BACKGROUND

This thesis will focus on death and dying, but some central concepts in this area will be discussed first: a good death, palliative care, euthanasia, dignity, suffering, autonomy, ethics, and research methods to increase our knowledge on these matters.

### 2.1 A GOOD DEATH

#### 2.1.1 Terminology: Death

When discussing death, for example, *a good death*, there might be multiple interpretations of the term that we need to be aware of. Death can be understood as the phase, still in life, when a person, most often gradually, approaches end of life, in other words the process of dying. It can also be understood as the exact moment of the transition from life to death, the moment when life ceases to be, the event of death. Furthermore, it can also be interpreted as the phase of being dead, and according to some beliefs involves the separation of the dead body and a soul, which continues to exist elsewhere. Or, it can be pictured as a final annihilation, a non-existence, which is difficult to comprehend for a living person. The content of a good death will of course be different according to which meaning you refer to (179). In this thesis a good death will refer to process of dying.

#### 2.1.2 Philosophy and death

In philosophy, especially existential philosophy, man's relationship to death is dealt with. Existential philosophy has developed since the 19<sup>th</sup> century, and deals with core issues of human life, such as how to lead one's life, and of meaning and freedom (211).

According to the American psychiatrist Irvin Yalom, death is an "existential given" that man must relate to during life (225). Being aware of impending death and finiteness of life can cause anxiety, but can also be used constructively to reflect on the choices of life and help one to lead an authentic life. However, being close to the reality of death, the imminence of death, and the idea of the shortness of the remainder of one's life, can cause a crisis.

The German philosopher Karl Jaspers called this situation a "limit situation" in life, and claims it evokes anxiety (97). However, Jaspers sees a possibility of using this anxiety to reflect on oneself and one's life, one's choices, and meaning. By trying to develop acceptance, changes of life might come about to become more true to oneself and therefore to become more content. However, according to Jaspers, it is also possible to fail at this, and to continue a life in despair or denial (97). In addition, the German philosopher Martin Heidegger focused on man's relationship to death, stating that man constantly lives towards death, calling it "being-towards-death" (175). To live fully, according to Heidegger, man must confront his own mortality, which may cause anxiety, but also creates freedom in life.

When discussing death, the status of the body also becomes apparent, since traditional Western medicine places the locus of disease, as well as the major locus of suffering, in the body. In Western society, Kant's dualistic dichotomy of the body vs. the soul has prevailed, where the body is seen as separated from the mind. The personhood is placed in the mind, while the body is *owned*, being something you *have*. A different apprehension has been presented by the French philosopher Maurice Merleau-Ponty, who argued that since we experience the world through our bodies and our senses, we cannot separate these dimensions from each other: we *are* our bodies, we do not merely *have* bodies (139). Therefore, the division between body and mind is cognitively constructed, and not experienced. In a holistic view of the person, which is increasingly used in modern medicine, the person is seen as a complex being with intertwined physical, psychological, social and existential dimensions, which is explicitly stressed in the definition of palliative care (216). This has bearing on the interpretation of suffering in the end-of-life stage, and on the status of the body in suffering (24,25,123,178).

### 2.1.3 History of a good death in Western society

Historically and culturally, there have been different ideals on how to die and what has been considered a good death. How Western man perceived death in ancient times has been studied by for example the French cultural historian Philippe Aries (7) and the British sociologists Tony Walter (208) and Allan Kellehear (106).

#### 2.1.3.1 *The traditional death*

Power over death was, until the development of medicine and science, out of man's reach. Death was something most people had an everyday experience of. It was a reality in life, taking place in society, at home. Lives were fragile, people died from acute diseases, accidents, or in battle, and death was accepted and viewed as an important moment that decided the fate of the soul in the after-life, in terms of divine judgement, and was handled by rituals. The church was the authority on death, being presented by a priest/clergyman. There was even a (Christian) genre of literature on how to die well, the *Ars Moriendi* (61), which focused in particular on the importance of rituals just before death for repenting sins and affirming faith in God. Aries named this phase the *tame* death, referring to death as not being a stranger, or something you could oppose (7). Walter calls it a "traditional" death (208). Kellehear separates the "stone age", when death was sudden and unanticipated, from the "pastoral age", when focus came on an anticipated good death (106).

#### 2.1.3.2 *The modern death*

In the 19th century, man began to be able to affect the process of dying, by the administration of drugs to relieve pain, and as modern medicine developed, doctors were able to do more and more to help the dying with symptom relief and comfort. Science, among other things, made people question religion, and secularization of society began. People moved into cities, living together with strangers. In the 20th century, the development of medicine and medical technology made it possible for man to fight and postpone death. More and more people could continue to live despite severe diseases, with increased health, hope for a cure, longer lives, and reduced suffering. The focus of care was transferred from comfort and relief, to hope for a cure.

In addition, the location of care, for both for the sick and the dying, was transferred from the individual home to hospitals, which in some way made death hidden from everyday life. The power of medical decisions, and therefore over death, was transferred from the church and the individual to medical professionals. A medicalization of death took place. Aries calls this phase the wild or forbidden death, meaning that death was no longer being counted on, and no longer took place in public, but was hidden and unwanted (7). Walter calls it the modern death, where science, medicine, and technology are authorities, being presented by physicians (208). Kellehear refers to the “age of the city”, where a chaotic life in city made people aspire for a tamed and well-managed death (106).

#### 2.1.3.3 *The neo-modern death*

Medical and technical developments during the 20<sup>th</sup> century have had the effect that, in Western society nowadays, death is mostly caused by gradual decline from a chronic disease, and more seldom by sudden events. Walter points to a development in society during recent decades where the neo-modern (or post-modern) society has adopted ideals on individualisation, autonomy, and independence. In the neo-modern society, the self is seen as the authority. Walter calls this the “neo-modern” death, where the importance is to personalize and control death according to one’s own personal views and preferences, for example, in terms of place and timing (208). Kellehear refers to the “cosmopolitan age” in pluralistic global societies, where death is seen as shameful, and focus is on the timing of death (106).

#### 2.1.4 Critique of medicalization of death

During the second half of the 20th century, there was criticism of how people were treated in modern medicine, with too much focus on prolongation of life and not enough on symptom relief and solace. The medical care created situations of suffering, where life without meaning and quality is maintained, in spite of the personal wishes of the patient and the family, whose autonomy is disregarded. Death was beginning to be viewed as a less bad alternative in some situations (180). Protests against the medicalization of natural parts of life such as childbirth and death began, and alternative movements in medicine developed in the 1960s and 1970s, for example, natural birth care (9).

These protests created reactions in several countries; for example, in Great Britain the palliative care movement focused on dying patients and their suffering (180,49), and in the Netherlands, euthanasia was introduced as a protest against medical power and a means for the empowerment of dying patients (86).

#### 2.1.5 Attitudes to a good death today

Attitudes to a good death differ, and can be related to factors such as culture, religion, and individual preferences, and also change over time, as presented above. In modern Western society today, among the general public as well as people with disease, some prefer sudden death, not anticipated and not preceded by any suffering. Another ideal is a prolonged death with gradual deterioration at an old age, with as few distressing symptoms as possible (76,82,128,169,209).

A good death has also been described in different scientific fields, such as sociology, psychology, and ethnography. Clark has described a *good death* in modern Western culture as comprised of a pain-free death, an open acknowledgement of death, a death at home surrounded by family and friends, an aware death with conflicts resolved, death as personal growth and death according to personal preference (38). Weisman's description of an *appropriate death* has had a great impact on palliative care, and is defined as a death with (1) resolved and reduced conflicts; (2) compatibility with one's own view of oneself achieved; (3) important relationships being preserved or restored; (4) and fulfilment of a wish being brought about (214). McNamara describes the *good enough death*, a definition focusing on the individuality of personal choices, where something is good because it is wanted (137). A good enough death is a death in accordance to personal choice or with the life lived by the dying person. She criticizes the normative aspects of the hospice movement, where a good death is supposed to contain certain elements such as awareness and acceptance.

## **2.2 END-OF-LIFE CARE: PALLIATIVE CARE**

In Great Britain, the hospice movement and the development of palliative care were started in the 1960s by Dame Cicely Saunders. They have since developed all over the world, with specialist palliative care available in many regions, and with research on the situation of dying people and ways to alleviate their problems performed globally. The World Health Organisation's definition of palliative care is as follows:

*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.(216)*

As stated in this definition, according to the palliative care philosophy, human suffering is seen not only to be of physical origin, but also psychological, social, and existential/spiritual. Man is seen as a social being in a social context, most often having family and/or friends who are affected by the dying person's situation and therefore need support as well as the patient. The goal of palliative care is to support the creation of a good end of life by the dying person, with quality of life until the end and a good death with great respect to the person's autonomy (216).

## **2.3 EUTHANASIA**

As mentioned above, in the Netherlands a debate started in the late 1960s on the medicalization of death, on futile care, and of the suffering of patients with severe diseases and injuries being kept alive by modern medicine. Euthanasia was suggested as a solution to these problems. After a court ruling in the Netherlands in 1973, when the court decided not to penalize a medical doctor who had euthanized a patient at her request, a practice of depenalization of euthanasia started. If a doctor fulfilled a fixed

set of requirements when performing euthanasia, he/she would not be punished, even though it was still illegal (86). This arrangement continued for almost 30 years and, according to official surveys, about 2,700-3,500 deaths/year were believed to be due to euthanasia in the Netherlands, which constituted about 2-3.5 % of all deaths (152). Surveys also showed the existence of the practice of medical killing of patients without their request, namely *in-voluntary* or *non-voluntary* euthanasia, numbering about 550-1.000 deaths/year, which constituted about 0.4 -0.8 % of all deaths (152).

In the 1990s, palliative care was also developed in the Netherlands, and co-exists with the practise of euthanasia, although it is often not provided by the same organisations (77). In addition, in Great Britain there have been attempts to legalize euthanasia or PAS, most recently in 2010, although they have yet to be successful (201).

### 2.3.1 Terminology: Euthanasia

The term euthanasia can be interpreted in several ways, and a general problem in debates and research on euthanasia seems to be the lack of common definition of the term. Euthanasia is derived from the Greek for “good death”. In the Netherlands, euthanasia is defined as “the intentional medical killing of a patient upon his/her request” (134).

#### 2.3.1.1 *Active, voluntary euthanasia*

The terms *active* euthanasia, and *voluntary* euthanasia, are also used for the same action. The term *active* refers to the action of administering drugs to kill the patient, whereas omitting to save/prolong life or discontinue life-support is sometimes named *passive* euthanasia.

There is a debate on the moral status of passive euthanasia, in which consequentialists tend to conclude that, since both actions (administering drugs and discontinuing life-support) have the same outcome or consequence (the patient dies), these actions are morally similar, and it is therefore logical that they are both named as forms of euthanasia. However, from a deontological perspective, there might be a moral difference depending on exactly what or who is responsible for a death: health care (when injecting a deadly dose) or a disease (when omitting to treat an infection and letting nature take its course). In modern medicine, medical technology makes it possible to prolong almost all lives for a short while when dying. This is often not desired from several aspects; delaying the inevitable death and prolonging suffering, and to the use of limited resources. The term “futile medical care” is used, which means when interventions no longer are deemed to benefit the patient, and life-prolonging interventions therefore are omitted. Therefore a refusal to administer treatment at the end-of-life stage can be seen as a normal part of modern medicine, and thus some argue that no special term is needed. In other words, this should be referred to as a normal medical procedure, and the term “passive euthanasia” should not be used (134). Some argue that, from a legal and semantic perspective, what is referred to by “passive euthanasia” is not a kind of euthanasia, since it does not fulfil the criteria of intentional killing, and thus should not be called euthanasia at all.



