

END-OF-LIFE CARE AND DECISIONS IN CHILDREN  
STUDIES OF ATTITUDES AND PRACTICES

GEERT POUSSET

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# End-of-life care and decisions in children Studies of attitudes and practices

Zorg en beslissingen aan het levenseinde van kinderen  
Onderzoek naar attitudes en praktijk

**Dissertation**

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“Yo [Liesje], I did it!” (R. Balboa, 1979)

Hasselt, 2 June 2010



## Chapter 1: Introduction

### 1.1. The death of a child

*[Klaas suffers from cystic fibrosis and is eleven years old when the illness reaches the terminal stage] “I am dying, am I?” “Yes Klaas, I’m afraid you are... It’s not yet completely hopeless, but I’m afraid you are.” “Okay.” He was quiet for a while when he tried to cope with this fact. With dry eyes. Clarity. That’s where children thrive. Even if that clarity is horrible. They can deal with that, better than grown-ups. “I don’t want to die... with a suffocating... shortness of breath.” I laid my hand on his arm. “No, I don’t want that either.” He looked at his parents. “Dad and mom... when I die... I want you... to be there... with me.” I won’t ever forget the sorrow I saw that moment. Something broke in those two big strong people, so intense, and I saw it happen before my own eyes. Tears rushed from their eyes. [...] “Are you scared?” [the father asked] [...] “No... no, there’s nothing more... that I wait for.” [...] He gave it some thought and then shook his head. “It takes too long... but I am... not afraid... to leave... I think it’s... pretty good over there.” He was quiet for a while. “Are you guys scared?” Whatever was left of his dad now evaporated in his son’s arms. “Yes,” he said, “yes... I’m so scared... scared of losing you.”*

Quoted and translated from Brand P, “De Stoel van God”, 2009, p. 278-279, Nieuw Amsterdam Uitgevers.

The death of a child is the most devastating and traumatic experience parents can face. Through advances in medicine and hygiene, a significant decrease in child mortality has occurred in the course of the 20th century. Worldwide, under five-year-old mortality has dropped from 93 in a thousand live births in 1990 to 68 in a thousand live births in 2007. Large differences however exist across the world. In 2007, under-five mortality was six in a thousand live births in industrialized countries, while it was still 169 in Western and Central Africa.(1) Although the incidence of cancer in European children and adolescents has increased significantly since the 1970s, overall five year survival rates have increased substantially from 44% in the 1970s to 64% in the 1980s and 74% in the 1990s.(2) The death of a child is consequently becoming a rare event in Western developed countries. In Flanders, the Dutch-speaking part of Belgium, with approximately six million inhabitants, between 400 and 500 live-born children die before the age of 18 every year, of which more than half die before the age of one. The absolute number of child deaths has steadily decreased between 2000 and 2005 in Flanders, mainly because of a decrease in traffic casualties amongst children.(3)

The small and decreasing number of child deaths should, however, not obscure the impact of the issue on families. The rarity of child death could even be one of the reasons why it has such an awesome impact on families, as it is no longer a part of

everyday life for most people in Western developed societies. Parents who lose a child risk being socially isolated because many friends and acquaintances will feel insecure about how to cope with the situation. Moreover, birth rates are currently at their lowest level in Western developed societies and parents who lose a child are often left childless, which increases the impact of the event even more.(4;5) Most parents experience feelings of guilt after the death of their child.(6) The impact of a child's death has been shown to be highest four to six years after bereavement, when bereaved parents have higher risks of depression and anxiety, and to decrease afterwards. Losing a child at age nine or older appears to be related to an increased risk of psychological distress.(7)

The mortality rate is highest for neonates and adolescents, and lowest for children in between. The causes of death vary strongly with age: neonates and infants die mainly from congenital abnormalities, older children from external causes, including suicide and traffic accidents.(3) In general, external factors are the leading cause of death for children in Western developed societies.(8) This implies that children often die suddenly and unexpectedly, which precludes any palliative or end-of-life care.

## **1.2. Pediatric end-of-life care**

### **1.2.1. Specific challenges**

Pediatric end-of-life care faces several critical challenges which make it different from end-of-life care in adults, and justify the need for specific approaches and research.

#### *a) Developing decision-making capacities in children*

Childhood is characterized by constant and extensive physical and psychological changes. Different levels of development will require different approaches by health professionals. Very young children will for instance lack skills to verbalize their symptom burden. Caregivers will then have to tailor symptom assessment to the developmental level of the child and use alternative ways to come to a good understanding of the child's symptoms, by for example using body charts or face scales.(9-11) Particularly relevant for our discussion, is the development of the required level of psychological competence in order for the child to be involved in medical decision-making.

The psychological competence of minor patients is evidently a crucial factor in determining whether they should be allowed to make decisions autonomously. The concept of psychological competence poses several challenges to health care professionals. Below, we will focus on two pivotal challenges: first, defining the

standards for competence, and second, establishing how these standards should be assessed. Both challenges are inherently related to each other, as an assessment of competence can only take place when it is sufficiently clear which standards it should be compared to.

An especially relevant aspect of competence, where decisions in pediatric end-of-life care are concerned, is the development by the child of a clear concept of death. Three components constitute a full concept of death: irreversibility (the understanding that once a living thing dies, its physical body can not be made alive again), non-functionality (understanding that all life-defining functions cease at death) and universality (the understanding that all living things die). Based on their 1984 review, Speece and Brent conclude that in general, healthy children achieve an understanding of all three components at age five to seven.<sup>(12)</sup> Other authors regard the age of ten as the age at which most children acquire a mature concept of death.<sup>(13)</sup> This is only a rough indication, as wide variations exist between children. Chronological age correlates significantly with understanding of death, as does death experience.<sup>(14)</sup> The different components of death are differentially affected by several factors: the acquisition of the more abstract component of universality is affected by cognitive development, verbal ability and cultural and religious experience, while direct experience affects the more physical components of non-functionality and irreversibility.<sup>(13)</sup> The acquisition of a mature concept of death has been shown to be an important part of end-of-life care, and reduces fear of death in young children.<sup>(15)</sup>

The acquisition of a clear concept of death is of course not in itself a sufficient standard of competence for a child to be involved in end-of-life decision-making. Other capacities are required in order to be able to fully participate in decision-making, such as understanding the diagnosis, the remaining treatment options and chances for survival, being able to weigh alternatives and being able to communicate preferences.<sup>(16)</sup> Some authors have tried to establish a comprehensive set of standards and thresholds for competence. In their MacArthur studies of competence, Appelbaum and Grisso have for instance identified four legal standards which constitute competence: the ability to communicate a choice, the ability to understand relevant information, the ability to appreciate the situation and its likely consequences and the ability to manipulate information rationally.<sup>(17-20)</sup> Until now, there is however no clear consensus on this set.<sup>(21;22)</sup>

Determining whether children are psychologically competent requires an assessment. This assessment creates additional challenges for health professionals. First, as outlined above, it is not clear which standards should be assessed. Second, the conditions for competence to be involved in decision-making vary with the risks of the decisions at hand, and will be more rigorous if far-reaching decisions, such as life and death matters, are concerned.<sup>(21)</sup> Third, psychological competence is a continuous concept: children can be more or less competent. An assessment thus faces the challenge of establishing the thresholds for sufficient competence to be involved in a particular decision, which is a normative judgment. The assessment of competence is thus necessarily a dynamic process. Finally, it is not clear who should make this assessment. In practice, it is often the treating physician who makes the assessment, and this judgment is seldom questioned in courts.<sup>(21)</sup> However, others argue that it may be

feasible to leave this assessment to specialized professionals, such as child psychologists.(23;24)

Some experts have attempted to provide a framework for assessment of competence.(23) Besides providing the child with all the relevant information to enhance competence, health care professionals are recommended to take several specific factors into account when assessing the competence of minor patients.(23) These recommendations include providing a developmentally appropriate assessment (with tailored communication), exploring systemic external influences and pressures, testing cognitive development in a specific rather than standardized manner, and assessing the child's ability to balance risks and benefits.(23) In the United Kingdom, the concept of "Gillick competence" is used to test whether children younger than sixteen years can consent to medical treatment independent of their parents. Children are deemed "Gillick competent" when they have reached sufficient understanding and intelligence to understand fully what is proposed.(25)

Most authors agree that most adolescents, at an approximate age of 14 and older, are competent decision-makers, and no less competent than adults.(26) Already in the 1970s, Grisso and Vierling concluded from their review that there are no psychological grounds to assume that children can not provide competent consent at age 15 and older.(20) They also concluded that children aged younger than 11 demonstrate developmental psychological evidence of diminished psychological capacities. The group of children between the ages of 11 and 14 appears to be in a transition period in the development of important cognitive abilities and perceptions of social expectations. In this group, it is possible that competence will be demonstrated in individual cases.(20) Again, age is only a rough indicator and competence has been shown to be influenced by experience with chronic illness, which can make experienced children more competent to decide on end-of-life matters than their inexperienced peers.(12;13;26-28) Some studies have reported differences in competence between adults and adolescents.(29)

The outcome of the assessment of a minor patient's psychological competence is of course a crucial factor determining whether a child should be allowed to be involved in medical decision-making, or even to make autonomous decisions. As a rationale, medical and ethical consensus exists to give minor patients decisional authority, and if full decisional authority is not appropriate, to have them express their treatment preferences.(30) But even if a minor patient is found competent, it does not necessarily follow that he or she should be able to make decisions autonomously.(31;32) Different arguments have been formulated that may impede involvement of minor patients in medical decision-making. Some authors have stated that allowing children to participate in medical decision-making is an undue burden on them, certainly if they are dying. Even when they are psychologically competent, it is suggested that they need a "protected period", in which they can learn from adults, who make decisions on their behalf, how to make competent decisions. (31;32) Furthermore, it has been noted that providing full decisional authority to minor patients undermines parental rights.(31;32) Additionally, warnings have been formulated that minor patients are highly suggestible to interventions from authority figures, which holds the risk that only fake consent or assent will be obtained from the minor patients and that their

autonomy will thus not be improved.(31;32) These arguments are however not widely accepted, and most guidelines suggest that there is a consensus that competent minor patients should be allowed to make autonomous decisions.(33-35)

Just as these arguments indicate that it does not necessarily follow from a positive competence assessment that minor patients should always participate in end-of-life decision-making, health care professionals should not simply disregard an incompetent minor patient's opinions.(36;37) It is generally recommended that incompetent minor patients should be involved in decision-making as much as possible, by informing them about treatment options, albeit without granting them full decisional authority.(38) Parents will decide as surrogates on behalf of their children, but professional caregivers face the challenge of involving the incompetent minor patient in an ethical way, without placing an undue burden on them.(33;38) It is recommended that incompetent children's assent with a decision should be sought, and that any strong and sustained dissent with the decision should be taken seriously by health professionals. (38)

b) *Involvement of parents and models of decision-making*

*“Eleven-year-old Samantha is a bright, loving child who was treated for osteosarcoma in her left arm. The arm had to be amputated, and Samantha was given a course of chemotherapy. She has been cancerfree for 18 months and is doing well in school. She is self-conscious about her prosthesis and sad because she had to give away her cat, Snowy, to decrease her risk of infection. Recent tests indicate that the cancer has recurred and metastasized to her lungs. Her family is devastated by this news but do not want to give up hope. However, even with aggressive treatment Samantha's chances for recovery are less than 20%. Samantha adamantly refuses further treatment. On earlier occasions she had acquiesced to treatment only to struggle violently when it was administered. She distrusts her health care providers and is angry with them and her parents. She protests, “You already made me give up Snowy and my arm. What more do you want?” Her parents insist that treatment must continue. At the request of her physician, a psychologist and psychiatrist conduct a capacity assessment. They agree that Samantha is probably incapable of making treatment decisions; her understanding of death is immature and her anxiety level very high. Nursing staff are reluctant to impose treatment; in the past Samantha's struggling and the need to restrain her upset them a great deal.”*

(Quoted from Harrison C, Kenny N, Sidarous M, Rowell M. Bioethics for clinicians: 9. Involving children in medical decisions. CMAJ 1997;156(6):825)