### 2.3.1.2 *Involuntary, non-voluntary euthanasia*

According to Dutch law, euthanasia must be voluntary: however, in the Netherlands official surveys have shown that the practise of the medical killing of patients without their consent has occurred. If the patient is mentally competent but has not requested euthanasia, and despite this is killed medically by his/her doctor, then the term *involuntary* euthanasia is used. If the patient is not mentally competent, and is killed medically by his/her doctor, the term *non-voluntary* euthanasia is used. Some argue that since these last two examples do not fulfil the criteria for euthanasia, these terms should not be used (134). Both involuntary and non-voluntary euthanasia are illegal in the Netherlands.

### 2.3.1.3 *Physician-assisted suicide*

If a medical doctor were to prescribe a lethal drug with the purpose of killing the patient upon his/her request, and the patient administers the drug (orally) him- or herself and dies, it is called *physician-assisted suicide* (PAS) or *assisted suicide*, which is also seen by some as a form of euthanasia (134).

### 2.3.1.4 *The doctrine of double effect*

A related concept in end-of-life care is the “doctrine of double effect”, where the intention of an action is regarded as important. The concept refers to when an action with a good intention is justified although it simultaneously has other, not intended (but possibly foreseen), effects. In reality in end-of-life care, this refers to when the administration of drugs to relieve severe symptom might shorten life, even if this is not the intention. From a consequentialist point of view, there might not be a moral difference between this and euthanasia, since the outcome is the same (drugs are administered, and the patient dies), and it should therefore be called euthanasia. However, according to other theories such as deontology, these actions are not morally equivalent, and different terms should be used. In Swedish law, this is not regarded as euthanasia, as long as the dose of drug used is reasonable to relieve the symptoms.

Since it is possible to take different ethical positions on these different practices, and to have different attitudes towards them, it is important to clarify in debates and research on euthanasia what is referred to.

## 2.3.2 Euthanasia today

For the latest 40 years, euthanasia has been debated all over the world, and attempts to legalize it have occurred in many countries, although most of them have been defeated (201-205). However, over the last 15 years though, a few countries have passed laws on euthanasia and/or physician-assisted suicide, but this seems to foremost be a project in Western countries, as those in Europe, the US and Australia. However, in Asia the debate is ongoing with attempts to legalize the practise in India and Japan. In South America, euthanasia is in a legal limbo in Colombia, and in South Africa, a legal attempt was made (29,206).

In 2001, the Dutch authorities passed legislation on euthanasia, and the law entered into force in 2002 (159). The law stipulates several conditions under which euthanasia is permitted, as described below in 2.3.3. The Dutch government has been trying to keep

tracks of the use of euthanasia by anonymous surveys since the 1990s, which have shown a slight decrease in the practice in the last five years. These surveys have also shown that the practice of involuntary/non-voluntary euthanasia has decreased, but is still significant (550 deaths/year, which makes up 0,4 % of all deaths) (89,152).

In Belgium, a law on euthanasia similar to the Dutch law was passed in 2002 (160). Recently, in 2009, a law on euthanasia was also passed in Luxembourg (161), although only after some controversy. The Dutch, Belgian, and Luxembourg laws all require the patient to be a resident of the country and to be known by a physician in the long term, in order to be accepted for euthanasia, which makes it impossible for “death-tourism” to develop, although this constraint has been questioned (141).

In Switzerland, on the other hand, “death-tourism” is increasing. This may be due to the Swiss laws that make the prescription of drugs to foreigners possible, and the decriminalization of assisted suicide (18). The Swiss professional codes of doctors do not permit them to participate in a professional capacity, but they can participate if they wish, in their spare time, as fellow humans. There are several Swiss associations related to assisted suicide that have gained a lot of attention globally. These include *Exit* and *Dignitas*, which for a substantial fee, supplies drugs and premises for a person wanting to commit suicide. There are no official statistics on how many deaths each year are caused by assisted suicide, but, according to the association, about 150-200 deaths/year are results from their work (63). There was an official attempt in 2010 to restrict the activities of these organisations, but it failed (52).

In the United States, physician-assisted suicide (PAS) has been legalized since 1997 in the State of Oregon, only for residents of Oregon. The law requires the patient to be terminally ill, to have an estimated length of life of less than six months, and is called the “Death with Dignity Act” (162). In 2008, a similar law was passed in the State of Washington, named “The Washington Death with Dignity Law” (163).

In the State of Montana in 2008, a court verdict ruled on a case of PAS that no punishment would be given, since PAS was ruled as legal given the state’s constitution (196). This ruling can be seen as a precedent, and therefore might serve as a basis to depenalize euthanasia. The reasoning for this verdict was presented by the judge as follows: a central theme in the constitution of Montana relates to the citizens’ dignity, and since dying from a severe disease can be undignified, physician-assisted suicide might enhance dignity for the residents, and therefore it is legal. This has not been formally set though, and is still debated legally.

### 2.3.3 Legal requirements for euthanasia

The laws regulating euthanasia in Belgium, Luxembourg and the Netherlands all have certain prerequisites that stipulates under which circumstances euthanasia is legal (159-161,187). The laws stipulate that the request for euthanasia must be voluntary, persistent, well considered, and well informed (an autonomous decision), that the person must suffer intolerably (or unbearably, different translations), with no hope of alleviation or improvement. Regarding life expectancy, the text in the laws differ between the countries, with Luxembourg law requiring the person to suffer from

terminal illness with a life expectancy of less than six months. The Belgian law mentions medical futility, while the Dutch law omits mention of life expectancy. The request must be assessed by two physicians who both agree. In the Netherlands the patient must be older than 12 years old, but must consult the parents until 16 years of age, after he or she can decide independently. In Belgium and Luxembourg only patients over 18 years old can request euthanasia.

#### 2.3.4 Attitudes to euthanasia

Attitudes to euthanasia have been studied in many different populations, and the findings vary between different groups. There have been studies of the attitudes in general populations in different countries, the result of which may reflect different cultures and religious beliefs. There have also been studies of attitudes in different professions, including health care, some with a focus on different medical specialities (210). When studying the attitudes of dying patients, the focus of research has mostly been on identifying those with a wish for a hastened death, and to explore the motives behind this wish. A general problem comparing results from different studies, is the different wording in questions posed, since this has been shown to affect the results (81).

##### 2.3.4.1 *General populations*

Previous studies on euthanasia have shown large variances in opinions correlating to differences in age, profession, religious belief and country, and can change over time (51,59,69,111,124,134,167,182,215). Young people have been shown to be more positive to euthanasia than the elderly and the general public (40), and lawyers appear to be more in favour of euthanasia than the medical profession (69,167).

##### 2.3.4.2 *Medical students*

Studies of medical students' attitudes to euthanasia have shown that variations in the attitudes may be correlated to different settings, countries, and times (1,3,79,213,218). Medical students are shown to have a less positive attitude to euthanasia than the general public, and also when compared to non-medical students (182). In addition, physicians are shown to have a less positive attitude to euthanasia, than the general public (170); however, medical students have been shown to be more positive to euthanasia than physicians (130). In studies comparing medical students at the beginning and at the end of their studies, their support for euthanasia seems to decrease throughout their studies (39,80). These previous studies have mainly consisted of quantitative explorations of the distribution/numbers that support or oppose fixed arguments on euthanasia (79,182,183,213,218). To our knowledge, no studies have explored the students' arguments and active reflections that they use to support their views.

##### 2.3.4.3 *Dying patients*

Among the terminally ill, studies have been conducted that indicate a positive attitude towards euthanasia in general; however, few dying patients express a personal wish for it (20,58,198,220). There are studies showing that cancer patients have an increased wish to die, demonstrated by suicide rates in cancer patients. Bolund et al. demonstrated that in Sweden, cancer patients commit suicide more often than the

general population (5,6). It has also been shown that cancer in certain sites with bad prognosis (lung, head and neck and pancreas) is connected to higher suicide risk (14). Studies also show that the suicide risk is most elevated after diagnosis (62), and returns to normal five years after diagnosis (142). Among the terminally ill, the proportion of those with a wish for hastened death (WHD) differs greatly between studies (1-100%), possibly being connected to study design, study population, definition of euthanasia, and differences in context such as the culture and religion of the subjects (143,174,195).

So far, there is a considerable number of studies of the sub-group of patients having a manifest and expressed WHD, but there have been few studies on the attitudes to euthanasia of dying patients irrespective of the presence of WHD or not. The studies of motives of WHD have been conducted in countries permitting euthanasia (the Netherlands and Belgium), in a US state permitting PAS (Oregon), as well as in countries where euthanasia is prohibited. Through different study designs patients with a WHD have been identified, and their motives for wanting to die have been examined. The study groups have consisted of both patients dying from cancer and/or other diagnoses. This has either been achieved by examining them personally in interviews or assessment scales, or by examining them secondarily through next-of-kin or medical staff. The studies have been performed by using both quantitative and qualitative research techniques.

Most research is driven from examining researchers' hypotheses. In the studies of terminally ill patients with a WHD, there seem to have been a development over time in terms of the hypotheses related to the major motives behind WHD. The early studies focused on pain and physical motives, but the focus has changed over the years. The phases presented below indicate these changes, but are not to be taken at exact face value in chronological order or as being completely separate. This is my personal interpretation of trends, overlapping to some extent in time and concepts.

1. *The pain and physical phase:* The first studies focused on the level of pain among those with a death wish. Investigations failed to demonstrate strong correlations between levels of pain and WHD (20,22,57,70) and focus was then shifted to other physical symptoms. Studies have demonstrated some correlations to physical symptoms such as dyspnoea, fatigue and lack of appetite and sleep (147,148,191).
2. *The depression phase:* Focus then shifted to the psychological suffering of patients with WHD. Many studies have demonstrated a correlation between depression, anxiety and WHD (4,119,148,191,220). Several studies also showed that dying cancer patients have an increased incidence of depression, compared with the general population (20,31,119,198,222).
3. *The burden phase:* Several studies examined the role of suffering in a social dimension, and showed that for example, poor social support and/or feelings of being a burden to others correlates with WHD (71,73,107,108,138,150). Chochinov et al. compared the feeling of being a burden, to the actual degree of physical dependency, and found no correlation (36). An Australian study

demonstrated another type of social effect, which indicated a connection between factors related to clinicians' attitudes and patients' wishes to hasten death: specifically, the doctor's willingness to assist the patient in hastening death was one significant factor predicting the probability of such a wish (109).

4. *The existential phase*: Existential suffering has also been shown to correlate to an increased WHD: lack of a sense of dignity, feelings of hopelessness, and lack of meaning (33,35,145,146,220).
5. *The pre-emptive phase*: Studies have shown that WHD is correlated more strongly to a fear of future suffering than to suffering at the present time (54,71,98,150). WHD and thoughts of euthanasia can be seen as mental strategies to endure life and a pre-emptive solution to an uncertain and frightening future.
6. *The personality phase*: Recent studies have indicated correlations between personality traits and WHD. Patients with neuroticism have been shown to have a stronger wish to die (37), as have patients with avoidant behaviour (72). Attachment theory is a psychological model of how our relational experiences with key figures (parents or similar) during development form our internal working models on how to attach to others (19). This has an impact across our lifespan on the quality of close relationships, social interactions, and behaviour. There are different attachment orientations (secure, anxious, avoidant, disorganized), where anxiously attached individuals tend to fear abandonment and to worry about the availability and closeness of others, and avoidantly attached individuals tend to believe that they should not depend on others, relying only on themselves. Studies have shown correlations between anxious attachment style and WHD (171,173).