Professional caregivers face the difficult challenge of choosing an adequate model of decision-making. Different models are possible: paternalistic, patient-centered and shared decision-making. In paternalistic models, decisions are predominantly made by the physician, in the patient's best interest. This has been the dominant decision-making model for a long time, based on assumptions that each disease has one single best treatment, that physicians know which treatments are best, and are best placed to weigh different alternatives and to make the decision.(39) Since the 1980s, these assumptions have been questioned and the model has been largely abandoned.(39) It has since been acknowledged that choices between different treatment alternatives require a careful comparison of risks and benefits, which are often weighed very differently by different individual patients, who each have their own preferences and values. With the rise of the concept of informed consent, the predominant decision-making model has shifted to a patient-centered paradigm of information-exchange. In this model, the physician's main responsibility is to provide the patient with all the necessary information regarding diagnosis, prognosis and treatment options. The patient can then deliberate options and make his or her own decisions autonomously, based on this information. This model however also has some flaws in that the patient's deliberation and choices will be influenced by their preferences, beliefs and fears, which may lead to suboptimal decisions that may ultimately even go against the patient's best interest. Therefore, the most widely accepted model is one of shared decision-making between patient and physician.(36;39;40;40-45) Characteristic for this model is the two-way information-exchange, where physicians will provide patients with all necessary information, but patients will also communicate their preferences, values, beliefs and fears to the physician. This two-way information enables patients and physicians to deliberate the available treatment options together, and will ultimately help patients to make an informed and well-deliberated decision, together with their physician, in their own best interest.(39;40) It has been argued that different partners can assume different decisional priority depending on the situation.(46) When cure is more likely, physicians can assume more decisional priority, as cure is usually the ultimate goal and represents the patient's best interest. When more than one reasonable treatment alternative exists, patients and parents can assume more decisional priority, because they are better placed to choose between reasonable alternatives in line with their preferences.(46)

Decision-making is already complex when only a physician-patient dyad is considered, but will be even more complex when a physician-parents-patient triad exists. As a general rule, parents or representatives are necessarily involved in pediatric end-of-life decision-making and they are legally assumed to exercise the rights of their child as a patient, and to make decisions in their best interest.(47-52) The involvement of minor patients will largely depend on their psychological competence. In situations where children have not reached a sufficient level of competence, the situation is fairly clear for professional caregivers, and they will turn to parents or representatives to make choices and decisions on behalf of the minor patient, in their best interest. This paternalistic approach is justifiable, as incompetent minors lack the skills to make their own autonomous decision, yet it remains a challenge to inform them adequately.(38) However, situations can arise where treatment-limitation is considered at the end-of-

life. In these cases, some studies recommend not leaving these decisions to the parents, as they may experience feelings of discomfort and grief when “signing a death warrant for their child”.(53;54) Some therefore suggest that members of the medical team can take on the responsibilities of healthcare surrogate for terminally ill patients.(54) The decision-making process will be complicated when parents and their children have different ideas about the treatments they (or do not) prefer, and conflict between patient, parents or physicians arises as to which plan should be followed.(55) This has led to conflict being resolved by judicial intervention, an option which is not to be recommended.(56;57)

The situation is more challenging when children approach adolescence, and may have reached adequate decision-making capacities.(58) As outlined above, professional caregivers will then have to assess to what degree the competent minor patient should be involved in decision-making and to what degree decisions can be made autonomously by the patient. Existing guidelines clearly recommend that decision-making should be shared with minor patients to the extent that they are competent.(44;47;48;59-61) This approach is substantiated in the Belgian law on patient rights, which also includes a cascaded model of decision-making, in function of the minor patient’s competence.(62) In Belgium, minors’ rights as patients are in principle exercised by their parents or legal representatives.(62) However, minors are to be involved in the exercise of their rights in function of their age and maturity. If they are deemed capable of making a rational assessment of their interests, they can exercise their rights as a patient independently. Additionally, the Belgian law on patient rights requires professional caregivers to involve minor patients as much as possible in exercising their rights as a patient, in function of their level of understanding. The result of the assessment of minor patients’ competence thus directly relates to the degree to which it is legally enforceable for minors to exercise their rights as a patient independently. The law does not, however, specify who should make the assessment of competence, and how this should be done. As minor patients are assumed to be incompetent, the risk exists of setting higher standards for minor patients’ competence than for adults.

*c) Limited experience and expertise in professional caregivers*

As outlined above, professional caregivers can accumulate limited specific expertise in pediatric end-of-life care due to the small number of children who die, and the high proportion who die from external causes. Pediatric end-of-life care is thus often provided by professionals who have little specific experience or training, which has been identified as one of the main challenges in pediatric palliative care.(10;63-67) American pediatric oncologists reported a lack of training in pediatric palliative care, and relied on trial and error in learning to care for dying children – a less than optimal situation.(68) Most expertise is usually available in pediatric oncology settings, where relatively many dying children are cared for. For children suffering from life-limiting illnesses other than cancer, end-of-life care provisions are often more limited. The

small population of minor palliative patients impedes the development of specialized centers of expertise and children's hospices in Belgium. Three initiatives currently provide liaison pediatric palliative home care in Flanders: the "Koester" project of Ghent University Hospital(69), the Palliative home care team of Leuven University Hospital and a team in Antwerp.(70) These projects are mostly operating from pediatric oncology settings, and try to use their expertise in palliative care to organize and coordinate palliative home care for children and their families. These projects have relied entirely on charitable fund-raising until 2009 when an act was accepted by the Chamber, providing a first structural financing for palliative home care for children.(71)

### **1.2.2. Place of end-of-life care and death**

It is not surprising that pediatric palliative care provisions in Belgium focuses strongly on home care, as the provision of palliative home care for children is regarded as an important aspect of high quality pediatric end-of-life care.(72;73) It has been long recognized that palliative home care is a desirable option and that good symptom control is possible for children dying at home.(74-76) Parents caring for a dying child generally prefer home as the place of care and death, because they value the time remaining and perceive this to be the child's wish.(77-84) However home care is not always the preferred option for parents.(85;86)

For parents who care for a child who is dying from cancer, being aware of their child's impending death and understanding the prognosis increased the chances that they prefer their child to be cared for, and for it to die, at home.(87;88) The child being able to die at home has been shown to be related to more positive psychological bereavement outcomes and less pathological grief in bereaved parents.(89;90) Being able to care for their terminally ill child at home meets one of the principal needs for parents in the palliative phase, that is to retain the responsibility of caring for their dying child.(91) Also for siblings, witnessing their brother or sister's death at home is related to more positive outcomes as compared to death in hospital.(90;92) Some authors have nuanced the importance of place of care and death, and emphasize that the match between the planned and actual place of end-of-life care and death is also important, and associated with parents being better prepared for their child's death.(93) Furthermore, one study showed that the establishment of a palliative care unit integrated in a Pediatric Hematology Oncology department actually decreased the proportion of home deaths among their patients.(94) This finding has led commentators to suggest that there may be better options than palliative home care(95), possibly because sending the child home to die can be considered as "giving up on us" by some families.(96)

Most studies on the actual place of death of children have been conducted in specific care settings and patient groups. Often, only children dying from cancer are reported on. As can be expected, proportions of home deaths among children vary considerably across studies, ranging between 9.5% in French cancer patients and 78% in an American



study on advance directives in pediatric patients.(77-79;82;85-87;97-104) These differences are almost impossible to interpret, as settings and patients groups are not comparable.

Unlike in adults, there are only a limited number of population studies on place of death in children. Important studies in this field were conducted by Feudtner and colleagues in the US.(105;106) In their study of death certificates, they found that among all deaths of people dying aged 19 or younger between 1989 and 2003 in the United States, the proportion of home deaths increased from 12.8% (1989-1993) over 16.0% (1994-1998) to 17.7% (1999-2003). The chances of dying at home were higher for children dying from complex chronic conditions and for children dying from malignancies.(105) For Europe, no population-based studies on place of death in children are yet available.

### **1.3. End-of-life decisions and sedation**

Through advances in medicine, imperiled lives can now be sustained for ever longer periods. This evolution has brought new challenges for health professionals, and they now face difficult questions and ethical dilemmas, including how to weigh quality and quantity of life. When the actual and expected quality of life drop below an acceptable threshold, physicians sometimes make decisions which impact on patient longevity. A framework to classify these decisions was developed in the Netherlands, and has been used in all population-based studies since.(107-111) These decisions include: the withdrawing or withholding of life-sustaining treatments, the intensified alleviation of pain and symptoms and the deliberate hastening of death by means of provision or administration of lethal drugs. The last category is often termed physician-assisted death, and comprises different kinds of decisions, depending on who administers or provides the lethal drugs: physician-assisted suicide (if the drugs are administered by the patient him or herself), euthanasia (if the drugs are administered by someone else than the patient, but at the patient's explicit request) and life-ending acts without explicit patient request. The fact that these decisions are often linked to an ever-ageing population should not obscure the fact that decisions to limit treatment and to shorten life are also considered in children. The specific challenges for pediatric health care workers, described above, become even more pronounced when end-of-life decisions are at hand.

Non-treatment decisions and intensified alleviation of pain and symptoms are generally accepted as a part of common and sound medical practice, and different professional pediatric organizations include these practices in their guidelines.(47;48;59;112) The intensified alleviation of pain and symptoms with a life-shortening effect is often excused by the principle of double effect: the act has two effects (pain relief and shorter longevity), the physician only intends the good effect, and accepts the negative effect as a necessary but unintended side-effect.(44) The practice of physician-assisted death on the other hand, where death is explicitly intended by the physician, is much more controversial.(113-124) The legal status varies

according to the different categories of physician-assisted death, and between countries. The administration of lethal drugs without an explicit patient request is illegal in all countries. Assisted suicide is legally allowed in the US states of Oregon, Washington and Montana(125-128), in Switzerland(129) and in the Netherlands.(130) Euthanasia, that is the administration of drugs with the explicit intention of ending the patient's life at the latter's explicit request, is legally allowed in Belgium, the Netherlands and Luxemburg.(131) All three laws on euthanasia list strict due care requirements, and require all cases of euthanasia to be reported to a commission. Minor patients can validly request euthanasia or assistance in suicide only in the Netherlands. A request for euthanasia or assisted suicide can be granted from the age of 12 when the parents consent to it, and from the age of 16 when parents are informed. Additionally, a protocol was developed at the University Hospital of Groningen to provide practical guidelines for intentional life-ending in neonates. An agreement with the public prosecutor was reached, in that physicians will not be prosecuted if they meet all criteria of due care, including certainty about the diagnosis, presence and confirmation by an independent second physician of hopeless and unbearable suffering and informed consent by the parents. The practice is to be reported to the local medical examiner, who in turn reports it both to the district attorney and to a review committee for public control.(132;133) The protocol was welcomed with a lot of international criticism, many critics seeing evidence of a "slippery slope" in the protocol.(134-141)

In Belgium, non-emancipated minors are explicitly excluded from the application of the euthanasia law. This seems to go against existing guidelines on minor patients' involvement in medical decision-making, and the right for competent minor patients to exercise their patient rights independently.(44;47;48;59-62) That does not take away the fact that the issue of extending the application of the Belgian law on euthanasia to include minors is being debated, both in public and in politics. This has led to several proposed amendments to the euthanasia law in recent years, some of which are still under consideration by the commissions of the Senate.(142-148)

Unlike in adult patients(109;111;149-154), end-of-life decisions have been infrequently studied in children, and studies are often limited in care settings and patient groups. Most studies have been conducted at pediatric and neonatal intensive-care units, and most have focused on decisions to withdraw or to withhold treatments. All these studies indicate that decisions to forgo life-sustaining treatment are frequently made in neonates and children, proportions often surpassing 50 percent of studied deaths.(96;155-168)

Population-based studies, which include deaths across care settings and patient groups, remain rare in children. Studies in neonates have been conducted in Belgium and the Netherlands, and indicate that end-of-life decisions are frequently made in this group. In Flanders, 57% of all neonatal deaths were preceded by an end-of-life decision, and 7% by physician-assisted death.(169;170) In the Netherlands, the incidence of end-of-life decisions in newborns was similar: 62% to 68% of all deaths were preceded by an end-of-life decision, and 9% to 10% by physician-assisted death.(170;171) In children dying after the age of one, only one population study has so far been conducted. In the Netherlands, 36% of all deaths of children dying between one and 17 years in 2001 were

preceded by an end-of-life decision. Intensified alleviation of pain and symptoms was the most frequent decision, with 21%, while physician-assisted death occurred in 2.7%. It was estimated that annually five cases of euthanasia of children occur in the Netherlands, and 15 cases where physician-assisted death occurred without a patient request, but at the explicit request of the family.(172)

In recent years, the practice of terminal or palliative sedation, ie lowering the conscience of patients in order to alleviate refractory symptoms, is gaining interest and has been studied frequently in adults.(173-184) The incidence of continuous deep sedation has been studied population-wide in Belgium and the Netherlands, and is shown to have risen significantly since 2001 in both countries.(111;185) Until now, very little has been known about the incidence and practice of sedation in minors. However, the clinical and ethical challenges linked to sedation at the end-of-life are likely to be similar in minor patients, while the specific challenges of pediatric end-of-life care remain present. Challenges of palliative or terminal sedation include the choice of drugs to be used, the optimal duration of sedation, whether sedation is to be used continuously or intermittently, whether or not artificial food or fluids are to be administered and whether or not shortening of life may be intended by the physician.(179;181;186-188) Several guidelines have been proposed to help practitioners deal with these challenges. They generally state that benzodiazepines should be the first choice of drugs, that sedation at the end-of-life should not last longer than two weeks, sedation should only be used to relieve refractory symptoms, artificial food and fluids should not be administered and life-shortening should not be intended.(182;189-191) One of the main problems with the practice of terminal or palliative sedation is that - contrary to the guidelines - it may sometimes be used as an alternative to physician-assisted death. A recent study in the Netherlands suggested that since 2001 some substitution has taken place between both practices, whereby euthanasia has become less frequent and the incidence of sedation has risen significantly.(185) This substitution may indicate that sedation is indeed sometimes used as a covert form of euthanasia, with the same life-ending intention. While euthanasia is legally regulated by strict due care requirements and an obligation to openly report the practice, no such requirements exist for sedation. This suggests that sedation is sometimes used as an alternative to physician-assisted death, but without any reference to due care requirements or societal control. In children, there are only a few studies which have addressed the practice of sedation at the end-of-life.(192-195) These studies were limited in scope and care setting, but suggest that sedation may also be used as an option at the end-of-life of children. To our knowledge, no specific guidelines on sedation at the end-of-life of children have been formulated thus far.

Attitudes towards end-of-life decisions have been studied frequently, revealing a large variance in attitudes between countries and between groups of subjects.(196-206) Studies are often difficult to compare, as different methodologies and groups of subjects are used. One study on public acceptance of euthanasia in 33 European countries however clearly demonstrated the substantial cross-national differences in attitudes, with the most positive attitudes towards euthanasia in the Netherlands, Denmark, France, Sweden and Belgium, and the most negative in Romania, Malta and Turkey.(197) In general, physicians are less inclined to accept euthanasia and

legalization of euthanasia as an option at the end of life than the general public.(201;204;207) Public acceptance of euthanasia has increased significantly between 1981 and 1999 in Europe.(208) A study in five European countries and Australia found a significant relation between religious stance and end-of-life attitudes and practices. Physicians with religious attitudes had significantly less accepting attitudes than non-religious physicians, and they engaged in physician-assisted death less frequently.(198) The link between attitudes and actual end-of-life practices was also demonstrated in other studies.(196) These studies indicate the importance of studying attitudes towards end-of-life decisions of all persons involved.

Most studies on attitudes towards end-of-life decisions have focused on adults. Studies on attitudes related to end-of-life decisions in pediatric and neonatal practice display a similar pattern of variability between physicians and the public and between countries.(169;209-220) Pediatricians and physicians generally accept limitation of life-support in certain instances, but in most countries explicit life-shortening in children is not acceptable for physicians, except in Belgium, the Netherlands and France.(169;212;218) Attitudes of children and adolescents towards end-of-life decisions in minors have largely remained unstudied until the present.

#### **1.4. Research questions**

The introduction above has made it clear that important questions still remain unanswered in the literature on pediatric end-of-life care. These questions are situated in different domains. A first gap concerns systematic population-based information on where children die in Europe. It was demonstrated that place of death is an important part of quality end-of-life care in children. Understanding the factors that facilitate home death in children is necessary to improve the rate of home deaths among children. It would also be interesting to compare the preferred (by parents or patients) place of death with the actual place of death of children, but collecting this information on an individual level is hard to reconcile with our goal of collecting population-wide data. We will therefore mainly focus on where children die, and which factors are related.

A second gap concerns data on end-of-life decisions in children dying between one and 17 years. As we described above, end-of-life decisions not only pose difficult challenges for health professionals; a possible extension of the Belgian law on euthanasia is also being debated. There is therefore an urgent need to learn more about these decisions, how they are made, and how minors and physicians view these issues. Until now, little has been known about these practices in children, and debates are currently largely being conducted without an empirical foundation. Therefore, we will first try to understand how adolescents think about end-of-life decisions in minors and whether experience with chronic illness influences these attitudes. Subsequently, we will focus on physicians' attitudes towards physician-assisted death in minors, and whether they think the Belgian law on euthanasia needs to be amended to include minors. As our methodology guarantees full anonymity of the patients (see below), it was not possible

to contact the parents to study their attitudes as well. Finally, for the first time in Flanders, we will try to estimate the incidence of end-of-life decisions in children dying at age one to 17. As decision-making is very challenging for health professionals, we also focused on how these decisions are made and which partners are involved in making them.

A third and final gap concerns continuous deep sedation in minors. Our discussion above makes it sufficiently clear that this practice is related to several clinical and ethical challenges, but that there are virtually no data available on this practice in minors. Therefore, and as far as we know for the first time in the world, we aim to estimate the population-wide incidence of continuous deep sedation at the end-of-life in minors, and to describe the characteristics of the practice and how these decisions are made. These data are indispensable in understanding the role of sedation in children's end-of-life care, and to finding out whether sedation is practiced with due care by physicians.

In summary, we will focus on the following main research questions in this dissertation:

1. Where do children die, and which factors are related to this?
2. What do minors think of end-of-life decisions in children?
3. Does experience with chronic illness influence the attitudes of adolescents towards end-of-life decisions?
4. What do physicians think about physician-assisted death in minors and a possible amendment to the Belgian law on euthanasia to include minors?
5. How often do end-of-life decisions, including continuous deep sedation, occur in children in Flanders, Belgium?
6. What are the characteristics of these decisions, and how are they made?

## **1.5. Methodologies**

To answer these research questions, different data sources and methodologies were used.

The first research question was approached by using a database containing information from death certificates for all children dying between the ages of one and 17 in 2002 or 2003 in nine European countries. Within this database, countries were selected where the data allowed for discerning home from other places of death. Six countries were retained in the dataset: Belgium (Flanders and Brussels), the Netherlands, Italy (the regions of Tuscany and Emilia Romagna and the city of Milan), Norway, Wales and England. Standard descriptive statistics were used to describe the proportion of home

deaths. Chi-square statistics and multivariate binomial logistic regressions were used to investigate which factors influence the chances of home death for children dying from complex chronic conditions.

For the second research question, data from a 2000-2001 study in 1.769 Flemish adolescents from second and fourth grades in 20 secondary schools were used. Hypothetical case descriptions were presented to these adolescents. All cases described a situation where a 14-year old was suffering from a terminal or non-terminal disease. Participants were asked whether the patient could ask the physician for different types of end-of-life decisions. Additionally, participants were surveyed on their opinion on the right of minor patients to be informed about a terminal prognosis, and whether they would want to be informed themselves when faced with a similar situation. Standard descriptive statistics were used to describe the participants' attitudes and chi-square statistics to test whether attitudes were related to participant characteristics.

A similar approach was used to answer the third research question. To this end, data were used from a 2004 interview study in 83 adolescents, aged between 11 and 18 years, who had been treated for cancer a least two years prior to the study. During the interviews, they were presented with similar hypothetical case descriptions and similar questions as in the study above. Besides describing the adolescent cancer survivors' attitudes, Chi-square tests were used to compare the answers of the cancer survivors with the answers of the students in the above mentioned study because questions were similar.

The third, fourth and fifth main research questions were answered with a population-based post-mortem physician survey, based on death certificates of all patients who died during an 18-month period in 2007 and 2008 in Flanders at age one to 17 years. The certifying physicians were sent an anonymous questionnaire asking about the end-of-life decisions, including continuous and deep sedation, made in the death concerned, characteristics of the end-of-life decision and the decision-making process prior to the decision. Additionally, physicians were asked about their attitudes towards 13 statements relating to euthanasia and physician-assisted death in minors. In order to guarantee strict anonymity of patients and physicians, a complex mailing procedure was used, with a lawyer as intermediary between the Flemish Ministry of Health who sent the questionnaires, and the researchers who received the questionnaires only after they were made fully anonymous by the lawyer. To enhance response, the Total Design Method was used, with three reminders.(221;222) Standard descriptive statistics were used to describe incidence, characteristics and decision-making process prior to end-of-life decisions. The attitudes of the physicians were described and clustered in a K-means cluster analysis. Cluster membership was used to investigate whether attitudes and actual end-of-life practices were related.

## 1.6. Dissertation outline

In Chapter 2, the data on place of death and factors related to home death in children dying from complex chronic conditions are presented. Chapter 2 will answer the first research question described above.

Chapter 3 to 5 will focus on attitudes towards end-of-life decisions in minors, and starts with the data from a study in adolescents in order to get a picture of how healthy adolescents think about end-of-life decisions in minors. Subsequently, the study in adolescent cancer survivors will be described, with a focus on how their attitudes differ from the healthy adolescents in the first study. Finally, the attitudes towards euthanasia and physician-assisted death of physicians who were involved in the care of all dying children in Flanders will be described. Chapter 3 to 5 will try to answer research questions 2 to 4 described above.

In Chapter 6 and 7, an answer to research questions 5 and 6 will be formulated. First, the prevalence of end-of-life decisions in children will be described, and descriptions of characteristics and decision-making process will be provided. Second, the focus will be on prevalence, characteristics and decision making prior to continuous deep sedation in minors.

In Chapter 8, the results will be summarized, integrated and discussed, and general conclusions will be formulated.

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## Chapter 2: Deaths of children occurring at home in six European countries

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## Abstract:

### Objectives

Until now there have been no population based European data available regarding place of death of children. This study aimed to compare proportions of home death for all children and for children dying from complex chronic conditions (CCC) in six European countries and to investigate related sociodemographic and clinical factors.

### Methods

Data were collected from the death certificates of all deceased children aged 1-17 in Belgium, the Netherlands, Norway, England, Wales (2003) and Italy (2002). Gender, cause and place of death (home vs. outside home) and sociodemographic factors (socio-economic status, degree of urbanization and number of hospital beds in the area) were included in the analyses. Data were analyzed using frequencies and multivariate logistic regression.

### Results

In total 3,328 deaths were included in the analyses; 1,037 (31.2%) related to CCC. The proportion of home deaths varied between 19.6% in Italy and 28.6% in the Netherlands and was higher for children dying from CCC in all the countries studied, varying between 21.7% in Italy and 50% in the Netherlands. Among children dying from CCC, home death was more likely for cancer patients and those aged over 10. After controlling for potentially related clinical and sociodemographic factors, differences in the proportion of home deaths between countries remained significant, with higher proportions in Belgium and the Netherlands as compared to Italy.

### Conclusions

Although home deaths comprise a substantial proportion of all deaths of children with CCCs, variation among disease categories and across countries suggest that considerable potential still exists for further improvements in facilitating end-of-life care in the home for those children and families who desire to be in this location.

## 2.1. Introduction

Guidelines on pediatric palliative care, as published by the American Academy of Pediatrics and the European Association of Palliative Care, state that care at the end of life of chronically ill children should preferably be provided in the child's home.(1;2) Although sometimes dying at home is either not desired by the patient or family, or not feasible due to limited possibilities of complex symptom control in the home setting, for the majority of parents home is still the preferred place of end-of-life care for children with life-limiting illnesses.(3-6)

Studies of bereaved parents show that the child's death taking place at home is related to more positive bereavement outcomes for parents and siblings.(7-10) This is not surprising as home care enables parents to sustain their relationship as caregivers for their children better than they can in hospital. This has been identified as a paramount need of parents at the end of their children's life.(3) For children, dying in a familiar environment can help to make the final stage of their life less confusing and psychologically more comfortable.

Studying place of death is particularly relevant for children suffering from chronic disease, as planning place of death and end-of-life care may be impossible for a significant proportion of children dying suddenly and unexpectedly. Population-based studies in the United States have shown that home is a frequent place of death for children suffering from chronic disease.(11-14) In the United Kingdom, a population-based study in children and adolescents dying from cancer from 1995 to 1999 showed that with 52% home was the most frequent place of death.(15)

Until now, studies on children's place of death have often been limited in setting and patient groups. As population based studies are not restricted to specific settings or patient groups, they can be helpful to generate hypotheses on factors influencing place of death and to inform clinicians and policy makers. To our knowledge, cross-national comparisons of place of death in children have not until now been reported. Comparing place of death in different countries with different organization of care could be useful to help identify factors that facilitate home death. For all the participating countries (Belgium, Italy, the Netherlands, Norway, England and Wales), this study addressed the following research questions: (1) what proportion of deaths of patients aged 1 to 17 occurs at home; (2) what proportion of patients aged 1 to 17 dying from complex chronic conditions (CCC) occurs at home; (3) which clinical and socio-demographic factors are related to home deaths for children dying from CCC; and (4) after controlling for related factors, are there differences between countries in the proportions of home deaths among children dying from CCC?