There are some studies indicating that the intensity of WHD fluctuates in patients at the end-of-life stage, and that these wishes can change frequently (98), even within a single day (30). In a study where patients were followed up over a couple of months, many of the patients who initially had WHD subsequently lost it, while others newly expressed it (58). Other studies show opposing results, where WHD instead is stable and enduring (150).

## **2.4 DIGNITY**

As seen in the examples of laws on PAS above, dignity is a core concept and argument used to support euthanasia (162,163). The term dignity is also often seen as an important component in palliative care; for example the government commission report on palliative care in Sweden was named "Dignified Care at the End of Life" (113).

A death with dignity is considered good and a death without dignity is feared (112,158). The importance of dignity in dying is expressed by both patients and caregivers as well as in philosophical and political contexts (99,135,162-164,196,200). In a study of terminally ill patients, those who described a great loss of dignity were

much more likely to have lost the will to live than those with an intact sense of dignity. (33). Studies have shown that loss of dignity, or fear of loss of dignity, are among the most common reasons for requests for euthanasia (112,125). In conclusion, dignity when dying seems important and has positive connotations.

Despite this, the term is seldom clearly defined, and has empirically been shown to have numerous potential meanings in different individuals (34,127,190). According to the findings of Chochinov et al. in their studies of dignity in dying patients, dignity at the end of life can consist of a broad range of dimensions, varying from issues directly related to the symptoms of the illness, intrinsic dimensions within the patient on handling his or her own perspectives and practices promoting dignity, and social dimensions concerning relationships and support (34).

A thorough analysis of the concept of dignity was performed as part of a European project on Dignity of Older Europeans (151), and the analysis suggested that there are four types of dignity:

1. *human dignity*, which all human beings have irrespective of their function, and which cannot be lost, as long as the person is alive.
2. *the dignity of merit*, a type of dignity that depends on formal positions and rank, which can be won and lost.
3. *the dignity of moral stature*, which depends upon the behaviour and character of the person according to morality and virtue, which can be won or lost due to morality of actions.
4. *the dignity of identity*, which is connected to integrity and self-image, and depends of both the treatment of others and personal internal perceptions.

Maybe individuals construct their personal dignity from these types of dignity in different proportions, which can explain the varying meanings of dignity in individuals found in previous studies. For example, someone who has always considered his or her social ranking as an important part of his/her self-image, reacts when becoming ill and having to leave work and accept help with daily activities; both dignity of merit and dignity of identity might be violated, causing suffering. However, for someone who has not shaped his/her dignity through social rank, but from the dignity of moral stature, by being a good person, losing his or her job might not harm the personal dignity much. Since healthcare staff are important agents who contribute to shaping the end-of-life situation, their personal view of dignity might guide them consciously or not. Little is known about medical students' attitudes to a dignified death and of what they consist. Their view of a dignified death might affect their future work as physicians and their handling of end-of-life care, and is therefore interesting to explore.

## **2.5 AUTONOMY**

### **2.5.1 Individual autonomy**

The term autonomy is defined as the “right to self-government and moral independence” (140). In Western society, individual autonomy is perceived as a human

right. The general norm is the existence of a right to make own moral choices and handle one's own affairs, and a duty to respect the personal decision-making of others. Patients' free choice, consent, and control are therefore central in healthcare today (11,207). The principle of autonomy is one of the cornerstones of medical ethics (11,207). Euthanasia is often promoted in the name of free choice, and patient autonomy is used as a main argument (11,91,118,166,167). In countries where euthanasia is permitted, such as Belgium, Luxembourg, and the Netherlands, patient autonomy is considered an important cornerstone in the legal regulation of euthanasia (159-161).

### 2.5.2 Relational autonomy

However, there is a critique of the concept of individual autonomy on the grounds of the excessive focusing on individuality and independence. Critics say that this is not how humans live and function in real life: people exist in a social context, depend on each other, and affect each other constantly. People tend to rely on each other, and are not as independent as the ideal describes; they form their attitudes collectively in relationships (126).

The concept of "relational" autonomy has been brought to attention by feminist ethicists, who criticized the ideal of individual independence (47). As an alternative view, they stress the important role that relationships have, and argue that people's identities are shaped through social relationships, both on a personal level and on a group level as being part of a gender, an ethnicity, and a class. According to Donchin, it is necessary to broaden the view of autonomy and recognize its relational component, which makes it more complicated than is often appreciated (47).

The importance of autonomy and social components in relation to patients' requests for euthanasia have been illuminated in previous studies, where relational aspects are often present. For example, McPhearson et al. showed that consideration of family is one of the most prominent arguments used by those requesting a hastened death, for the reason of feeling like a burden on the family (138).

### 2.5.3 Conflicting views

Another potential problem when focusing on the right of execution of personal autonomy is that individual autonomies can collide. If my autonomous choice includes someone else's action, for example, to have something done to me by someone else, the other person also has an autonomy that is to be respected. If that person's autonomous choice is to not perform this task, our autonomies collide. Therefore, it might be difficult to have individual autonomy as a sole norm.

In addition, American bioethicists Beauchamp and Childress state that the relational aspects of autonomy can be integrated into the concept of individual autonomy, by the individual choice to rely on others in decision-making (11). The excessive focus on autonomy and independent decision-making in healthcare is sometimes the result of a misunderstanding of the concept, according to them.

## 2.6 SUFFERING AT END OF LIFE

Alleviation of suffering in end-of-life stage is an important goal in palliative care (181,216). It is also used as a main argument to justify euthanasia, since death can be seen as preferable to ongoing life with suffering, and therefore death alleviates suffering (11,84,85,118,166,212). However, there is no consensus on what suffering consists of, which suffering is intolerable, and how it is formed (105).

There are discussions of the preciseness of the concept of suffering, and of the level of embodiment of suffering. The level of embodiment concerns how much of the suffering is about the physical body, and how much is perceptual (105). Eric Cassel criticizes physicians of often misunderstanding the nature of suffering due to the traditional mind-body dichotomy, where bodily suffering is regarded as objective and “real”, while psychological suffering is subjective and not therefore not truly “real”. In Cassel’s theoretical definition of suffering, the personal interpretation of suffering is central, and he expresses that suffering is “an affliction of persons, not bodies” (28). He states that suffering is experienced when the personal identity is threatened, control is lost, and a state of distress threatens the ‘intactness’ of a person. Others mean that suffering is composed of different proportions of the following: a bodily experience, a psychological experience, a social role, or mainly grief and loss (105). In studies of suffering in dying patients at a hospice, the patients viewed pain and suffering as different entities (8). There are also epistemological differences in the apprehension of possibilities to understand the suffering of another person, where some mean that it is a completely subjective experience and therefore impossible to understand someone else’s suffering (105).

As mentioned above, the existence of intolerable suffering is one of the legal prerequisites for euthanasia in Belgium, Luxembourg and the Netherlands (159-161). However, there are no clear definitions of what constitutes intolerable suffering in the law, which makes the assessment by physicians subjective (46). Previous studies in the Netherlands have shown that there are differences in the assessment of intolerable suffering between physicians, and that there seems to be a preference for judging physical suffering as intolerable rather than suffering from other dimensions (23,154,168,199).

When studying the motives of patients who have actually requested euthanasia in countries where it is legal, aspects of suffering are commonly identified (23,46,74,75,88,96,187). However, in contrast to physicians’ preferences for seeing physical suffering as intolerable, studies show that physical dimensions is not the most prominent motive for patients’ WHD, but rather that suffering from psychological, social, and spiritual dimensions is more important (31,35,74,94,143). This corresponds well to previous research on the suffering of patients at the end-of-life stage generally (21,32,46,74,96,107,138,143,154,171,174,187,220,221). Previous findings also support the connection between anticipatory fear of suffering and WHD (71,98).



## 2.7 ETHICS

Ethics covers the nature of morality, that is, what is right, what is good and what conduct is right respectively wrong. An ethical problem arises when several justified arguments collide, and there is a conflict on what is right or wrong. Euthanasia is one of the classical ethical problems in bioethics.

### 2.7.1 Normative vs. empirical ethics

There are different types of ethical enquires and ethical deliberations. In normative ethics the goal is to find the appropriate ground if moral reasoning and the morally appropriate or justified alternative of action, for example what is the right thing to do in this situation, and why is it right (11). This often involves the application of theoretical ethical reasoning from given premises, then the application of arguments from different ethical theories, and analysis of consistencies and inconsistencies in reasoning. Dominant ethical theories include consequentialism, deontology, virtue ethics and feminist ethics (also known as caring ethics) (43-45,117). The position on value theory also affects the ethical deliberation, since opinions vary if one considers that there are absolute values that are intrinsically good or bad, or if a more relativistic value theory is used (something is good when someone considers it good) (13).

Empirical ethics (sometimes called descriptive ethics) does not attempt to solve an ethical problem, but instead to examine how people conceive ethical problems and how they reason morally (11,17,120,217). While normative ethics tries to find how an ethical problem *ought* to be solved and to find justifications for this, empirical ethics try to describe how an ethical problem *is* conceived. There are several reasons why solely using normative ethics to reason on an ethical problem may be problematic: there may be several norms that contradict, and it is not clear which are to be used, especially in contemporary societies, where there is seldom a shared normative framework, and there might also be a discrepancy to the lived normative ethics of people (114). When trying to solve an ethical problem by using normative ethics, ethicists sometimes try to simplify the problem to make it less complex and less ambiguous, in order to make the analysis clear. By doing so, they often face the problem that the usefulness of the advice is lessened, since the transformed problem no longer is realistic (120).

Empirical investigation of a moral problem has many potential benefits. According to Leget et al., these include 1) to discover the, for ordinary people, morally relevant ethical problems, instead of those problems theoretically interesting for ethicists, 2) to fully describe a moral problem, which in real life can be much more complex than when contemplated theoretically, and 3) to describe the effects and alternatives, foreseen or not, intended or not, that a normatively weighed policy might have (120). Therefore, the role of empirical ethics may be as a complement to normative ethical reasoning, and to increase the relevance of the moral deliberation, by more fully understanding the complexity of the actual problem and the consequences of actions (115).

In ethical deliberation of euthanasia, the studies of motives behind euthanasia requests or WHD provide a good examples of why empirical ethical inquiry is needed. The pre-

conceived notions and theoretical reasoning might not accurately reflect the actual situation (as seen above in 2.3.4.3), and therefore a solely normative ethical deliberation on euthanasia without consideration of empirical evidence might lack validity owing to insufficient premises.

## 2.7.2 Empirical studies on end-of-life care: choice of populations

In this thesis, the choice of populations were set on medical students and dying patients. They were chosen due to having unique and important roles and experiences, which might affect their attitudes and make them differ from those of the general public. Knowledge of their attitudes is important for the understanding aspects of euthanasia, as well as understanding their unique situations.

### 2.7.2.1 *Medical students*

Medical doctors have an important role in the making of a good death, in the practical application of the concept of dignity due to their participation in end-of-life decisions and by influencing the environment around the dying patient. In addition, if euthanasia were to be legalized in Sweden, it might be as in almost all other countries with euthanasia laws, the medical doctors who are supposed to carry out the task of medically killing patients. Therefore physicians' perspectives are important. Medical students are young and gradually developing an identity as doctors throughout their education (144,186). Since values change over time, a new generation might bring different opinions into the medical profession, but they might also change their views when assimilating to their new professional identity. In pedagogical research, it is established that the learning process starts in the already known, and it is therefore important for educators to have an understanding of the views of the students (132).