## 2.2. Method

When studying characteristics of deaths on a population level, death certificates are a useful tool in providing valid and reliable information.(13;14;16;17) From a database containing data from death certificates in nine European countries, all deaths of children aged 1 to 17 were selected.(16) Six countries where data from death certificates made it possible to discriminate between home and other places as place of death were retained in the dataset: Belgium (year of death 2003, the regions Flanders and Brussels, approximately 65% of all deaths in Belgium), Italy (2002, the regions Tuscany, Milan, Emilia Romagna, approximately 17% of all deaths in Italy), the Netherlands (2003), Norway (2003), England (2003) and Wales (2003). Procedures to obtain the data differed between countries but all necessary approvals were obtained. These procedures are described elsewhere in full.(16)

Variables included in the database were, on an individual level, retrieved from death certificates: gender, age, underlying cause of death (ICD-10 code) and place of death. For Norway, the variable age only allowed the identification of the group of 1 to 17 year olds from the population database but provided no further detail. Information on cause of death was only available as a recoded variable consisting of 38 categories for Italy (see Appendix). For computation of variables based on cause of death, estimations had to be made for Italy, based on these 38 categories. To identify the group of children dying from chronic condition, we used Feudtner's operationalization of "complex chronic condition" (CCC) and recoded the included ICD-9 codes into ICD-10 codes (see Appendix) (11-14): *"Complex chronic conditions (CCC) are defined as medical conditions that can be reasonably expected to last at least 12 months (unless death intervenes) and that involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center."*

Besides individual information from death certificates, three variables were included based on community characteristics, providing information on an aggregated level using the municipality or province codes of the residence of the deceased child: number of hospital beds in the region, socio-economic status (SES) and degree of urbanization. For Italy, data on SES was not available.

The first research question was answered using descriptive statistics. Age was recoded into two categories (1-10y and 11-17y). Using ICD-10 codes, the underlying cause of death was recoded into eight categories: external causes, cancer (haematological and non-haematological), diseases of the central nervous system, congenital causes of death, cardiovascular diseases, respiratory diseases and other causes of death. Additionally, the proportion of deaths caused by CCC was calculated per country (see Appendix). Place of death was recoded into two categories: home and outside home.

The third and fourth research questions were answered using Chi-square statistics and multivariate logistic regression in the subgroup of children dying from CCC, with home death (vs. death outside the home) as dependent variable and gender, age (1-10y and 11-17y), underlying cause of death (recoded into two categories: cancer and non-

cancer), the number of hospital beds in the region (median split per country), socio-economic status (SES, per country: high, average and low, derived from average income in the community where death occurred) and the level of urbanization per country (very high, high and average/low) as independent variables. To gain insight into how factors influence home death and how these factors can explain differences between countries, a stepwise multivariate binary logistic regression model was constructed. Model 1 contained country as independent variable, Model 2 added the individual variables age, gender and cause of death while Model 3 added number of hospital beds and degree of urbanization. SES was not included in the regression because detailed data on this variable were missing for Italy. Norway was excluded from multivariate logistic regression because detailed data on age were missing. The logistic models do not account for possible clustering of observations within countries. Adjusted odds ratios and 95% confidence intervals (CI) were calculated. Significance was set at  $p$ -values  $<.05$ . SPSS 15.0 was used for all analyses.

### 2.3. Results

In all the countries studied, 3,328 (0.37%) deaths were of children between 1 and 17 years of age (see Table 1). The proportion of deaths from external causes varied between countries, from 30.6% in England to 42.5% in Belgium. The proportion of 1-17y-olds dying from cancer ranged between 13.5% in Belgium and 19.5% in Italy. Cancer was the second leading cause of death in all countries studied. A total of 1,037 children (31.2%) died of complex chronic conditions (CCC), ranging between 27.6% in Belgium and 35.0% in England.

The proportion of all children dying at home was 19.6% in Italy, 20.5% in England, 20.6% in Wales, 21.0% in Norway, 23.8% in Belgium and 28.6% in the Netherlands. The proportion of home deaths for children dying from CCC was higher than the proportion of home deaths in the total population of 1-17y-olds in all countries studied, although differences were small in Italy and Norway. The proportion of home deaths for children dying from CCC varied significantly between countries and was highest in the Netherlands (50.0%) and lowest in Italy (21.7%) (see Table 2).

Bivariate analyses showed that the proportion of deaths occurring at home was higher in cancer patients as compared to non-cancer patients in Belgium, the Netherlands, England and Wales. Age was significantly related to the proportion of home deaths in England, where children dying after the age of 10 were more likely to die at home. SES was only related to the proportion of home deaths in Belgium, where children living in regions with higher SES were more likely to die at home.

Table 1: Characteristics of the population (1-17y) by country of residence (N = 3,328).

	Country of residence*					
	Belgium 2003	Italy 2002	Netherlands 2003	Norway 2003	England 2003	Wales 2003
Total N of deaths	N=67,264	N=99,849	N=141,936	N=42,550	N=505,341	N=33,810
Total N of deaths 1-17y (%)	N=214 (0.32)	N=185 (0.19)	N=650 (0.46)	N=146 (0.34)	N=1,890 (0.41)	N=102 (0.30)
Gender						
Male	57.9	64.3	60.0	56.2	57.9	61.8
Female	42.1	35.7	40.0	43.8	42.1	38.2
Age						
1-10y	53.7	51.4	56.3	†	51.4	46.1
11-17y	46.3	48.6	43.7	†	48.6	53.9
Cause of death‡						
External	42.5	34.6	32.3	31.5	30.6	36.3
Cancer - Non-hemat.	11.2	10.3	11.4	10.3	14.0	9.8
- Hematological	2.3	9.2	5.1	6.8	4.7	3.9
Central nervous system	8.9	6.5	11.2	13.7	13.3	8.8
Congenital	6.1	13.0	7.8	13.0	7.9	10.8
Cardiovascular	4.2	3.2	4.9	4.1	6.3	5.9
Respiratory	4.2	2.2	4.5	3.4	5.9	6.9
Other	20.6	21.1	22.8	17.1	17.2	17.6
Total CCC§	27.6	32.4	27.7	32.9	35.0	28.4
Place of death						
Home	23.8	19.6	28.6	21.0	20.5	20.6
Outside home	76.2	80.4	71.4	79.0	79.5	79.4

Presented figures are percentages per country.

\* Belgium: Flanders and Brussels Capital Region; Italy: Tuscany, Milan and Emilia Romagna

† Detailed data on age were missing for Norway, because aggregated data were used

‡ Because cause of death was available in 38 categories instead of ICD-10 codes for Italy, the categories of complex chronic conditions had to be estimated on the basis of these 38 categories

§ The criteria proposed by Feudtner were used to operationalise deaths from complex chronic conditions (CCC) (11-14)

Table 2: Percentage of deaths occurring at home by country of residence and background variables for all deaths 1-17y caused by a complex chronic condition\*\* (N = 1,037).

	Country of residence*						p-value§
	Belgium	Italy	Netherlands	Norway	UK	Wales	
Total N of CCC-deaths	N = 59	N = 60	N = 180	N = 48	N = 661	N = 29	
% of home deaths (N)	35.6 (59)	21.7 (60)	50.0 (180)	22.9 (48)	31.8 (661)	37.9 (29)	<.001
Gender							
Female	23.1 (26)	30.4 (23)	45.0 (60)	12.5 (24)	31.6 (304)	35.7 (14)	.077
Male	45.5 (33)	16.2 (37)	52.5 (120)	33.3 (24)	31.9 (357)	40.0 (15)	<.001
p-value¶	.075	.215	.343	.086	.922	.812	
Age							
1-10y	31.4 (35)	13.5 (37)	50.0 (108)	†	27.6 (370)	30.0 (20)	<.001
11-17y	41.7 (24)	34.8 (23)	50.0 (72)	†	37.1 (291)	55.6 (9)	.267
p-value¶	.420	.063	>.999	-	.009	.237	
Cause of death‡							
CCC-cancer	51.7 (29)	22.2 (36)	62.9 (105)	16.0 (25)	42.8 (353)	71.4 (14)	<.001
CCC-non-cancer	20.0 (30)	20.8 (24)	32.0 (75)	30.4 (23)	19.2 (308)	6.7 (15)	.109
p-value¶	.011	.898	<.001	.235	<.001	<.001	
N Hospital beds							
Above median	33.3 (33)	23.3 (30)	44.9 (89)	16.7 (18)	32.2 (323)	30.8 (13)	.101
Below median	38.5 (26)	20.0 (30)	54.9 (91)	26.7 (30)	33.3 (318)	43.8 (16)	.001
p-value¶	.683	.754	.180	.499	.759	.702	
Urbanization							
Very strong	20.0 (20)	24.4 (41)	38.7 (31)	25.0 (12)	34.1 (135)	50.0 (2)	.564
Strong	45.5 (22)	15.8 (19)	51.2 (41)	30.8 (13)	37.5 (96)	27.3 (11)	.137
Average/low	41.2 (17)	0.0 (0)	52.8 (108)	17.4 (23)	31.2 (410)	43.8 (16)	<.001
p-value¶	.193	.522	.379	.644	.466	.643	
SES							
High	64.3 (14)	†	45.8 (59)	23.5 (34)	32.6 (193)	31.3 (16)	.030
Average	36.4 (22)	†	56.1 (57)	30.0 (10)	33.3 (234)	71.4 (7)	.008
Low	17.4 (23)	†	49.2 (61)	0.0 (4)	33.0 (185)	16.7 (6)	.018
p-value¶	.015	-	.524	.477	.989	.091	

Presented figures are percentage (number of cases per country per category of background variables) of home deaths per country. Numbers of denominators do not always add up to the total number of CCC-deaths because of missing values.

\* Belgium: Flanders and Brussels Capital Region; Italy: Tuscany, Milan and Emilia Romagna

† Detailed data on age were missing for Norway because aggregated categories were used; data on SES were missing for Italy

‡ Because cause of death was available in 38 categories instead of ICD-10 codes for Italy, the categories of complex chronic conditions had to be estimated on the basis of these 38 categories

§ Pearson Chi-square test, testing differences between countries and within categories of background variables

¶ Pearson Chi-square test, testing differences between categories of background variables and within countries. Fisher's Exact test was used when expected cell counts were less than five.

\*\* The criteria proposed by Feudtner were used to operationalise deaths from complex chronic conditions (CCC) (11-14)

Table 3: Factors related to home death for all deaths caused by complex chronic condition§ (N = 989). Results from multivariate logistic regression analyses.

	Model 1§		Model 2§		Model 3§	
	OR	95% CI	OR	95% CI	OR	95% CI
Country of residence*						
Italy	1 [ref]	1.0-1.0	1 [ref]	1.0-1.0	1 [ref]	1.0-1.0
Belgium	1.2	0.9-4.5	2.4	1.0-5.6	2.4	1.0-5.6
England	1.7	0.9-3.2	1.9	1.0-3.6	1.9	1.0-3.9
Wales	2.2	0.8-5.8	2.8	1.0-7.7	2.7	1.0-7.6
Netherlands	3.6	1.8-7.1	4.1	2.0-8.2	4.0	1.9-8.3
Gender						
Female			1 [ref]	1.0-1.0	1 [ref]	1.0-1.0
Male			1.1	0.8-1.4	1.1	0.8-1.4
Age						
1-10y			1 [ref]	1.0-1.0	1 [ref]	1.0-1.0
11-17y			1.4	1.1-1.8	1.4	1.1-1.9
Cause of death†						
CCC-non cancer			1 [ref]	1.0-1.0	1 [ref]	1.0-1.0
CCC-cancer			3.3	2.5-4.4	3.3	2.5-4.5
N Hospital beds						
Above median					1 [ref]	1.0-1.0
Below median					1.1	0.9-1.5
Urbanization						
Very High					1 [ref]	1.0-1.0
High					1.1	0.7-1.7
Average/low					1.1	0.7-1.5

Results from multivariate logistic regression analyses, with home death vs. death outside home as dependant variable. Independent variables were entered in block and were: country of residence in Model 1; country of residence, gender, age and cause of death in Model 2; and country of residence, gender, age, cause of death, number of hospital beds in the region and degree of urbanization in Model 3. Presented figures are odds ratios (OR) and 95% confidence intervals (95% CI). Norway was excluded from the analysis because detailed data on age were missing.

\* Belgium: Flanders and Brussels Capital Region; Italy: Tuscany, Milan and Emilia Romagna

† Because cause of death was available in 38 categories instead of ICD-10 codes for Italy, the categories of complex chronic conditions had to be estimated on the basis of these 38 categories

§ The criteria proposed by Feudtner were used to operationalise deaths from complex chronic conditions (CCC) (11-14)

§ Nagelkerke R<sup>2</sup> for Model 1: .035; Model 2: .138; Model 3: .142

For children dying from CCC (excluding Norway), Model 1 of the multivariate binary logistic regression showed that home death was more likely for children dying from CCC in the Netherlands (OR 3.6; 95% C.I. 1.8-7.1) as compared to Italy (see Table 3). Controlling for gender, age and cause of death, in Model 2, differences between countries were more pronounced: children dying from CCC in Belgium, Wales and the



Netherlands had higher chances of dying at home than children dying from CCC in Italy. Model 2 fitted the data better than Model 1 (Likelihood Ratio Test: 78.8, 3 df,  $p < .001$ ). The final Model 3 included the number of hospital beds and the degree of urbanization and differences between countries remained significant. Children dying from CCC in the Netherlands and Belgium still had higher chances of dying at home than those in Italy, while the chances of home death approached significance in Wales and England. The higher chances of home deaths for children dying after the age of 10 (OR 1.4; 95% C.I. 1.1-1.9) and children dying from cancer (OR 3.3; 95% C.I. 2.5-4.5) remained significant, while both community-based variables were not significant factors in the final model. Children dying after the age of 10 and children dying from cancer had a higher chance of dying at home. Model 3 fitted the data better than Model 2 (Likelihood Ratio Test: 18.8, 3 df,  $p < .001$ ).

## 2.4. Discussion

The results of our study show that of all children dying at age 1 to 17 in the six European countries studied, about one in five died at home. Children dying from CCC were more likely to die at home than those not dying from CCC. The proportion of home deaths amongst children who died from CCC varied strongly between countries, from 21.7% in Italy to 50.0% in the Netherlands. The chances of dying at home for children dying from CCC were higher for those dying after the age of 10 and for those dying from cancer. After controlling for differences in age, gender, cause of death and community-based variables, differences in the chances of dying at home remained significant between countries. Children in Belgium and the Netherlands had significantly higher chances of dying at home than children in Italy.

This study was the first, to our knowledge, to study systematically the place of death of children at a population level in different European countries. The use of death certificates allowed for studying different individual variables and making reliable estimates at a population level. The analyses made it possible to focus on cross-national comparisons across different care settings and patient groups. Moreover, the group of children dying from CCC could be identified by detailed information on cause of death on the death certificates, which allowed for more relevant analyses.

This study has several limitations that should be kept in mind when interpreting the data. Place of death may be considered a robust indicator of how societies, from a broad perspective, approach death and dying, and how they have accordingly organized their end-of-life care. However, it does not give information on the palliative care before death, on the quality of care at that time in the disease trajectory, or on the (cultural) preferences which might account for part of the country differences, which makes interpretation of appropriateness of home death in specific instances difficult. SES was only available on an aggregated level and was estimated by average income in the region. It cannot be ruled out that this measurement was too imprecise to capture the

SES of the actual households of individual children. Categories of cause of death had to be estimated on the basis of 38 categories instead of ICD-10 codes for Italy. It is possible that this caused some bias in the results as for Italy the subgroup of children dying from CCC was not as distinct.

The finding that about one in five of all children dies at home was in line with findings from a population based study in the United States.(13;14) The percentage of deaths occurring at home for children dying from CCC in the six European countries studied, ranging between 21.7% and 50.0%, was only consistent with findings in the United States that about 30% of 1 to 19y-olds died at home following CCC in 2002 for some of the countries.(14) While research indicates that home is the preferred place of care for parents caring for terminally ill children, especially when they are emotionally and intellectually aware and well informed about their child's impending death, a large majority of children do not die at home, even if they are suffering from a complex chronic condition.(18) As the present study did not measure parents' or children's preferences on place of death, or medical complications making hospitalization necessary, only cautious conclusions can be drawn.(19)

The observed proportion of children dying at home was generally lower than the proportion of adults dying at home in the same countries.(17) This could be related to different patterns of illness and differences in availability of specialized homecare for children.(20) The proportion of home deaths was highest for children in the Netherlands which equally applies to the proportion of home deaths among adults.(17) This suggests that the general organization of health care in the different countries may influence place of death. General practice is well developed in the Netherlands, which can facilitate the organization of homecare.(21) Although every Norwegian citizen has a general practitioner since the country's reform of general practice in 2000, the proportion of home deaths was low in Norway. Perhaps, a possible effect of this reform on place of death will need some more time to become evident in the admission practice at the end-of-life.

We found cancer to be positively related to children's chances of dying at home in four of six of the countries studied. This finding was in line with previous research (14;22), and could be related to the more predictable course of cancer which makes it easier to plan end-of-life care (23-26); home death is also more frequent in adults dying from cancer (23;27). Furthermore, pediatric palliative homecare, eg in Belgium, is often developed from oncology settings where professional caregivers are the most experienced in providing homecare for terminally ill children. It is important to notice that the biggest potential in improving the rates of home deaths exists in children not dying from cancer.

An important finding was that after controlling for differences in age, gender, cause of death and community-based variables, children dying from CCC in Belgium and the Netherlands still had higher chances of dying at home than those dying from CCC in Italy. Different explanations can be suggested to account for these differences. First of all, differences in organization of care and homecare provision for chronically ill children may be influential. The finding that in Belgium, the Netherlands, England and

Wales, children dying from cancer were more likely to die at home as compared to children dying from other causes suggests that opportunities for home care for child cancer patients are already better developed in these countries. In Italy and Norway, we found no significant differences between cancer and non-cancer patients, indicating that home care provisions for child cancer patients may not be better developed than provisions for children suffering from other diseases in these countries. It should however be noted that recently an agreement on a national plan for pediatric palliative care was reached in Italy, including the promotion of home care for children with life-threatening illness.(28)

Secondly, cultural differences may also be of influence. In Italy, while for older people home death is desirable, young patients are often treated intensively in hospital even when death is imminent, whereas in the Netherlands a greater openness exists in accepting death.(29;30) This is confirmed by studies showing that end-of-life decisions with a possible life-shortening effect are less frequently taken in Italy than in other European countries.(31;32) It was not possible to conclude from the data whether end-of-life care had been aggressive, because no information was available on the specific hospital setting where death occurred (eg pediatric intensive care). However, our findings provided some support for the influence of a cultural factor, as the chances of dying at home for children under the age of 11 were especially low in Italy as compared with the other countries. This aggressiveness of care, rather than a palliative approach focusing on comfort and symptom management, may be specific to Italy. Research is needed to investigate whether the low proportion of children dying at home in some countries (eg Norway) also is related to specific cultural factors, such as attitudes of both physicians and the general public towards life-supporting treatment at the end-of-life as well as towards home as an appropriate place of death.

## **2.5. Conclusion**

Although parents of children with life-limiting complex chronic conditions mostly attest that home is their desired location of end-of-life care for their children, in most countries included in this study, less than half of the patients died at home, indicating that there are considerable opportunities to increase the proportion of these deaths occurring at home. The proportion of home deaths was largest for children with cancer. Furthermore, this proportion varied considerably across countries, suggesting that closer comparative investigation among countries may uncover important related factors to improve pediatric home-based end-of-life care.

## 2.6. Acknowledgement

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## Appendix: Complex Chronic Conditions (CCC) - list of ICD-10 codes

CCC Category	Subcategory	ICD-10
Neuromuscular	Brain and spinal cord malformations	Q000, Q001, Q002, Q019, Q02, Q039, Q043, Q048, Q050, Q051, Q052, Q054, Q055, Q056, Q057, Q059, Q062, Q064, Q068, Q078, Q079
	Mental retardation	F719, F729, F739
	Central nervous system degeneration and disease	E752, E754, G10, G111, G114, G118, G120, G121, G122, G128, G129, G20, G210, G211, G212, G213, G218, G219, G238, G241, G242, G243, G244, G245, G248, G250, G253, G255, G256, G258, G259, G309, G310, G311, G318, G319, G320, G328, G900, G908, G909, G910, G911, G937, G950, G951, G958, G959, G990, G992, M890
	Infantile cerebral palsy Epilepsy Muscular dystrophies and myopathies	G801, G802, G808, G809 G403, G410, G411, G412 G710, G711, G712, G723
Cardiovascular	Heart and great vessel malformations	Q200, Q201, Q203, Q204, Q205, Q208, Q209, Q210, Q211, Q212, Q213, Q220, Q221, Q223, Q224, Q225, Q230, Q231, Q232, Q233, Q234, Q240, Q242, Q243, Q244, Q245, Q246, Q248, Q249, Q250, Q251, Q252, Q254, Q257, Q262, Q263, Q268, Q269
	Cardiomyopathies Conduction disorders and dysrhythmias	I421, I423, I424, I428, I515 I440, I441, I442, I443, I446, I447, I451, I452, I453, I454, I455, I456, I458, I459, I471, I472, I479, I48, I490, I491, I494, I495, I498, I499
Respiratory	Respiratory malformations	Q300, Q308, Q310, Q324, Q330, Q334, Q336, Q338, Q339, Q348, Q349
	Chronic respiratory disease Cystic fibrosis	P279 E840, E841, E848, E849
Renal	Congenital anomalies	Q600, Q610, Q611, Q612, Q613, Q614, Q615, Q618, Q619, Q623, Q628, Q638, Q641, Q643, Q644, Q647, Q649
	Chronic renal failure	N189
Gastrointestinal	Congenital anomalies	Q391, Q419, Q429, Q431, Q441, Q442, Q445, Q446, Q453, Q458, Q459
	Chronic liver disease and cirrhosis	K730, K738, K739, K745, K746, K760, K769
	Inflammatory bowel disease	K500, K501, K508, K509, K510, K511, K512, K513, K514, K518, K519
Hematology and immunodeficiency	Sickle cell disease	D570, D571, D572, D573
	Hereditary anemias	D551, D558, D569, D580, D581

	Hereditary immunodeficiency	D71, D720, D800, D801, D802, D803, D804, D805, D808, D814, D819, D820, D821, D830, D831, D838, D849, D898, D899, M303, M359
	Human immunodeficiency virus disease	B24
Metabolic	Amino acid metabolism	E700, E708, E710, E720, E721, E722, E728, E728, E729
	Carbohydrate metabolism	E739, E740, E741, E742, E748, E749
	Lipid metabolism	E756, E780, E781, E782, E783, E784, E786, E788, E789, E881
	Storage disorders	E763, E806, E853, E858
	Other metabolic disorders	E798, E806, E830, E831, E833, E834, E880, E888, E889
Other congenital or genetic defect	Chromosomal anomalies	Q909, Q913, Q917, Q930, Q950, Q952, Q968, Q984, Q988, Q999
	Bone and joint anomalies	E343, M410, M411, M412, M413, M965, Q750, Q751, Q752, Q753, Q758, Q759, Q760, Q761, Q762, Q764, Q765, Q766, Q773, Q776, Q780, Q781, Q782, Q788, Q789
	Diaphragm and abdominal wall	K449, Q791, Q795
	Other congenital anomalies	Q870, Q871, Q872, Q874, Q878, Q897, Q898, Q899, Q992
Malignancy		C000-D489, H350, N648, Q850

For Italy, cause of death was available in following categories:

- 1: Tuberculosis
- 2: Viral hepatitis
- 3: Human immunodeficiency virus (HIV) disease
- 4: Malignant neoplasm of stomach
- 5: Malignant neoplasms of colon, rectum and anus
- 6: Malignant neoplasm of pancreas
- 7: Malignant neoplasms of trachea, bronchus and lung
- 8: Malignant neoplasm of breast
- 9: Malignant neoplasms of cervix uteri, corpus uteri and ovary
- 10: Malignant neoplasm of prostate
- 11: Malignant neoplasms of urinary tract
- 12: Non-Hodgkins lymphoma
- 13: Leukemia



- 14: Other malignant neoplasms
- 15: Diabetes mellitus
- 16: Alzheimers disease
- 17: Hypertensive heart disease with or without renal disease
- 18: Ischemic heart diseases
- 19: Other diseases of heart
- 20: Essential (primary) hypertension and hypertensive renal disease
- 21: Cerebrovascular diseases
- 22: Atherosclerosis
- 23: Other diseases of circulatory system
- 24: Influenza and pneumonia
- 25: Chronic lower respiratory diseases
- 26: Peptic ulcer
- 27: Chronic liver disease and cirrhosis
- 28: Nephritis, nephrotic syndrome and nephrosis
- 29: Pregnancy, childbirth and the puerperium
- 30: Certain conditions originating in the perinatal period
- 31: Congenital malformations, deformations and chromosomal abnormalities
- 32: Sudden infant death syndrome
- 33: Symptoms, signs and abnormal clinical and laboratory finding
- 35: Transport accidents
- 36: All other and unspecified accidents and adverse effects
- 37: Intentional self-harm (suicide)
- 38: Assault (homicide)

To identify the group of children dying from CCC, these were recoded as follows:

CCC-cancer: 4-14

CCC-non-cancer: 15, 25, 27, 31

No CCC: else



## **Chapter 3: Attitudes of Flemish secondary school students towards euthanasia and other end-of-life decisions in minors**

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## Abstract:

### Background

The aim of the study was to investigate attitudes of secondary school students towards acceptability of requests by minors for end-of-life decisions (ELDs) with a possible life-shortening effect: non-treatment decisions, potentially life-shortening alleviation of pain and symptoms (APS) and euthanasia.