### 2.7.2.2 *Dying patients*

Patients dying of cancer are naturally a heterogeneous group of people, with different backgrounds, life situations, educations and professions. However, they all share the experience of severe disease and the knowledge of their impending death. This might make them reflect more on death, dying, dignity and maybe also on euthanasia. Having possibly reached a "limit situation" in life, as described by Jaspers (97), their attitudes might have changed on these matters. Their experiences and attitudes might therefore differ from those of healthy people, and might make an important contribution to decisions on palliative care and euthanasia. For healthcare staff to be able to give the best possible care for the dying, an understanding of dying patients' situation, attitudes, and wishes is very important.

## **3 AIM**

### **3.1 GENERAL AIM**

The aims of the thesis are as follows:

1. Explore medical students' attitudes and arguments toward euthanasia and a dignified death
2. Explore dying cancer patients' attitudes and arguments toward euthanasia

### **3.2 SPECIFIC AIMS OF THE INDIVIDUAL PAPERS**

The aims of the papers in this thesis were as follows:

#### **3.2.1 Study 1 (Papers I and II)**

The results from study 1 are presented in paper I and II (101,104).

##### *3.2.1.1 Paper I*

To explore medical students' attitudes to and definition of a dignified death.

##### *3.2.1.2 Paper II*

To explore medical students' attitudes and arguments toward euthanasia.

#### **3.2.2 Study 2 (Papers III and IV)**

The results from study 2 are presented in paper III and IV (102,103).

##### *3.2.2.1 Paper III*

To explore dying cancer patients' perspectives on autonomy in relation to euthanasia.

##### *3.2.2.2 Paper IV*

To explore dying cancer patients' perspectives on suffering in relation to euthanasia.

## **4 MATERIAL AND METHODS**

The thesis consists of material collected in two different studies. The results from data from study 1 are presented in papers I and II, and the results from study 2 are presented in papers III and IV. Since the goal of this thesis was to gain deeper knowledge grounded in human experiences, a qualitative study method was suitable(155).

### **4.1 START OF STUDY**

#### **4.1.1 Study 1 (Papers I and II)**

The first study started as a student project initiated by Professor Peter Strang. He planned a study of medical students' attitudes to euthanasia, designed the original questionnaire, and recruited a medical student who was to perform the study. The student collected data in 2001, and then left the project. The doctoral student MK, at that time a clinically working physician under specialist training, was recruited to complete the study. The study was reviewed, and a decision was made for additional data to be collected to increase the validity of the results.

#### **4.1.2 Study 2 (Papers III and IV)**

The study was initiated by a fellow researcher and colleague in 1997, who planned and executed the interviews with dying cancer patients as part of a study with a larger scope aiming to explore the whole situation of dying. Not only was information on perspectives on euthanasia sought, but also perspectives on how to die well/ a good death, communication, support, care forms and also evaluation of patients using structured symptom assessment instruments were performed. Unfortunately the researcher fell ill, and the study stopped. The researcher subsequently passed away, but prior to this the material was given to Professor Strang, which occurred before the analytic process had begun.

Later, the study was continued by PhD-student MK, under the supervision of professor Strang and Assistant Professor Milberg. The study was redesigned, with decisions to focus on the qualitative aspects of the study of perspectives on euthanasia and a good death, and to conduct some additional interviews. Interviews were carried out in 2007 with patients in a palliative home care setting (since that group was the least represented in the material), to reach data saturation. All analyses of data were performed by MK, PS and AM.

### **4.2 SETTINGS**

#### **4.2.1 Study 1 (Papers I and II)**

The setting for this study was a medical education centre at the faculty of health science of a Swedish university. Data were collected twice, in 2001 and 2003.

#### 4.2.2 Study 2 (Papers III and IV)

Data were collected twice for this study: in 1997 data were collected from patients recruited from a palliative home care organization, a palliative care ward and an oncological outpatient clinic. Data were collected in 2007 in a palliative home care setting. Data were collected in two different counties in Sweden.

**Table 1. Summary of studies and papers in thesis.**

	Material	Method	Analysis	Papers
Study 1	165 medical students	Questionnaire with open-ended questions	Qualitative content analysis with manifest analysis (of the obvious, visible content)	Paper I: Dying with dignity according to Swedish medical students. Support Care Cancer 2006; 14: 334-339.
				Paper II: Attitudes toward euthanasia among Swedish medical students. Palliative Medicine 2007; 21; 615-622.
Study 2	66 cancer patients in palliative phase	Open interviews on fixed topics	Qualitative content analysis with latent analysis (analysis of the deeper meaning in the content)	Paper III: Dying cancer patients' own opinions on euthanasia: an expression of autonomy? [In press 2011, Palliative Medicine Med]
				Paper IV: Suffering and euthanasia: a qualitative study of dying patients' perspectives. [submitted, 2011]

## 4.3 PARTICIPANTS

### 4.3.1 Study 1 (Papers I and II)

To get a broad range of perspectives from students with varying degrees of experience of healthcare, the questionnaire was distributed to first- and fifth-year medical students. The questionnaire was distributed to 379 medical students in total, and completed by 165 students, which makes a response rate of 44%. Since the questionnaire was submitted anonymously, a formal analysis of the drop-out rate was not possible, but the responders did not differ in age or gender ratio from the entire study population, see Table 2.

**Table 2. Demographics of respondents (n=165) and the overall student population (n=379).**

	Age in years (average range)	Gender in % (male/female)	Experience from working in healthcare sector (%)	Personal experience from the death of a relative or patient (%)
1 <sup>st</sup> year medical students				
Respondents (n=94)	23.6 (19-40)	40/60	66	31
Student population (n=243)	23.7 (18-40)	43/57		
5 <sup>th</sup> year medical students				
Respondents (n=71)	27.1 (23-35)	37/63	96	76
Student population (n=136)	27.6 (23-40)	40/60		

### 4.3.2 Study 2 (Papers III and IV)

Since the study aimed to explore cancer patients' perspectives, a goal was set to capture as much variation of patients' perspectives as possible. Therefore, the participants were selected through maximum variation sampling regarding age, gender, social status, diagnosis and time since diagnosis (155). The inclusion criteria for informants were as follows: being an adult (over 18 years old), suffering from cancer in a palliative phase and having being informed of this, being fluent in Swedish, having no obvious disorientation, and being judged by the staff as being fit enough to be interviewed (not being very tired or currently suffering from a psychological crisis). Staff members made a first selection in collaboration with researchers. Participation in the study was voluntary and could be stopped at any time without an explanation. Participation was anonymous, in the sense that only the interviewer knew the identity of the participant.

The study is based on data from 66 dying cancer patients (54 informants interviewed in 1997 and 12 interviewed in 2007). Since euthanasia is a complex and difficult issue, a fairly large sample was judged necessary to answer the research questions. According to Krippendorff the sample must be large enough to answer the research question with

sufficient confidence, which can be affected by the amount of information in each interview, and also how similar different themes are (116).

The informants differed in age, between 30 and 90 years old, gender, life situation, diagnosis, time since diagnosis, time from interview to death, religiosity, and type of care when interviewed, see Table 3.

**Table 3. Demographics and characteristics of study sample, percentage (n).**

Age mean (range)		64.7 years (30-90)
Gender men/women (n)		44% (29) / 56% (37)
Social status cohabitant/living alone (n)		52% (34) / 48% (32)
Having children yes/no (n)		83% (55) / 17% (11)
Having religious faith (n)		21% (14)
Diagnosis: Malignancy (n)	Digestive organs	30% (20)
	Female genital organs	17% (11)
	Lymphoid and haematopoietic system	14% (9)
	Respiratory tract	12% (8)
	Breast	12% (8)
	Urinary tract	5% (3)
	Various (skin, central nervous system, male genital organs, unspecified)	10% (7)
Time from cancer diagnosis to interview	< 3 months	9% (6)
	4-12 months	33% (22)
	> 1 year	58% (38)
Time from interview to death	< 1 month	12% (8)
	1- 3 months	30% (20)
	4-12 months	27% (18)
	> 1 year	30% (20)
Type of care when interviewed	Oncological outpatient clinic	35% (23)
	Palliative care ward (hospice)	35% (23)
	Palliative home care	30% (20)
Ongoing palliative oncological treatment		12% (8)

## 4.4 DATA COLLECTION

### 4.4.1 Study 1 (Papers I and II)

The first study set out to explore medical students' attitudes to a dignified death and euthanasia. To obtain perspectives from many individuals, a questionnaire was chosen

as the method to gather information. The authors developed a questionnaire containing open-ended questions regarding a dignified death and euthanasia, see Table 4. The questionnaire was validated with a pilot study, and some changes were made and a definition of euthanasia was added. Euthanasia was defined as “the intentional killing of a patient at his voluntary, expressed and competent request, often by the administration of a lethal dose of medication”.

Data were collected on two separate occasions by slightly different methods. In 2001 the questionnaire was sent to the students by mail and in 2003, the questionnaire was handed out to the students at lectures by the first author after a very short presentation. They were not filled in during the lecture but later. All questionnaires were unlabeled and returned anonymously by mail.

**Table 4. Questionnaire for medical students’ attitudes to euthanasia and dignity. Translation of questions in questionnaire.**

<b>Attitude to euthanasia – questionnaire for medical students 1<sup>st</sup> and 5<sup>th</sup> year</b>	Open answers if not stated otherwise
State gender, age, term at medical school 1. Do you have work experience from the health care or home help provided by the county for the elderly? 2. Have you ever witnessed anyone die?  3. If yes, how was this experience? Good, bad, or mixed? Please comment. 4. In debates on euthanasia the term “a dignified death” is used. What meaning do you ascribe to the term a dignified death? 5. Do you think that there is a difference ethically between active euthanasia and discontinuing life-support treatment, for example ventilator support? Please explain your answer. 6. Do you favour legalization of euthanasia? Why or why not? 7. If no, please continue to question 11. If yes, in what conditions should euthanasia be permitted? 8. With what symptoms and degree of difficulty, should euthanasia be permitted? 9. Who should make the decision for euthanasia? 10. Who should perform euthanasia? 11. Is there a situation when you would ask for euthanasia for yourself?	Yes/No  Yes- a relative Yes – a patient No

#### 4.4.2 Study 2 (Papers III and IV)

The second study set out to explore the perspectives on euthanasia in patients suffering from cancer in a palliative phase. Interviews were chosen as an appropriate method to



gather deep and detailed descriptions of participants' personal perspectives and experiences (155). Since the topic were believed to be potentially distressing for some patients, interviews were seen as the best method since they could be sensitively and respectfully adapted according to the patients' potential distress.

The participants were recruited by healthcare staff, who indicated possible study participants according to inclusion criteria and researcher sample instructions. Selected patients were given information on the study by staff, both verbally and by a letter of invitation, at a regular consultation or visit at the patient's home.

The letters of invitation distributed to patients in the two separate data collection periods (1997 and 2007) were slightly different. The first letter (1997) contained general information of the study and its goals, which was broad (exploring the situation of being severely ill by interview and also using different instruments), and examples of the topics to be discussed were given, where euthanasia was one of many. In the letter of invitation for the second data collection (2007) the interview was stated to concern perspectives on big questions on life and death, and the mention of euthanasia was omitted in the letter. This was due to several reasons: 1) to avoid possible speculation by patients that the home care organisation was supporting euthanasia, and 2) to avoid selection of patients to include only those with a clear attitude to euthanasia. The staff informed the patient that the study was not in any way connected to the healthcare provided by the staff, and that participation, or refusal to participate, did not affect the care situation.