### Methods

A cross-sectional survey was conducted among second and fourth grades students in 20 secondary schools in Flanders, Belgium. An anonymous structured questionnaire was administered to measure attitudes towards acceptability of requests for euthanasia and other ELDs, towards the right to be informed about terminal prognosis and their own desire to be informed.

### Results

In total, 1769 students participated. In case of a terminal patient, 61% found a request for euthanasia acceptable, 60% a request for APS and 69% a request for non-treatment decision, compared with 18% (euthanasia) and 50% (APS) in case of a non-terminal patient. Acceptance was highest among: boys, participants older than 14 years and participants from general as opposed to technical and vocational education. Sixty-six per cent said the parents' opinion not being asked was a circumstance that should hold back a physician from administering a lethal drug. Ninety per cent of participants thought a minor has the right to be informed about terminal prognosis of a disease while 78% would like to be informed themselves.

### Conclusions

Attitudes towards ELD requests varied with case and participant characteristics and type of ELD. The studied adolescents have a clear wish to be informed about terminal prognosis. Physicians and caregivers should adequately involve adolescents in decision making and tailor prognosis-related information to their needs and level of competence.

### 3.1. Introduction

In the final phase of a patient's life, physicians often balance quality of life against prolongation. Medical end-of-life decisions (ELDs) which possibly or certainly hasten death are frequently taken (1-6). ELDs comprise several kinds of decisions:

- (1) withholding or withdrawing life-sustaining treatments (non-treatment decisions, NTDs);
- (2) alleviation of pain and other symptoms with a possible life-shortening effect (APs);
- (3) the administration of drugs, by a physician, with the explicit intention of ending the patient's life at the explicit request of the patient: euthanasia.

The high prevalence of ELDs is usually associated with an ageing society but ELDs are also frequently taken in relation to minors, defined as not having reached the age of adulthood (in Belgium < 18 yrs.), and infants (7-10). For minors aged 1-17 yrs, a nationwide Dutch study reports that ELDs precede 36% of all deaths in this age category (11).

The involvement of minors in decision-making at the end of life raises questions about the patient's competence to make such decisions. This competence is continually evolving in developing children, and influenced by different factors such as illness experience, the development of a clear concept of death and the extent to which the child is adequately informed about his/her illness and prognosis (12-14). The evolving nature and context-dependency of the minor's competence makes it difficult to assess. In addition according to the Belgian law on patients' rights, unless minors are judged to be competent, their rights as a patient are exercised by their parents or legal representatives. Striking a balance between the patient's interests and the legitimate interests of the parents and achieving multi-party consent are crucial. These factors, among others, complicate the decision-making process in minors. This complexity is present in all ELDs, but while APS and NTD are more accepted as part of normal medical practice, the complexity is heightened by the controversial nature of physician-assisted death.

In the Netherlands minors (< 18) may request euthanasia from the age of 12 years (15). Their legal representatives must be informed and their assent to euthanasia is required when the child is between 12 and 16. In Belgium, minors are excluded from the application of the euthanasia act altogether (with the exception of emancipated minors, who are removed from guardianship by a juvenile court) and extending the application of the law to those under 18 has become the objective of proposals submitted to the Senate and widely discussed in the national media (16-18). Whereas

the actual legal position of minors regarding euthanasia currently does not differ from other countries where euthanasia is not legal, the open debates on this issue in society and politics may be specific for Belgium.

While the results of end-of-life attitude research are available for many adult groups (19-25) at present no representative data have been published on how minors themselves think about euthanasia or other ELDs.

In this study we examine the following research questions:

- whether and under which conditions adolescents ( $\geq 12$  yrs. and  $< 18$  yrs.) find requests from their peers for euthanasia and other end-of-life decisions (NTD, APS) acceptable;
- which circumstances should hold a physician back from administering a lethal drug?
- whether adolescents think a minor has the right to be informed about a terminal prognosis and whether they would want to be informed about a terminal prognosis themselves.

We also study some characteristics (age, gender, type of education and educational network) in relation to the opinions of the adolescents studied.

### **3.2. Method**

An anonymous questionnaire consisting of pre-structured questions concerning requests for ELDs by minors undergoing intense suffering was presented to students by means of touch-screen units. The study population consists of students from the second and fourth grades of Flemish secondary schools in the school year 2000-2001 (before the legalisation of euthanasia in Belgium). These students were reached via a sample of twenty secondary schools.

The school sample was drawn from the registry of schools of the Flemish Department of Education, containing 891 secondary schools and 133.053 students in second and fourth grades (Statistics of the Flemish Department of Education 2000-2001). The school sample was stratified according to province (Flanders has five provinces) and to school network. In Flanders, schools belong to the “free network” (private, most of which are Catholic, schools; 76% of all students in ordinary secondary education) or to the “official school network” (schools run by state, province or town; 24% of students)

Four schools were sampled from each province, of which three were from the “free network” (75%) and one from the “official network” (25%), thus assuring representativity for the network variable. If a school refused to participate in the study another school from the same network and province was chosen at random.

In each school the principal was asked to propose which classes would participate to make up a total of 100 students of which 50 were from the second grade and 50 from the fourth grade. If the populations proposed consisted of fewer than 50 then all students were included.

In order to avoid a priori class consensus, the students were only informed of the content of the questionnaire beforehand in general terms.

#### Box 1: Description of hypothetical cases

##### 1. Acceptability of requests for euthanasia and other ELDs by minors

###### Case 1:

Femke is a 14 year old girl with bone cancer. She experiences a lot of pain. The treatment she receives is very painful and burdensome. Everyone, including Femke herself, knows that she has only a limited time to live. Femke cannot tolerate the pain any longer and wants to die.

###### Case 2:

Nathalie, a 14 year old girl, is severely burnt over the whole of her face and body. She has a lot of pain and because of the burns she cannot move very well. Nathalie does not want to continue living like that, although she has a normal life expectation.

##### 2. Information about terminal prognosis

###### Case 3:

Katrien is a 14 year old girl. She has a disease that will not allow her to live much longer. Everyone around her knows that she will die soon. Katrien has asked repeatedly whether she will die, but nobody will tell her.

Attitudes towards euthanasia and other kinds of ELDs were measured by two hypothetical cases, both describing situations in which a minor clearly expresses the wish to die and asks the physician for an ELD (Cases 1 and 2, Box 1). After discussion with an expert panel, the case descriptions were constructed to distinct a terminal and a non-terminal situation and to reflect realistic situations, which were based on unstructured interviews with severely ill children. The first hypothetical case describes a terminally ill girl suffering from cancer (Case 1). The second describes a non-terminally ill girl suffering intensely from burns (Case 2). The respondents were asked their opinion of the acceptability of requests by these minors (“Yes”, “No” or “I don’t know”) regarding the following decisions: (1) the administration of a lethal drug with the explicit intention of ending the patient’s life (“Can the patient ask the physician for

a lethal injection which will end the patient's life?"); (2) the alleviation of pain and symptoms with a possible life-shortening side-effect (APS) ("Can the patient ask to increase pain medication? This might shorten the patient's life"), and (3) the withdrawing or withholding of life-sustaining treatment with a possible life-shortening effect (NTD) ("Can the patient ask to stop the treatments? This will shorten the patient's life") (this question was not asked in Case 2). The questions were formulated in this way to learn about participants' opinions on feeling free to discuss these end-of-life decisions with a physician. Instead of using value-laden words like "euthanasia", descriptions of what the physician would do were used.

The case descriptions and questionnaire were tested in four students from secondary school. The descriptions were found to be easy to understand and clearly formulated. No subsequent changes to the questionnaire were necessary.

The next question aimed to identify in which circumstances should hold back the physician from a lethal drug. Participants could indicate one or more from following circumstances: refusal by the patient of a lethal drug, the patient being badly informed about his/her condition, the patient expressing the wish to die because of fear of becoming a burden to his/her parents, the parents disagreeing with wish of the adolescent, the physician not having asked the parents' opinion and the request being considered to be due to illness-induced depression.

Two questions were designed to chart the attitudes of the participants towards being informed about a terminal prognosis (Case 3, Box 1). The first question asked whether the girl in Case 3 should have the right to be informed about her terminal prognosis, the second whether participants would like to be informed themselves if faced with a similar situation.

Further questions concerned general background variables (age and gender). Information on other background variables (type of education, educational network and province) was provided per participating class by the school principal. In Belgium students in normal secondary education select one of three types of education. Students in "general education" are offered only theoretical courses: "general education" is intended to prepare students to continue their education at university or college. Students in "technical education" participate in a mixture of theoretical and practical courses and may then choose to enter the labour market or to continue their education at university or college. "Vocational education" is intended to teach the students the skills for a trade, by offering practical courses and internships.

All descriptive research questions were answered using standardised descriptive methods (frequency tables). Confidence intervals were calculated to examine the differences between the two hypothetical case descriptions (terminal vs. non-terminal) and between different types of ELDs. The relations between background variables (age (two groups: 14 and > 14 years), gender, network and type of education) and the opinions of the adolescents were analysed exploratory using multiple logistic regression. Answers on the questions related to the case descriptions were dichotomised (1 = yes, 0 = no and I don't know).



The consent to participate was secured at all levels i.e. students and parents by the school principals. Data were collected by a trusted third party, an independent company specialised in quantitative data collection, using touch screen units. The data file was also prepared by this trusted third party and given to the researchers when all data were collected and anonymised. The students participating in the study were offered the opportunity to attend a debriefing session with the main researcher. At the time of the study, review by an ethical review board was not required, nor usual, for studies of this kind in Belgium.

### 3.3. Results

All students from the classes selected by the school principals participated in the study (N = 1769, Table 1). Characteristics of the response population were compared to the population (data registry of all students of the Flemish Department of Education). The response population differed significantly from the research population for age, gender and school network.

Table 1: Characteristics of participants (N = 1.769) and population (N = 133.053)

Variable		Sample % (N = 1.769)	Population % (N = 133.053)
Gender	Male	52.5	51.3
	Female	47.5	48.7
Age	13 years	30.6	39.1
	14 years	15.0	10.7
	15 years	31.7	34.5
	16 years	15.4	11.9
	17 years	7.4	3.8
School network	Free/Catholic	78.3	75.8
	Official/State	21.7	24.2
Type of education*	General	33.4	-
	Technical	33.3	-
	Vocational	33.3	-

\* Population data on type of education are not available for second grade of secondary education.

In Case 1 (cancer patient, terminal situation), 61% of participants would find a request for euthanasia acceptable, 60% a request for APS and 69% a request for NTD (Table 2). In Case 2 (serious burns, non-terminal situation), 18% would find a euthanasia-request acceptable while 50% would find a request for APS acceptable.

Table 2: Percentage of respondents finding requests for euthanasia and other end-of-life decisions acceptable, unacceptable or undecided (N = 1.769)

Requests of minors for:		Case 1 (terminal cancer patient)	Case 2 (non-terminal burns patient)
Injection of a lethal drug, in order to end her life (EUTH)	Yes	60.7 (58.4-63.0)	17.6 (15.8-19.4)
	No	24.4 (22.4-26.4)	72.5 (70.4-74.6)
	Don't know	14.9 (13.2-16.5)	9.9 (8.6-11.3)
Increased pain medication so that her life may be shortened (APS)	Yes	60.0 (57.7-62.3)	49.7 (47.4-52.0)
	No	26.7 (24.6-28.7)	39.2 (36.9-41.5)
	Don't know	13.3 (11.8-14.9)	11.1 (9.7-12.6)
Stopping treatment, so that her life will be shortened (NTD)	Yes	69.5 (67.3-71.6)	-
	No	20.9 (19.0-22.8)	-
	Don't know	9.7 (8.3-11.0)	-

Percentage of 'yes', 'no' and 'don't know'-answers and 95% confidence intervals.

In the terminal situation (Case 1, Table 3), acceptability of a request for euthanasia is higher for male students than for female, for students in the older age-group than for the younger and for students from general education than for students from technical and vocational education. The acceptability of a request for APS and NTD in a terminal situation is related to age and type of education: older participants and students from general education show more acceptability than younger participants and students from technical and vocational education.

In the non-terminal situation (Case 2, Table 3) more male participants found a request for euthanasia acceptable than did their female counterparts. In the same case, male participants, students from the older age-group and students from general education showed the highest rate of acceptability regarding a request for APS.

The most frequently cited circumstances that should hold back a physician from administering a lethal drug were: the child not agreeing (76%), the child being badly informed about his/her condition (68%) and the opinion of the parents has not been sought (66%). Agreement of the parents was indicated by 40% of participants, while 34% find that the administration of lethal drugs is not acceptable when the child doesn't want to live any longer because of the burden he/she causes to the parents. For 42% of participants it was not acceptable that the physician should be allowed to administer a lethal drug when the adolescent longs to die because of a depressed state of mind induced by their illness (data not shown in table)

Table 3: Acceptability of minor's requests for euthanasia and other ELDs according to the minor's characteristics.