In the 1997 collection of data, patients not interested in participation could decline participation by mail or phone, and the researcher contacted all others by telephone after a week to supply more information. In the 2007 collection of data, the patients interested in participation wrote their name and phone number on a form, agreeing to receive more information by telephone, and this was delivered to the researcher via staff or by mail. The researcher then contacted the patient by phone and gave additional information. If the informant agreed to participate, the time and place of interview were settled according to patient preferences. For background data of participants, see Table 3.

The interviews were carried out at locations chosen by the participants, most often at their homes. If patient had been admitted to a ward the interview took place there. The interviews were recorded on tape (1997) or digitally (2007). Two senior physicians, experienced in oncological or palliative care, but not involved in the participants' medical care, performed the interviews. The informants were only interviewed once.

In the 1997 interviews, an interview guide was constructed, but only partly used in the interviews. The 2007 interviews were open with set topics, but without pre-phrased questions owing to the possible sensitivity of the topics. The interviews started with general, less sensitive questions asking the patient to tell a bit about himself or herself, which by most informants was interpreted as telling about their history of disease, but by some also about their lives and important events in it. The interviewer introduced the topics when she saw fit, judging from the patients' verbal and non-verbal behaviour

and reactions. The interviewer tried to follow rather than lead the patient as much possible through the interview.

The both 1997 and 2007 interviews, the topics consisted of perspectives on euthanasia and opinions on the legalization of euthanasia in Sweden. In the interviews performed in 1997, other topics were also discussed, such as perspectives on communication, alternative care forms, quality of life, and assessment scales were used. In the 2007 interviews dignity, dignified and good death was discussed, which were topics that that emerged during the 1997 interviews without being specifically asked for. The terms autonomy and suffering were not specifically introduced by the researchers to informants, but aspects of them emerged in the interviews.

## 4.5 METHODS

Knowledge of phenomena connected to the human experience of existence can only be explored by asking humans to share their experience. Since the goal of this study was to gain deeper knowledge grounded in human experience, a qualitative study method was suitable (155). The inner world experienced by a human is subjective, the lifeworld, and interpreted through his or her understanding. Each human is an individual, but at the same time, share common traits with others. Therefore, it is meaningful to explore human experience empirically, since results can be transferred to other humans (41).

In quantitative research, while controlling study results for the impact of chance and bias, there might be problems of the relevance of results. Research subjects only give answers to what they are asked, nothing else. When conducting quantitative research on attitudes to euthanasia, there are problems on 1) the concept of euthanasia, where studies show that people are not sure about what practice the concept euthanasia refers to, therefore it is unclear what the results really mean, and 2) the fact that subjects are often asked their view based on a presumption (as expressed in study questions) that euthanasia is needed for unalleviated severe physical suffering, despite this not being the case according to previous research. Therefore, simply examining the numbers supporting or opposing euthanasia have its limits, and there is a need to understand how people reason on euthanasia, and to explore this without prejudice.

### 4.5.1 Qualitative content analysis

The term content analysis was used for the first time to describe an empirical scientific method in the 1950s by Berelson (12), in his studies of messages and propaganda in mass communication in the post-war era. Content analysis focuses on the characteristics of language as communication, with attention to the content or contextual meaning of a text. Content analysis has thereafter been used as a research method in various research fields as a *research method for making replicable and valid inferences from data to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action* (116). Content analysis has been used both in a quantitative approach, when analysing the frequency of specific words/sentences in a text, and in a qualitative approach, where meanings in the text are analysed and classified (116). Qualitative content analysis is defined as a

*research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns*, and has become increasingly popular in healthcare research.

Since the content of communication can be expressed more or less directly, different levels of interpretation can be used. The concepts of *manifest* and *latent* are used to describe the levels of abstraction and depth of analysis. A manifest content analysis describes the analysis of the obvious, visible content, where less interpretation is used. A latent content analysis is a deeper analysis of the underlying meaning of the text, a method that has been influenced by the hermeneutical tradition. The term “category” is mostly used in the analysis of manifest content, and the term “theme” is mostly used in a latent analysis.

These studies were set out to explore new knowledge without preconceived categories, and were inductive as described by Elo (56), or conventional as described by Hsieh (93). There are other types of qualitative content analysis that analyse the occurrence of predetermined categories in a material, a deductive method according to Elo, which is not used in these studies.

## **4.6 ANALYSIS**

### **4.6.1 Study 1 (Papers I and II)**

The responses to the open-ended questions were analysed using qualitative content analyses with no predetermined categories (56,78,93). A manifest analysis was performed. After reviewing data which consisted of written statements, some short and some extensive, without possibility to pose clarifying questions, a decision to concentrate on a manifest analysis was made.

The method of analysis consisted of the following stages: 1) The material was read through to obtain an overall impression and to identify themes (naive reading). 2) The responses were then re-read carefully to identify significant text segments (meaning units) and to develop codes and preliminary categories. The students’ own words were used to the greatest extent possible. 3) The preliminary categories were then scrutinized and compared to find the central component. 4) The final categories were compared to avoid overlapping and content descriptions, and relations to other categories were developed. Quotations were used to exemplify the categories.

### **4.6.2 Study 2 (Papers III and IV)**

The interviews were transcribed verbatim transferring the spoken language to text (the interviews from 2007 were transcribed by MK herself). The interviews ranged in size from about 800 to 10,000 words.

Since euthanasia and death were perceived as potentially sensitive topics for the informants, statements were expected to vary in levels of concrete-hidden expressions because patients discussing severe disease and death might not always express

themselves explicitly. Consequently, there was a need for interpretation of the data by the researchers. Therefore, a latent qualitative content analysis method was chosen, in order to be able to interpret the underlying meanings of the text (48).

The analysis, influenced by descriptions by Elo (56), was performed according to the following steps: (1) The material was read through to obtain an overall impression (naive reading). (2) The responses were re-read carefully to identify significant text segments (meaning units). (3) The meaning units were condensed and abstracted to codes. (4) The codes were then compared and sorted into sub-categories, sub-themes, categories, and themes. (5) The categories and themes were compared to the entire interview, to make sure that the interpretation was consistent and coherent with the text as a whole. (6) The categories and themes were compared to avoid overlapping and content descriptions were developed. (7) Quotations were used to exemplify the categories and themes. For examples of the steps of analysis, see Table 5.

An initial analysis of the whole resulted in two major themes, which were attitudes to euthanasia being related to aspects of 1) autonomy and 2) suffering. A decision was made to present the results of these themes separately; in two separate papers and the separate aims of paper III (euthanasia in relation to autonomy) and IV (euthanasia in relation to suffering) were set. Thereafter, a second analysis was made for each paper according to separate aims by the method described above.

**Table 5. Examples of steps of analysis from study 2, paper IV.**

Meaning unit	Code	Sub-theme	Theme
“I don’t want to be bedridden for long, you know. That’s the most terrifying thing I can imagine, being bedridden and just waiting and waiting.”	Long wait for death reason for euthanasia	Temporal aspects (extended suffering)	Suffering justifies euthanasia
	Being bedridden reason for euthanasia	Frailty	
“The most important reasons for euthanasia? When I see life as completely meaningless.”	Life meaninglessness reason for euthanasia	Meaninglessness	Suffering justifies euthanasia
(euthanasia) “Not just for my sake, but for my family’s. It must be hard on them.”	Being hard for family reason for euthanasia	Social factors	Suffering justifies euthanasia

The software application NVivo was used in the analysis of results (165).

## 4.7 TRUSTWORTHINESS

In qualitative research, there is often a discussion of the effects the researcher has on data and the results of analysis. There are different measures to be taken in order to try to control these, and also to openly address these effects, so that readers can judge for themselves.

Dialogical validation, in the sense of controlling if statement is correctly understood by rephrasing or re-questioning informant, was performed when deemed possible (129,177).

### 4.7.1 Preconceptions

In data collection there is an interaction between the participant and the researcher, where the researcher, however subtly, might influence the answers provided by the informant. The researcher might also affect the analysis, since he/she is interpreting the text, which can contain subjective elements. There is therefore a need to address researcher preconceptions, and according to Hewitt the researcher should be described from several characteristics (92).

The researchers participation in design, data collection and analysis in these studies are all physicians, senior consultants in palliative care: therefore they have experience of meeting dying cancer patients and addressing sensitive topics such as death and suffering. Two of the researchers are female and in their 40s, and one is male in his 50s. All are middle-class and native Swedish speakers. None of the researchers has a fixed attitude on euthanasia.

The now deceased colleague who initiated and participated in data collection in study 2 did not participate in the analysis of any material.

### 4.7.2 Reflexivity

In order to reduce investigator bias and increase reflexivity, several researchers participated in the analysis processes (129). Coding and development of categories were mainly carried out by the first author (MK), and the co-authors (AM, PS) concentrated on validation of the results and questioning the categorization to find possible alternative interpretations. The categories were discussed until agreement was reached.

When presenting the results of the analysis, content descriptions were made of each theme, category, sub-theme and sub-category and all are exemplified with one or several citations to strengthen the validity of the results.

To test the agreement of classification in analysis, an intercoder reliability (percentage agreement between the coders) was calculated in Paper I. One-third of the questionnaires (n=54) were randomly assigned and coded blindly by the second author, using the categories set by the first author. "Full reliability" (total agreement in categories used) and "partial reliability" (no contradictory coding but one author had

used additional categories in coding the responses) were calculated and were as follows: 85% full agreement, 15% partial agreement, and no disagreements.

### 4.7.3 Transferability

The studies were not primarily designed to examine possible differences between sub-samples: in order to do this, another study design would have been needed, using statistical sampling to avoid results affected by chance. Since the sample is not statistically representative in either study, the distribution of attitudes supporting or opposing euthanasia cannot be generalized to a larger population in either of the studies, but instead used to describe the characteristics of the participants of the studies.

**Table 6. Summary of distribution of attitudes on euthanasia in both studies.**

	Supporting euthanasia	Opposing euthanasia	Undecided
Study 1: Medical students	34%	52%	13%
Study 2: Dying cancer patients	29%	20%	51%

#### 4.7.3.1 Study 1

As stated above, the response rate was too low to make statistically valid inferences, but there was still material consisting of 165 written answers, with rich data for the qualitative analysis.

#### 4.7.3.2 Study 2

Possible biases in this study might concern the sampling, given that 65% of the participants were receiving specialized palliative care, which might have been associated with good symptom control and support. Therefore, these informants may have less interest in euthanasia than patients without palliative care, which might affect the transferability of the results to other groups. One must also bear in mind that this study was performed in Sweden where euthanasia is illegal today, which might be perceived as a norm and affect the informants' replies.

The data were collected on two separate occasions (1997 and 2007), but we found no indications of differences in the results, despite the changes that might have happened in public debate, health care organisation and availability.

## 4.8 ETHICAL CONSIDERATIONS

Both studies were approved by regional boards of ethics (dnr 97-042, 03-445, 167-06).

#### 4.8.1 Ethical considerations on research on medical students

Since medical students are adults with a free will to decide whether to participate or not, they cannot be considered a vulnerable group. The students were not coerced in any way, they did not have any connection to the researchers outside the study, and it was stated that participation was voluntary in the letter concerning the study.