Variables		Case 1 (terminal cancer patient)						Case 2 (non-terminal burns patient)			
		EUTH		APS		NTD		EUTH		APS	
		%*	OR (95% CI)\$	%*	OR (95% CI)\$	%*	OR (95% CI)\$	%*	OR (95% CI)\$	%*	OR (95% CI)\$
Gender	Male	63.4	1 (Ref.)	59.9	1 (Ref.)	68.6	1 (Ref.)	21.0	1 (Ref.)	53.3	1 (Ref.)
	Female	58.3	0.7 (0.6-0.9)	60.0	0.9 (0.8-1.2)	70.3	1.0 (0.8-1.2)	14.4	0.6 (0.5-0.8)	46.4	0.7 (0.6-0.9)
Age	14	56.5	1 (Ref.)	52.6	1 (Ref.)	63.8	1 (Ref.)	18.1	1 (Ref.)	46.2	1 (Ref.)
	> 14	64.3	1.6 (1.3-1.9)	66.1	2.0 (1.6-2.4)	74.2	1.8 (1.5-2.2)	17.1	0.9 (0.7-1.2)	52.6	1.4 (1.2-1.7)
Network	Free/ Catholic	60.2	1 (Ref.)	61.2	1 (Ref.)	69.5	1 (Ref.)	17.9	1 (Ref.)	50.5	1 (Ref.)
	Official/ State	62.5	1.0 (0.8-1.3)	55.7	0.7 (0.6-0.9)	69.3	0.9 (0.7-1.2)	16.4	0.9 (0.7-1.3)	46.9	0.8 (0.6-1.0)
Type	General	71.4	1 (Ref.)	68.0	1 (Ref.)	76.4	1 (Ref.)	18.3	1 (Ref.)	57.5	1 (Ref.)
	Technical	60.6	0.6 (0.5-0.8)	61.3	0.6 (0.5-0.8)	72.0	0.7 (0.5-0.9)	18.0	1.0 (0.8-1.4)	49.6	0.7 (0.5-0.9)
	Vocational	50.2	0.4 (0.3-0.5)	50.7	0.4 (0.3-0.5)	60.0	0.4 (0.3-0.5)	16.4	0.8 (0.6-1.1)	42.0	0.5 (0.4-0.6)

Abbreviations: EUTH: administering a lethal drug to the patient, knowing that this will shorten the patient's life; APS: increasing pain medication, which might shorten the patient's life; NTD: stopping or withholding life-sustaining treatment, which might shorten the patient's life.

\* Percentage of acceptance

\$ Odds Ratios and 95% confidence intervals. Results of multiple logistic regression. Gender, age, network and type of education were entered in block as independent variables, with acceptance of euthanasia and other ELDs (1 = yes, 0 = no or don't know) as dependent variables.

Table 4: Characteristics of respondents in relation to attitudes towards the right and willingness to be informed about terminal prognosis.

Total % (95% C.I.) Variables	Has Katrien the right to be informed that she will die?		Would you want to be informed?	
	%*	OR (95% C.I.)\$	%*	OR (95% C.I.)\$
	89.7 (88.3-91.1)		78.4 (76.3-80.3)	
Gender				
Male	86.3	1 (Ref.)	75.3	1 (Ref.)
Female	92.8	1.9 (1.3-2.6)	81.1	1.4 (1.1-1.7)
Age				
≤ 14	88.5	1 (Ref.)	74.6	1 (Ref.)
> 14	90.8	1.4 (1.0-1.9)	81.5	1.5 (1.2-1.9)
Network				
Free/Catholic	89.5	1 (Ref.)	78.5	1 (Ref.)
Official/State	90.4	1.0 (0.7-1.5)	77.9	1.0 (0.7-1.3)
Type				
General	92.0	1 (Ref.)	78.1	1 (Ref.)
Technical	92.0	0.9 (0.6-1.4)	81.5	1.1 (0.8-1.5)
Vocational	85.1	0.5 (0.3-0.7)	75.4	0.8 (0.6-1.1)

\* Percentage of acceptance

\$ Odds Ratios and 95% confidence intervals. Results of multiple logistic regression. Gender, age, network and type of education were entered in block as independent variables, with answers on questions concerning information about terminal prognosis (1 = yes, 0 = no or don't know) as dependent variables.

Ninety percent of the respondents find that the terminally ill patient described in Case 3 (see Box 1) has the right to be informed about her terminal prognosis (Table 4). Seventy-eight percent of the participants would like to be informed themselves if in the same situation. Agreement with the right to be informed about a terminal prognosis and the willingness to be informed themselves is highest among female participants and students from the older age-group. Agreement with the right to be informed about terminal prognosis is lowest for students from vocational education.

### 3.4. Discussion

The present study found that the acceptability of ELD requests varied with case characteristics (terminal vs. non-terminal), type of ELD (euthanasia, potentially life-shortening pain and symptom alleviation or non-treatment decisions) and participant characteristics, with higher acceptance in male participants, participants aged 14 and older and students who are in general education as opposed to students from technical

and vocational education. A large majority of participants agreed with the right of minors to be informed of a terminal prognosis and demonstrated willingness to be informed themselves. The rate of agreement was higher for female participants, participants aged 14 or older and students from general and technical education as opposed to vocational education. Participants cited the parents not being asked their opinion as an important condition that should hold the physician back from administering a lethal drug. Fewer participants thought the lack of parental consent was a reason for not administering a lethal drug.

This study is the first, to our knowledge, to study systematically the attitudes of minors towards end-of-life decision-making. The study design, using clear and brief vignettes and descriptions of the medical decisions concerned, rather than specialised terms, assumed no prior knowledge of the study-topic, making it well-suited to capturing the perspective of minors from different age-groups and different cognitive levels. The computerised touch-screen units were intended to appeal to the adolescents' sphere of interest, motivating them to participate. The study design further prevented missing values on the questionnaires, no non-response at the level of participation of students, while a priori class consensus on the study topic was avoided. The study also has some shortcomings. Because the vignettes presented were very brief, some complexity and differentiation could not be covered. The answer categories "yes", "no" and "don't know" possibly didn't give enough opportunity for participants to nuance their opinions. Participating classes were proposed by the school principals, which could have caused some selection bias. It is however unlikely that this has systematically distorted the data, as principals may propose classes for different reasons (e.g. most motivated classes or classes who had already addressed end-of-life issues during their courses), which could bias the attitudes of students in the study sample in different directions (both more and less permissive towards end-of-life decisions).

The first important finding, that attitudes vary strongly with case characteristics and type of ELDs, clearly demonstrates that adolescents are capable of nuancing their opinions according to the characteristics of the actual situation. The high rate of those wanting to be informed about terminal prognosis further indicates that adolescents would want to be actively involved in end-of-life decision-making relating to themselves. Although the importance they ascribe to the involvement of parents suggests that they would prefer not to be left alone with the difficult decisions at the end of life, their opinion that parental consent was not necessary points to their willingness to be regarded as capable of taking responsibility for themselves. These findings are in line with previous studies which found that cancer patients who are minors want to be informed about a terminal prognosis, and adapt their willingness to be involved to the type of decisions concerned (26-28).

The higher acceptability of ELD-requests and the higher rate of agreement with the right to be informed about terminal prognosis and the wish to be informed themselves found in older participants was perhaps not surprising and is in line with a previous study of cancer patients who are minors (26). As adolescents mature they become increasingly capable of making autonomous decisions, while they find individuality and

independence increasingly important. These developments may lead adolescents to prefer a more active role in the decision-making process, by wanting prognosis-related information and agreeing more with the acceptability of requests by minors for ELDs. Maturity in thinking about end-of-life issues is not only linked to age-related cognitive development however but also to experience with chronic disease (29-31). Unfortunately, as illness experience was not measured in the present study, its possible effect on opinions concerning end-of-life issues could not be investigated.

We found very little relation between the adolescents' attitudes and the school network, which roughly coincides with the distinction between Catholic and non-Catholic schools; other studies have demonstrated the important influence of life-stance on attitudes towards end-of-life decisions (23;32). We presume that, although the school network variable coincides well with the school's religious stance it does not relate as well to the participants' individual life-stance, as choice of school is probably more determined by other factors e.g. closeness to the place of residence and the perceived quality of education than by the underlying ethos of the school.

The clear effect of the type of education on the opinions of adolescents in this study was in accordance with a previous study on values in Flemish adolescents (33). We hypothesise that the type of education influences adolescents' opinions in that students in general education are more often required to think about ethical issues in class, which makes thinking about these issues more familiar for these students. This might lead them to adopt a more nuanced attitude towards requests for ELDs, and to find being informed about these topics more important.

### **3.5. Conclusion**

The findings of the present study show that adolescents want to be involved in medical decision making at the end-of-life even though their attitudes varied strongly according to case characteristics, type of ELD and they believe that parents should be involved in the process. Attitudes were also related to participant characteristics, although the observed differences in attitudes were smaller than these in relation to case characteristics and type of ELD. Physicians and caregivers should take these variations into account when faced with adolescents at the end of their lives. As not all adolescents find requests for ELDs equally acceptable and not all adolescents want to be informed about terminal prognosis, the results suggest that a differentiated approach taking into account the different views of adolescents is needed for the optimal involvement of adolescents in the decision-making process. Careful assessment by paediatricians or other caregivers of the adolescent's needs and competence and the subsequent tailoring of prognosis-related information to the level of competence and needs of the adolescent will be necessary to create the conditions for high quality care at the end of life for adolescent patients.

### 3.6. Acknowledgement

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## **Chapter 4: Attitudes of adolescent cancer survivors towards end-of-life decisions in minors**

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## Abstract:

### Objectives

The present study aimed to investigate the attitudes of adolescent cancer survivors towards end-of-life decisions (ELDs) with a life-shortening effect: non-treatment decisions (NTDs); intensified alleviation of pain and symptoms (APS), and euthanasia, and the influence of illness experience on these attitudes.

### Methods

Adolescent cancer survivors were interviewed with a structured questionnaire using hypothetical case descriptions to assess their attitudes towards: requests for ELDs by minor patients, the circumstances in which physicians should hold back from administering a lethal drug to a minor, their right to be informed about a terminal prognosis and their willingness to be informed. The results were compared with a study of 1.769 adolescents without experience of chronic illness.

### Results

Eighty-three adolescents, 11-18 years old, were interviewed. In a terminal situation, 70% to 90% found a request for NTD acceptable, 84% a request for APS and 57% to 64% requests for euthanasia. Requests for ELDs were less acceptable in a non-terminal situation, where 28% found a request for NTD acceptable, 39% to 47% requests for APS, and 11% to 21% requests for euthanasia. Frequently-cited reasons for holding back physicians from administering a lethal drug to a child were: the child not being well-informed about his/her condition (92%) and the parents' opinion not being asked (92%). Compared to adolescents without experience with chronic illness, cancer survivors were more acceptant toward requests for NTD and APS in a terminal situation.

### Discussion

Adolescent cancer survivors, like other adolescents, want to be involved in medical decision-making at the end of life. They value autonomous decision-making, without excluding parents from the process. The experience of living through life-threatening illness can alter adolescents' attitudes towards requests for NTD and APS. When trying to involve adolescents and their parents adequately in medical decision-making, the adolescent's illness-experience should be taken into account.

## 4.1. Introduction

Medical end-of-life decisions with a possible life-shortening effect (ELDs) precede about 40% of deaths, not only in adults but also – and this is less clearly recognized – in minors (<18y) (1-5). The legal status of these ELDs generally depends on the category they belong to: (1) the withholding or withdrawing of life-sustaining treatments (non-treatment decisions, NTDs); (2) intensified alleviation of pain and other symptoms (APs); (3) the provision, prescription or administration of lethal drugs by the physician with the explicit intention of ending the patient's life, subdivided into: (1) euthanasia: if the physician administers lethal drugs at the patient's explicit request; (2) physician-assisted suicide: if the physician prescribes or provides lethal drugs administered by the patient him or herself; (3) the administration of lethal drugs by the physician without explicit patient request.

In minors several factors complicate an ethically and legally justifiable decision-making process. According to the Belgian Law on Patient's rights (2002), a minor's legal rights as a patient are exercised by the parents or guardian unless the minor is regarded as competent. Thus, a minor may refuse treatment, even without parental consent, if he or she is judged sufficiently competent to make the medical decision. On the other hand, even if the minor is fully competent according to the Law on Patient's Rights, he or she may not choose euthanasia, as the Belgian Law on Euthanasia (2002) explicitly excludes persons under the age of 18 (6). Because of this perceived inconsistency, the possibility of the inclusion of minors in the application of the euthanasia act is being heavily debated, both in politics and in wider society. This has resulted in several proposals for amendments to the law, some of which are under consideration. (7-9)

Other challenges in the decision-making process preceding ELDs in minors are specifically related to minor patients' decision-making competencies. The concept of competence, however, is difficult to establish for several reasons. First of all, it is not clear who should assess the competence of a minor patient and how this might be done. Secondly, as children are developing physically and mentally, their level of competence is continually evolving, making it more difficult to assess unequivocally. Finally, several factors may influence a child's normal competence, one of which is experience with severe and chronic illness. (10-13).