Anonymity was guaranteed, and the researchers also strived to retain anonymity when quoting informants in the manuscripts, so as not to give out too many details on age, gender and course term, which could have made it possible for initiated persons to identify the source.

If the topic of the questionnaire would trigger anxiety or sadness, the students had access to support from social workers and a psychologist at the university student health services.

#### 4.8.2 Ethical consideration on research on dying patients

Ethical considerations are important in all research, but might be considered extra-important when dying persons are the research subjects. It can be questioned whether it is ethical to ask dying persons to dedicate some of their limited time and energy to research, especially when possibly suffering from fatigue and other symptoms of disease. Dying persons might be extra vulnerable owing to personal crises, and perhaps have a low level of autonomy, so there is a risk of exploitation of weak groups in this kind of research. Therefore, it can be argued that people at the end-of-life should be excluded from research. On the other hand, there are also arguments in favour of research concerning care in end-of-life, since it should contribute to making interventions for dying persons evidence-based, instead of based on tradition or belief. There are studies on the attitudes of dying patients to participation in research, showing a generally positive attitude to this, owing to the sense of meaningfulness and usefulness that participation may create (10,60).

Ethical considerations must be made when interviewing participants on sensitive topics. Forcing participants to reflect upon perhaps unwanted sensitive topics by overly intrusive interviewing might cause harm and distress, and this risk should be acknowledged and minimized. Other risks are misconceptions of the interview situation as having therapeutic aims (92). There might also be conflicts between therapeutic goals and research goals when interviewing patients, where getting as much information from a participant might be an advantage for the research project, but at the same time harmful for the patient. For example, in this study this might involve pressing the patient to reflect upon his/her impending death despite the patient showing anxiety or sadness (92). The position of the researchers in this study was that participant needs preceded research needs. If the participant was emotionally moved or in emotional distress, the researcher backed away to a less sensitive topics. If much distress was exhibited, the participant was offered the opportunity to pause or stop the interview. The researcher tried to minimize the risks of distress of the participants during the interview as described above, but if distress occurred nonetheless, supportive services were available if needed through the healthcare organisation that cared for them.

In this study, the interviewers stated that they were not representatives of the healthcare system. In the interviews performed in 2007, many informants expressed a great need to speak to someone on important issues, and they often expressed gratitude after the interview.



## 5 SUMMARY OF PAPERS

### 5.1 PAPER I: DYING WITH DIGNITY ACCORDING TO SWEDISH MEDICAL STUDENTS

In this paper, an analysis of the students' descriptions of a dignified death is presented (100,101).

The students describe a dignified death as a death:

- 1) without suffering, in terms of good control of physical and psychological symptoms, and maintained quality of life;
- 2) with limited medical interventions, where the imminence of death should be recognized, life-supporting medical-technical interventions should be avoided, as well as unnecessary examinations and treatments. Some argued for a natural death, without medical interventions;
- 3) with a sense of security, which implied being nursed by professional staff a calm environment, not being left alone in fear;
- 4) with respect for autonomy, implying being treated with respect for personal integrity, as well as being allowed to make own choices and individualise the care; and finally
- 5) with acceptance, being described as existential maturity having accepted death, finished earthly businesses and bid farewell to loved ones.

**Discussion:** The findings show similarity in many ways to the established concepts of a good death, as well as the view of a dignified death by terminally ill patients. However, the findings suggest, that the students perceive that the medical system is over-treating patients and sometimes causing harm to dying patients. The results reveal potential misunderstanding and contradiction relating to death without suffering and the use of necessary palliative interventions. These findings are important when planning education as regards to palliative care and dignified death.

### 5.2 PAPER II: ATTITUDES TOWARD EUTHANASIA AMONG SWEDISH MEDICAL STUDENTS

This paper presents the analysis of data on the attitudes of medical students attitudes toward euthanasia (101). In the study population, 52% expressed a negative attitude toward euthanasia, 34% expressed a positive attitude toward euthanasia and the rest were undecided, while when discussing whether they might personally consider euthanasia in the future for them selves, only 18% ruled this out.

The students' arguments opposing euthanasia were based on opinions of:

- 1) euthanasia being morally wrong;
- 2) fears of possible negative effects of legalized euthanasia on society (the slippery slope argument);
- 3) that euthanasia would cause guilt and strain on healthcare staff;

- 4) doubts about the true meaning of requests for euthanasia from patients, in other words patients' wishes were not to be taken at face value, and;
- 5) the position that euthanasia is not a task for the health care system.

Arguments supporting euthanasia were based on:

- 1) patients' autonomous right to decide for themselves, and;
- 2) the relief of suffering. Suffering motivating euthanasia according to the students could be caused by severe diagnoses and symptoms, reduced integrity and autonomy, hopelessness, social factors and complications of old age. Some expressed that euthanasia was appropriate for physically and cognitively disabled people, such as after a major stroke, for patients with dementia, blindness and for patients with paraplegia.

**Discussion:** The students arguments show many similarities to both formal normative deliberations on euthanasia, and arguments from previous empirical studies. The students expressed ambiguous attitudes to euthanasia, where more negative on a societal level (legalization), than on a personal level (for themselves in the future). There were several contradictions in the students' arguments, concerning for example the importance of autonomy and at the same time euthanasia for the cognitively impaired, which is not legal even in countries with legalized euthanasia. The results indicate a need for education focusing on the possibility of symptom control in end-of-life care and on patients' perceived quality of life.

### **5.3 PAPER III: DYING CANCER PATIENTS' OWN OPINIONS ON EUTHANASIA: AN EXPRESSION OF AUTONOMY? A QUALITATIVE STUDY**

In this paper, an analysis of dying cancer patients' perspectives on euthanasia in relation to autonomy is presented (102). The informants expressed various positions on euthanasia, ranging from support to opposition, but the majority were undecided owing to the complexity of the problem. None of the informants wanted euthanasia for themselves at the time of the interview.

The informants' perspectives on euthanasia in relation to autonomy focused on the decision-making process, being affected by different aspects of 1) power and 2) trust. Legalization of euthanasia was perceived as either a) increasing patient autonomy by patient empowerment, or b) decreasing patient autonomy by increasing the medical power of the healthcare staff, which could be frightening. There were various attitudes to the power of medical decision-making, were some argued for an autonomous decision-style, some opted for shared decision-making, while some preferred a paternalistic style, where the physician made the decisions.

The informants experienced dependence on others, both health care staff and family. They were dependant of information from health care staff to make decisions, and depended on other for help and support, which could be perceived both in a negative and a positive way.

The informants expressed various levels of trust in others, ranging from full trust to complete mistrust. The trust in others concerned their intentions, competence, and willingness to help.

**Discussion:** Dying cancer patients perceive that they cannot feel completely independent, which affects true autonomous decision-making. The dependence considers need for qualified medical information, dependence on medical staff and family, where relational aspects of autonomy are recognized. Some patients' experienced euthanasia as increasing medical power, which could be frightening especially in connection to sparse economical resources. Trust seemed to be an important component in the attitude to euthanasia.

#### **5.4 PAPER IV: SUFFERING AND EUTHANASIA: A QUALITATIVE STUDY OF DYING PATIENTS' PERSPECTIVES**

This paper presents an analysis of dying cancer patients' perspectives on suffering in relation to euthanasia (103). The analysis demonstrated patients' various differing perspectives on suffering in connection to their attitude to euthanasia (see Figure 1). None of the patients wanted euthanasia for themselves at the time of the study.

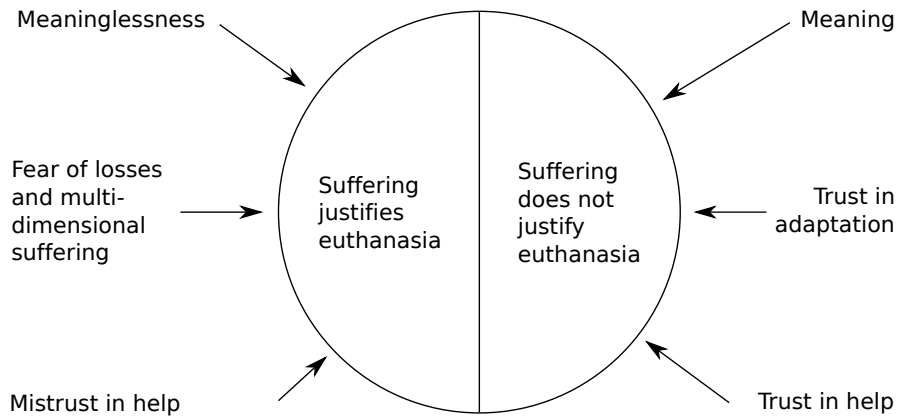
Those advocating euthanasia did so owing to:

- 1) perceptions of suffering as being meaningless;
- 2) anticipatory fears of losses and multi-dimensional suffering, or due to;
- 3) doubts of the possibility of receiving help to alleviate future suffering. The patients described suffering in a temporal dimension; not only suffering right *now*, but also suffering from *before* when remembering passed times and of what has been lost, and suffering *then* in fears of an unknown future with suffering and possibly lack of help.

Those opposing euthanasia did so owing to:

- 1) perceptions of life being meaningful, despite suffering;
- 2) placing trust in bodily or psychological adaptation to reduce future suffering, a phenomenon personally experienced by the informants, and;
- 3) by placing trust in the provision of help and support from healthcare services to reduce future suffering.

**Discussion:** Dying cancer patients draw varying conclusions from suffering: suffering can, but does not necessarily, lead them to advocate euthanasia. Patients experiencing meaning and trust, and who find strategies to handle suffering, oppose euthanasia. In contrast, patients with anticipatory fears of multi-dimensional meaningless suffering and with lack of belief in the continuing availability of help advocate euthanasia. These results have possible implications on the understanding of suffering in end-of-life, and on the measures taken by healthcare professionals. This indicates a need for healthcare staff to address issues of trust, meaning, and anticipatory fears. The results also serve as a background to the current debate on euthanasia in end-of-life care.



**Figure 1. Description of dying cancer patients' perspectives on suffering in relation to euthanasia.**

## 6 DISCUSSION

This work set out to explore attitudes on euthanasia in two groups; medical students and dying cancer patients. The results demonstrate that there is no homogeneous attitude towards euthanasia in either medical students or dying cancer patients, but rather that the attitudes differ among them, as in the general population.

### 6.1 ATTITUDES TO EUTHANASIA

When comparing the attitudes to euthanasia between the students and the patients, there seemed to be a difference in patterns of supporters to opponents to those unclear on the issue. The students had more often a fixed opinion on opposition to or support of euthanasia, while the dying cancer patients were more often undecided (see table 6). There were also qualitative differences in attitudes that will be discussed below. This can possibly be interpreted as it being easier to reason on a problem on a theoretical level, rather than on a practical level where real experiences affect the reasoning process. When lacking personal experience of a problem, theoretical speculation on how to reason in a future hypothetical situation is carried out.

The medical students are young and in a transition phase in their entry into the medical profession, but have yet to obtain substantial experience of meeting severely ill or dying patients. They might possibly be influenced by imagining their future medical responsibilities, and reflect to some extent upon this. They are also probably reasoning from their own perspectives, imagining themselves and their preferences if they were to find themselves as patients in such a position. For them, their attitude to euthanasia and a good death is mostly based on such a hypothetical future. For the medical students, this means reasoning on a hypothetical “possible self” (131), in terms of both working as a physician and being severely ill themselves. Psychological research has found the formation of “possible selves” being related to personality, self-esteem, efficacy, meaning and belonging (131,219).

For the dying cancer patients, they have personal practical experience of the situation of being ill and in need of healthcare, and have perhaps had more personal reflections on euthanasia. Nonetheless, even for dying patients, reasoning might still involve consideration a future possible self. In the interviews, the patients gave answers from different perspectives: on a general level for society, when referring to others, or when referring to themselves in a future situation.

There is naturally a chance that these views will change in actual situations that develop in the future, or from obtaining further experience.

## 6.2 EMPIRICAL ETHICAL REASONING

When analysing the perspectives on and motives behind euthanasia positions in data, empirical ethical reasoning emerges (11,120). Empirical ethical inquiry plays an important role to add realistic premises to the deliberation of a problem, thereby making the advice more usable and urgent (115,120,217). It might also help in understanding possible effects of a chosen action, which might not always include those considered a-priori (16,120). Therefore, in both studies in this thesis, empirical exploration of the reasoning and interpretation of 1) medical students and 2) dying cancer patients on euthanasia was performed, to try to add more facts and premises to the ongoing ethical discussion on euthanasia. By this exploration, knowledge is also gained on the perspectives of both populations, which can be of use when planning education for students and medical care for patients.

The medical students' attitudes and reasoning on euthanasia were close to theoretical deliberations on euthanasia: respect for autonomy and relief of suffering were recognized as major arguments justifying euthanasia. Meanwhile, moral norms of the sanctity of life, the slippery slope argument, the strain put on medical staff, and also the psychological interpretation of euthanasia requests, with doubts of their true meaning, were stated as major arguments in the opposition to euthanasia (11,86,91,118,166,197).

Interesting findings were the examples of illnesses or symptoms that the students found as factors that justified euthanasia, which according to them involved suffering so severe that death would be preferable to ongoing life. Losses of cognitive, sensorial, and motor functions, are all connected to a loss of independence, which to the medical students seems to lessen the quality of life so much that the will to live is lost. Besides this indicating that their future selves would potentially wish to die if disabled, this raises questions on how some of the medical students view people with disabilities, and whether these attitudes might affect their medical decisions in the future. In a study by Carmel, medical students and elderly people rated their will to live and the students also rated their perception of the elderly people's will to live (27). The students believed that the elderly had a will to live much weaker than their own will to live, as well as the will reported by the elderly themselves. This was believed to affect how they handle patients. However, these attitudes might change in the future after more experience and knowledge are obtained.

The dying cancer patients' perspectives on euthanasia were less formal, and a more complex picture of euthanasia emerged that recognized more practical problems and complications in these arguments. For example, the respect of autonomy was not recognized as an argument supporting euthanasia by all patients, primarily due to aspects of power over the decision-making and trust. In addition, the patients problematized euthanasia as a means to relieve suffering, owing to perspectives on suffering as not being intolerable because of the existence of supportive strategies.

### 6.3 AUTONOMY

Among students advocating euthanasia in the name of autonomy, some argued in a libertarian fashion, in that humans possess an inherent right to decide for themselves without interference (15). According to some of the students, there should not be any exterior assessments of euthanasia requests, since humans are to decide whatever they want for any reasons. This focus on the right to autonomy, where the self is the authority with a right to shape when and how to die, is a clear example characteristic of the neo-modern death according to Walter (208).

The students expressed fears of euthanasia causing strain on the medical staff participating in decisions and performance of euthanasia. The effects on physicians if performing euthanasia have been sparsely studied, but there is some support for the students' fears of a negative effect on physicians emotionally and psychologically (87,133). The Dutch physicians in these studies expressed that euthanasia had a major impact on them, and they battled with loneliness, loss, relationship issues with patient and family and the expectations of society. To recognize medical staff as agents, whose personal autonomy is also to be considered in the euthanasia discussion, is interesting. Whether the patient's individual autonomy has priority to the physician's autonomy, or if the physician's autonomy can be just as important, is a contemporary political question. The European Union has recently discussed a bill proposing the rights of medical staff to act on personal conscientious objections to participation in medical interventions (153).

From the perspectives of severely ill cancer patients on euthanasia, the common definition of autonomy, focusing on the individual's right to self-government, is challenged. Several different complementing perspectives of autonomy were identified. Apart from the ideal of patient empowerment and wishes to personally control and shape the end of life, the study also shows difficulties in making one's own decisions on vital matters and trusting others, sometimes even oneself. In this study, perspectives on euthanasia were not homogeneous among the dying cancer patients: some regarded it as a desired alternative in end-of-life care, while others regarded euthanasia as a means for others to gain power over patients, possibly threatening their lives. The attitudes to euthanasia seem to be complexly constructed by many different factors that interact, where positions on power and trust seem important.

The dying cancer patients expressed difficulties in individual medical decision-making. When severely ill, dependence, lack of trust and lack of information make autonomous decision-making difficult according to the patients. This thesis indicates that some patients want to participate to a high degree in medical decision-making, while others want to participate less. A review study on cancer patients' communication and decision-making preferences demonstrated that patients vary in their preferences and that there is a need to individualize the consultation (172).

Previous studies on decision-making in the health care system have shown that many patients do not choose individual informed decision-making when asked (53,55,121). In a large Canadian population-based study, almost all subjects stated that they wanted to be given the option to participate in medical decisions, but at the same time, more

than half stated that they preferred that their physician made the final decision (121). Elkin et al. showed that, in patients over 70 years old with advanced cancer, 52% preferred a passive role in decision-making (55). Fraenkel et al. showed that many patients preferred to execute their medical decision-making not by choices in treatments and screenings, but instead by choosing their physicians and whether to trust them and accept their recommendations (65). Drought and Koenig argued that the current focus on autonomy, “the autonomy paradigm”, is taken too literally, and has showed in a study that patients at the end of life are more interested in focusing on managing daily life, than in making choices on advanced care planning (50). They stated that “*autonomy is an important principle, but not the only one, and that autonomy is to be respected, not imposed and it is not everyone’s need*” (26). Finally, from an existential point of view, important choices trigger existential anxiety (225). Totally autonomous decision-making would imply total responsibility and total loneliness in the decision-making.

The wish for a paternalistic decision-style, to leave medical decisions to a trusted physician, for example, can be seen as a way to execute autonomy (65). American bio-ethicists Beauchamp and Childress state that there seems to be a misunderstanding in healthcare today about the concept of autonomy: it is to be seen as a right, but not a duty. They state that if the patient does not want to make decisions and prefers leaving them to the medical staff, then that is a result of an autonomous choice and should be respected, and that it is obtrusive and wrong to force patients to make medical decisions when they do not want to (11). Therefore, it is perhaps worth considering whether it is a simplification to imagine that important decisions of patients at the end-of-life are to be made individually and independently, a factor that we tend to stress.

In end-of-life care, the family and healthcare staff are often closely involved together with the patient, all being individuals with personal autonomies that may affect each other and be affected by the autonomous decisions of others (223). Recognising that one makes decisions together with others, depends on information from others, or is affected by others when making decisions, is expressed in the concept of “relational autonomy” (47).

To summarize, autonomous decision-making might be an ideal that is advocated when independent and healthy, and for one’s future self: however, from patients’ perspectives in the end-of-life situation, the concept is more problematic, which has implications on their attitudes to euthanasia.

## **6.4 SUFFERING**

In studies of both the medical students and dying cancer patients, suffering is expressed as multi-dimensional. Suffering is described as originating in body and mind, in social relations, and to be interpreted through existential dimensions such as meaning. For the dying cancer patients, suffering does not only exist in the *now*, but also in other temporal dimensions relating to what used to be and losses, as well as fear of what will come in the future. This seems to agree with Eric Cassel’s definition of suffering, where he abandons the traditional mind-body dichotomy, and sees suffering as a result



of the whole person's reaction and interpretation of the threat from illness and its consequences (28).

However, patients also describe factors that protect against or reduce suffering, which were based on the presence of meaning, trust in adaptation to future suffering and the trust in help being provided. Such adaptation can be compared to the concepts of "attitudinal values" by Frankl (66,67), or by the "shift-response" theory (184,185,188), where a shift of attitudes in a new situation is seen to reduce suffering. In the concept of attitudinal value, Frankl focused on how humans respond to and interpret experiences when in difficult circumstances and how senses are reframed and meaning and values are changed. In addition, according to the response shift theory, severe illness generates changes in perceptions, values, and concepts of quality of life, which enable life to be perceived as highly valuable despite situations that previously would have been perceived as intolerable.

Adaptation is also discussed in psychological research, on adaptation to threatening events. The Cognitive Adaptation Theory (sometimes referred to as CAT) argues that psychological adaptation to illness occurs through search of meaning, attempts to regain mastery, enhancing self-esteem and by the ability to find positive illusions (194). Previous studies on patients' adaptation abilities show that those with higher adaptive abilities are less anxious, have less depression and have better mental functioning (90,189). In a study by Peeters et al on patients with rheumatoid arthritis, a stronger adaptive ability was connected to better mental health (156). Especially the ability to find a positive illusion is important for adaptation (193), which can be compared to the "creative illusions" created by cancer patients as studied by Salander (176). "Creative illusions" serve to maintain hope despite severe threat.

How is healthcare today addressing suffering from multiple dimensions? When the medical students described a dignified death, they criticized of the medicalization of death in healthcare today. They described that the dying phase is not always recognized, and that modern healthcare could generate suffering instead of alleviating it. There is some support of this in other studies of patients' experiences in health care. In a study by Daneault et al., the perceptions of dying cancer patients on their own suffering were explored (42). They found that the actions of healthcare staff actually increased the patients suffering, instead of decreasing it. This occurred by doctors and patients constantly trying to avoid suffering. In patient-doctor consultations, discussions of death and a poor prognosis were avoided or muffled in order to create an optimistic situation at the time of the consultation, but leaving sad and lonely patients with increased suffering afterwards: the patients felt abandoned difficult issues left unresolved (42). In addition, a failure to recognize multi-dimensional suffering in health care might contribute. According to a Norwegian study, physicians were observed to use strategies to readdress their patients' concerns into a medical context, while their existential meanings were removed and neglected (2). In a recent comprehensive review, Khan et al show needs of a holistic approach to patient suffering due to the multi-dimensional origins of suffering evident in many studies (110). They suggest improved interventions to reduce suffering by identification of patients at risk, alleviation of physical and psychosocial distress and focus on the therapeutic alliance.

Some medical students expressed that, since they perceived that the healthcare system increases suffering by medicalization of death, they advocated the ideal of a natural death. A natural death was according to them to be devoid of all medical interventions, also medications. This seemed to partly be based on a lack of knowledge of possibilities of medical interventions in symptom relief, of which the students needed education. When comparing to other areas of healthcare such as obstetrics, the debate on medicalization has resulted in the natural birth movement, which is a clinical alternative for childbirth with less medical interventions (9). To imagine this ideal to develop into the clinical practice of palliative care in the future might seem a far-fetched idea (“natural palliative care at the end of life”?).

To summarize, suffering can be seen as the reaction to and interpretation of a threat to the whole person, with an integrated body and mind, a personal history and personality, and can therefore be expressed in multiple dimensions. This study shows that patients use strategies to reduce suffering, and maybe healthcare can learn from these strategies. To identify multi-dimensional suffering, identify and pre-empt fears for future suffering focus on trust, and support patients in their creation of meaning, might be accessible ways to help patients reduce suffering.

## **6.5 TRUST**

In the study of patients’ perspectives on euthanasia (as presented in Paper II and IV), aspects of trust in relation to others were central, in relation to both autonomy and suffering. Trust in the good intentions of others, trust in others’ willingness to provide help when in need, trust in their competence and information provided, but also trust in their own internal own ability to handle difficult situations.

Trust in the patient-physician relationship is seen as a vital component (68,136), being described as scarce social capital and a foundation for the patient-physician relationship, which should be conserved due to the significant benefits it promotes (95). In addition, in this study, trust was described as a central factor in relation to autonomy and decision-making in the important matter of euthanasia. There was a vast range of levels of trust expressed by the patients in the study; from complete trust in others to grave mistrust in others, both staff and family.

Why some people tend to trust others and some do not is unclear. This seems to be, in some cases, due to life experience, but in others is maybe due to the patient’s personality: maybe they simply have different capacities to trust (83). There are several aspects of trust that is unclear: how it is formed, what role personal experiences play, and to what extent personality affects the trusting capacities. Whether the level of trust identified in relation to perspectives on euthanasia, in the same person extends to other areas in health care is not clear either. It seems to be a vital issue to address trust with patients (95,224), but a report by the Cochrane collaboration has shown difficulties in increasing trust, despite several studies with different interventions (136).

In attachment theory, a person's experiences in childhood form a "working model" on how to attach to others and form relationships throughout life, forming special attachment strategies that are evoked especially when under stress (19). Facing death can be a situation where such strategies are evoked, which has been explored in end-of-life research (122,157,171,173,192,226). Trust is a basis for forming a relationship, and might be part of the attachment style of patients. Therefore, it might be possible to interpret the findings of these studies relating to trust issues from the perspective of attachment theory. Those with a deep distrust in the reliability and intentions of others, and who fear dependence, express common features of the avoidant attachment style. In contrast, those who fear that others will not be there for them when they are in need, show common feature of the anxious attachment style.

Canadian studies have linked the anxious attachment style to WHD, which supposedly depends upon the increased levels of anxiety and depression that these people experience when they are under the stress of facing death and dying (171). A study from Oregon linked personalities similar to the avoidant attachment style with WHD (72). This hypothesis does not characterize people with these attachment styles as having pathological personalities; but instead gives a better understanding of the complex connections that might aid in identification of better ways to meet the demands and needs of patients. Therefore, there are needs both for further exploration of the role of attachment styles in suffering in end-of-life care and wishes to hasten death, and for research on possible interventions to address the suffering of patients. Maybe patients with an avoidant style would benefit from increased continuity of staff (fewer staff members around the patient) and attempts to achieve independence for the patient: those with an anxious attachment style might benefit from more frequent contact, and if wanted, more support.

## **6.6 HEALTHCARE**

Both medical students and dying cancer patients, stress the importance of good care in end-of-life situations. In the medical students' definition of a dignified death, being nursed by professional staff in a secure setting was central. Lack of good care was, according to the students, a reason for suffering that justified euthanasia. For the patients, the ability to trust the motives of healthcare staff to deliver proper healthcare at end-of-life was connected to their views on euthanasia. Those with solid trust in the healthcare services, in terms of its willingness, availability, and knowledge to support and relieve suffering, did not see the need for euthanasia, which contrasted with the expectations of those who doubted the possibilities of receiving future relief of suffering, who were in favour of euthanasia.

Therefore, the discussion of euthanasia does not stand free and independent from the arrangement of resources and competences of health care. Trust is not merely an interior feeling, but it has correlations to real events: whether there is something that proves that trust is warranted. If healthcare services cannot deliver high-quality medical treatments, support, good communication and care, then there is nothing to trust. Such inadequacy can stem from lack of resources or lack of appropriate organisations. If people have the impression that the provision of healthcare is inadequate, fears of

several types of future suffering might arise. This might trigger discussions on euthanasia owing to these fears of future suffering, and not primarily in terms of the issue on autonomous choice.

## **6.7 FUTURE RESEARCH**

The possible clinical and educational implications of these studies need to be evaluated through further studies, and further research is also needed to expand knowledge in several areas.

Further quantitative research on the attitudes to euthanasia in Swedish medical students and dying cancer patients would be very interesting. A larger material with national coverage would also make comparisons between first year and last year students possible.

Medical students need better knowledge of palliative interventions at the end-of-life, but also education on the perspectives of living with disabilities and diseases: these are the educational implications from Paper 1 and 2. How this should be accomplished in the best and most effective way must be studied.

Further studies on patients' attitudes to decision-making in the end-of-life are needed, which has implications wider than the scope of euthanasia. How to guide patients according to their personal decision-making preferences in the best way needs to be researched.

More work on identifying multi-dimensional suffering, as well as supporting patients in their creation of meaning, needs to be carried out to find ways to help patients reduce suffering. Clinical research is needed to identify fears for future suffering, and to find successful ways to pre-empt these fears. Also clinical research on the role of adaptation in end-of-life situations, and whether there are ways for health care to facilitate adaptation.

There is also a need for future research on attachments styles in end-of-life care, and their usefulness in designing appropriate care for different patients. In clinical research, focusing on trust and trying to find successful interventions to increase patients' trust, irrespective of patients' attachment style, is needed.

## **6.8 METHODOLOGICAL CONSIDERATIONS**

General issues regarding trustworthiness, such as preconceptions, reflexivity and generalization, are discussed in section 4.7, but some methodological considerations remain to be discussed here. The pattern of medical students' and dying cancer patients' support and opposition to euthanasia might have been affected by the study design in several ways.

First, considering the students, they were clearly informed that this study concerned attitudes to euthanasia, which could have made students with firm beliefs on the issue more prone to enter the study, than those without a clear stance. When recruiting patients, the aim of discussing euthanasia was not as evident: this might have also attracted patients without a fixed attitude to enter the study. Therefore this can have affected the different patterns of euthanasia support, opposition and uncertainty in the studies.

Secondly, the data collection method might have affected how much deliberation had gone into the given answers. In the study on students, the questionnaire was taken home, where the topics could be reflected on for days and weeks if necessary, before being returned to the researchers. In the interview study, even in discussions without the pressure of limited time, there was significantly less time to reflect upon topics if patients lacked a well-thought-through opinion beforehand. Therefore, the questionnaire might have provided opportunity for statements to be made after more reflection. On the other hand, it might have been easier to fully express a complex attitude to euthanasia in an interview, than in writing.

Third, in communication, people tend to adjust to each other, and adapt more or less to the other person. In interviews, the interviewers might, through verbal and non-verbal communication, signal their own attitudes to the informants' responses, which might cause an adjustment in statements by the informants, which would affect the data. In a questionnaire, this effect might be smaller, but not completely absent, since people might perceive signals in the written text in the questionnaire as well. The questionnaire was designed with an awareness of these effects, and attempts were made to choose expressions that are as free from values and ambiguity as possible. In interviews, awareness of these factors are known as potential problems, and thus attempts were made to control and minimize them.

In the study of dying cancer patients' attitudes, the selection of the population might have naturally affected the data collected. In this population, it must be noted that 65% of the informants were receiving specialized palliative care, which might have been associated with good symptom control and support. Therefore, these informants may have less interest in euthanasia than patients without palliative care, which might affect the transferability of the results to other groups. One must also bear in mind that this study was performed in Sweden, where euthanasia is currently illegal, which might be perceived as a norm and thus affect the informants' replies. Knowing that euthanasia is illegal and not an option right now in Sweden, might make it "safe" to request, knowing that it will not be performed. This situation might differ from one in which euthanasia is a real alternative.

Since the topic of euthanasia was perceived as a complex phenomenon, a relatively large number of informants were considered to be necessary to make valid inferences. In the first study on students, 165 questionnaires were analyzed, containing statements of various lengths. In the second study on patients, instead of 15-30 informants, which is common in qualitative studies, we expanded the study to 66, with variation in terms of type of cancer, age, education, and proximity to death.

Both study populations are heterogeneous in some aspects that might have affected the results.

- 1) First- vs. fifth-year students: The student population in study 1 consisted of both first-year and fifth-year students, and originally there was an intention to try to compare these subgroups for differences. However, owing to the low response rate (44%), there were no possibilities for such comparisons to produce valid results. In the results, there were no apparent differences between these sub-groups either in pattern of supporting or opposing euthanasia, or in distribution of attitudes.
- 2) Ten years apart: In the study of dying cancer patients, data were collected at two different occasions, ten years apart. In the time that passed between the data collection periods, there might have been changes in public norms, public debate, organization of healthcare, and medical symptom relief possibilities, all of which might have affected the results. Therefore, the two subgroups could be very different in terms of perspectives to euthanasia since attitudes could have changed over time. Since the population was not randomly selected, there was no possibility or intention to draw any statistical inferences from a comparison. However, in the results there were no apparent differences in the pattern of supporting or opposing euthanasia, or the types of attitudes expressed, between the two subgroups.
- 3) Closeness to death: The dying cancer patients had all received information that their disease was terminal, and that they were going to die from it. For some of them, the illness had progressed further than for others, giving rise to more symptoms and making them closer to the end of their lives. This might have affected the attitudes, where terminal patients had one set of attitudes while others with fewer symptoms and more vitality had another. The goal of a qualitative maximum variation sampling is to gain as many different aspects of a phenomenon as possible and variation in the closeness to death (days-weeks-months) is one way of increasing the variation. However, in the results there were no apparent differences in pattern between those close to death and those with longer life expectancy at the time of the interview.

## 7 CONCLUSION

In conclusion, in this thesis, no homogeneity in either medical students' or dying cancer patients' attitudes to euthanasia was found. However, medical students seemed more sure on their positions on euthanasia than patients, who were more often undecided.

When exploring the attitudes to euthanasia, medical students' motives were closer to those outlined in academic discussions on these issues, while dying cancer patients' reasoning was more problematizing and involved consideration of practical problems.

A focus on individual autonomy may work theoretically, but in real life, autonomy is a more complex issue. The patients state that, when someone is severely ill, full independence is lost; therefore, they can experience problems in terms of the ability to make completely autonomous decisions. This was described, for example, as being due to a lack of knowledge, and from being affected by and dependent on others. However, dependence was not always experienced as negative or as a problem, but could be experienced as a source of support. Relational aspects of autonomy were important, which might not always be recognized in healthcare.

This thesis indicates that some patients want to participate to a high degree in medical decision-making, while others want to participate less. Therefore, there is perhaps not one model for decision-making that suits all, but instead a need to individualize the healthcare-patient relationship. This may affect the attitude to euthanasia.

Patients express different levels of trust, which affects their attitude to euthanasia. There is a need to identify patients with a lack of trust in others, and to try to support ways for the healthcare system to increase trust, maybe by increased continuance in care relations and improved communication.

The presence of, or fear of, multi-dimensional suffering can promote support for euthanasia; however, according to this thesis, patients can also come to different conclusions regarding this issue. Patients who utilize protective strategies to reduce suffering through trust in adaptation, who have trust in the availability of help, and who have meaning in their existence, oppose euthanasia. Therefore, there might be possibilities for the healthcare systems to support such strategies to reduce suffering.

Medical students need education focusing on the internal experience of living with severe diseases and disabilities, and how to handle this. They also need education on the possibilities of palliative care, knowledge of which was lacking according to the results.

Legalization of euthanasia might be a positive and welcome development according to some patients and some medical students. However, it might also be unwanted and frightening, both to patients and to medical students. When discussing euthanasia, all possible effects must be considered and carefully weighed before reaching a conclusion.

Finally, both medical students and dying cancer patients recognize the connection between euthanasia and the quality of healthcare provided, in terms of its availability and capacity to reduce suffering. Therefore, a focus on the quality of healthcare provided should be central when deliberating on euthanasia.



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