Despite the frequent occurrence of ELDs in minors, the current debates on non-treatment decisions and euthanasia, and the complexity of the decision-making process preceding ELDs, little is known about how minors themselves think about ELDs and how experience of illness influences their attitudes. Although attitudes towards ELDs have been extensively studied in adults (14-20), they have received less attention in minors. One study among students in Flemish secondary schools showed that adolescents find requests for ELDs, including euthanasia, acceptable in hypothetical cases under certain circumstances (21). This study will address the following research questions in adolescents who survived cancer:

- whether and under which conditions they find requests from their peers for end-of-life decisions - non-treatment decisions (NTD), intensified alleviation of pain and symptoms (APS) and euthanasia - acceptable;
- in which circumstances they consider a physician should hold back from administering a lethal drug to a minor patient;
- whether they think a minor has the right to be informed about terminal prognosis and whether they would want to be informed about a terminal prognosis themselves;
- and, by comparing the attitudes of adolescent cancer survivors with the attitudes of adolescents never diagnosed with cancer: does illness experience change an adolescent's attitudes towards ELDs.

## 4.2. Method

Adolescent cancer survivors were contacted via the Department of Pediatric Hemato-Oncology of Ghent University Hospital in 2004. Participants were included in the study if they were between 11 and 18 years of age and clear from treatment for at least 2 years. The adolescent's parents were sent a letter explaining the research objectives and details, and were asked to give informed consent for their child to participate in the study. One week after the informed consent form was sent, the parents were contacted by psychologists from the department. Adolescents for whom parents provided informed consent were subsequently asked to consent to participation in the study and, if they agreed, interviewed at their home or at another place of their choice. Parents or adolescents who did not want to take part in the study were asked about the reasons they preferred not to participate.

Interviews were administered by three trained interviewers and structured by a questionnaire with closed questions, based on a previous study in secondary schools (21). The questionnaire consisted of three parts, measuring acceptability of requests for ELDs, circumstances in which a physician should not administer a lethal drug to a child, and attitudes towards information about terminal prognosis.

In the first part, hypothetical case descriptions concerning adolescents with an explicit wish to die (see Box 1) were presented to the participants. Case T1 and Case T2 concerned terminal situations, while Case NT1 and Case NT2 concerned non-terminal situations. Questions were asked about acceptability of requests for different types of ELDs: the withdrawing or withholding of life-sustaining treatment with a possible life-shortening effect (NTD) ("Can the patient ask to stop the treatments? This will shorten the patient's life"); the alleviation of pain and symptoms with a possible life-shortening side-effect (APS) ("Can the patient ask to increase pain medication? This might shorten the patient's life"); and the administration of a lethal drug with the explicit intention of ending the patient's life (euthanasia) ("Can the patient ask the physician for a lethal

injection which will end the patient's life?"). To prevent misconceptions about value-laden words like "euthanasia", descriptions of what the physician would do were used.

#### Box 1: Description of hypothetical cases

##### 1. Acceptability of requests for ELDs by minors

###### Case T1:

F is 14 years old and has bone cancer. F experiences a lot of pain. The treatment is very painful and burdensome. Everyone, including F, knows that F has only a limited time to live. F cannot tolerate the pain any longer and wants to die.

###### Case T2:

D, 14 years old, has cancer and has become dependent on other people. D has to undergo different treatments and is has no privacy. D can for instance no longer go to the toilet alone. This causes a lot of fuss, with changing diapers, using bedpans,... D knows that he doesn't have long to live, and can no longer stand that he is deprived of all feeling of honor. D wants to die.

###### Case NT1:

N, 14 years old, is severely burnt over the whole of her face and body. She has a lot of pain and because of the burns she cannot move very well. N does not want to continue living like that, although she has a normal life expectation.

###### Case NT2:

A, 14 years old, has had a severe bicycle accident. A has to undergo difficult and painful surgery to stay alive. A does not want to continue this way.

##### 2. Information about terminal prognosis

###### Case 3:

K is 14 years old. She has a disease that will not allow her to live much longer. Everyone around her knows that she will die soon. K has asked repeatedly whether she will die, but nobody will tell her.

The first three research questions were answered using standard descriptive statistics with 95% confidence intervals. Data from both studies were compared with Chi square statistics, with answers on attitude-items dichotomized into two categories (yes vs. no/don't know). Level of significance was set at  $p < .05$ . All analyses were performed with SPSS 15.0.

### 4.3. Results

Table 1: Description of participant characteristics (N=83)

		N(%)
Gender	Male	43 (51.8)
	Female	40 (48.2)
Age	11 years	2 (2.4)
	12 years	13 (15.7)
	13 years	15 (18.1)
	14 years	12 (14.5)
	15 years	7 (8.4)
	16 years	10 (12.0)
	17 years	11 (13.3)
	18 years	13 (15.7)
Age at diagnosis	0-1 years	18 (21.7)
	2-3 years	22 (26.5)
	4-5 years	14 (16.9)
	6-7 years	11 (13.3)
	8-9 years	6 (7.2)
	10 years or older	12 (14.5)
Cancer type	leukemia	32 (38.6)
	central nervous system	13 (15.7)
	lymphoma	10 (12.0)
	sympathetic nervous system	9 (10.8)
	renal tumors	7 (8.4)
	bone tumors	4 (4.8)
	other	8 (9.6)
Treatment	chemotherapy	65 (78.3)
	surgery	35 (42.2)
	radiotherapy	7 (8.4)
	bone marrow transplantation	3 (3.6)
	transplantation	
Duration of treatment	less than 2 years	8 (9.6)
	2 years or more	75 (90.3)



Parents of 198 adolescents were approached for their consent to the participation of their child in the study. Parents of one adolescent could not be reached because they were abroad during the study period. Parents of 179 adolescents gave their informed consent. Of these 179, 83 consented to participate in the study (total response rate of 83/197, 42%) and were interviewed. The main reasons indicated by the adolescents for not participating in the study were: the subject of the study was too confrontational (indicated by 56) and lack of interest (indicated by 12).

Of the 83 participating adolescents, 52% were male and 51% were 14 years or younger (see Table 1). Leukemia was the most frequent diagnosis (39%), followed by malignancies of the central nervous system (16%). Participants had been in treatment for two years or longer in a large majority of cases (90%). Treatment was often a combination of treatment modalities and comprised chemotherapy for 78% of participants and surgery for 42%. Radiotherapy and bone marrow transplantation were less frequent.

Table 2: Acceptability of different types of end-of-life decisions (ELDs) in different case descriptions

		Terminal		Non-terminal	
		Case T1	Case T2*	Case NT1*	Case NT2
NTD	yes	90.4 (83.9-96.8)	69.9 (59.8-80.0)	-	27.7 (17.9-37.5)
	no	8.4 (2.3-14.5)	26.5 (16.8-36.2)	-	72.2 (52.5-82.1)
	don't know	1.2 (0.0-3.6)	3.6 (0.0-7.7)	-	0.0 (0.0-0.0)
APS	yes	84.3 (76.4-92.3)	-	47.0 (36.0-58.0)	38.6 (27.9-49.2)
	no	8.4 (2.3-14.5)	-	44.6 (33.7-55.5)	57.8 (47.0-68.7)
	don't know	7.2 (1.5-12.9)	-	8.4 (2.3-14.5)	3.6 (0.0-7.7)
Euthanasia	yes	63.9 (53.3-74.4)	56.6 (45.7-67.5)	20.5 (11.6-29.3)	10.8 (4.0-17.7)
	no	34.9 (24.5-45.6)	37.3 (26.7-48.0)	75.9 (66.5-85.3)	88.0 (80.8-95.1)
	don't know	1.2 (0-3.6)	6.0 (0.8-11.3)	3.6 (0.0-7.7)	1.2 (0.0-18.8)

Percentages of participants answering 'yes', 'no' and 'don't know', per ELD and per hypothetical case description (95% confidence intervals).

Abbreviations: APS: increasing pain medication, which might shorten the patient's life; NTD: withdrawing or withholding life-sustaining treatment, which might shorten the patient's life.

\* For case T2 attitudes towards APS were not asked, for Case NT1 attitudes towards NTD were not asked.

In response to the two hypothetical cases describing terminal situations, 90% (Case T1) and 70% (Case T2) of participants found a request for NTD acceptable (see Table 2). The level of acceptance of a request for NTD was substantially higher in the terminal than in the non-terminal case descriptions: 28% (Case NT2). A request for APS was found

acceptable by 84% of participants when a terminal situation was concerned, which was significantly higher than acceptance of APS-requests in the non-terminal examples (47% in Case NT1 and 39% in Case NT2). Requests for euthanasia were found acceptable in terminal situations by 64% (Case T1) and 57% (Case NT2) of participants, which was significantly higher than in the non-terminal situations: 21% (Case NT1) and 11% (Case NT2). In Case T1 a requests for euthanasia was significantly more acceptable for participants aged 15 or older (78%) than for younger participants (50%) (data not shown in table).

Table 3: Conditions under which administration of a lethal drug is not acceptable and attitudes towards right and willingness to be informed about terminal prognosis

	yes	no	don't know
Can a physician administer a lethal drug to a child when:			
- Child doesn't want a lethal injection	-	100.0	-
- Child isn't well informed about its illness	3.6 (0.0-7.7)	91.6 (85.5-97.7)	4.8 (0.0-9.5)
- Child wants to die because of burden to parents	8.4 (2.3-14.5)	91.6 (85.5-97.7)	-
- Parents don't agree with the child's death wish	39.8 (29.5-50.5)	49.4 (38.4-60.4)	10.8 (4.0-17.7)
- Parents opinion is not asked	6.0 (0.8-11.3)	91.6 (85.5-97.7)	2.4 (0.0-5.8)
- Child wants to die because of illness-induced sadness	8.4 (2.3-14.5)	89.2 (82.3-96.0)	2.4 (0.0-5.8)
If a child is suffering from terminal illness:			
- Has he/she the right to know that he/she will die soon?	96.4 (92.3-100)	2.4 (1.0-5.8)	1.0 (0.0-3.6)
- Would you be willing to know yourself?	85.5 (77.8-93.2)	12.0 (4.9-19.2)	2.4 (1.0-5.8)

Percentages of participants answering 'yes', 'no' and 'don't know' (95% confidence intervals)

Participants identified different circumstances that should hold a physician back from administering a lethal drug to a child (see Table 3). None of the participants thought a physician can administer a lethal drug to a child when the child doesn't want it, while 92% thought it should not be allowed when the child isn't well informed about his/her condition, when the child wants to die because of the burden he/she causes to the parents and when the parents' opinion is not asked by the physician. Eighty-nine percent of participants found a physician should not administer a lethal drug to a child when he/she wants to die because of illness-induces sadness. Participants significantly less frequently thought a physician should not administer a lethal drug to a child when the parents do not agree with their child's wish to die (49%).

All but two participants (96%) agreed that a terminally ill minor should have the right to be informed about the terminality of his/her condition, 86% also indicated that they would want to be informed themselves, if ever faced with a similar situation.

When comparing the results of the present study with a previous study in secondary schools, distribution of age and gender did not differ significantly between the two studies (data not shown in table) (21). Where a terminal situation was concerned, acceptance of requests for NTD and APS was significantly higher in the cancer survivors than in participants without cancer diagnoses (see Table 4). Percentage of acceptance of requests for APS did not differ significantly between the two studies when a non-terminal situation was concerned. Participants from both studies did not differ in their level of acceptance of euthanasia requests, both in terminal and in non-terminal situations. Adolescent cancer survivors agreed more than participants from the study in secondary schools with the right of minor patients to be informed about a terminal prognosis.

Table 4: Acceptability of different types of end-of-life decisions in adolescents with (N=83) and without (N=1.769) cancer diagnosis.

		Cancer Survivors N=83	Adolescents without cancer diagnose* N=1769	p-value§
Case T1 (terminal cancer patient):	NTD	90.4	69.5	<.001
	APS	84.3	60.0	<.001
	Euthanasia	63.9	60.7	.566
Case NT1 (heavily burnt patient):	APS	47.0	49.7	.630
	Euthanasia	20.5	17.6	.499
Right to be informed about terminal prognosis		96.4	89.7	.048
Willingness to be informed about terminal prognosis		85.5	78.3	.118

Percentage of participants answering 'yes'.

Abbreviations: APS: increasing pain medication, which might shorten the patient's life; NTD: stopping or withholding life-sustaining treatment, which might shorten the patient's life.

\* Pousset G, Bilsen J, De Wilde J, Deliens L, Mortier F. Attitudes of Flemish secondary school students towards euthanasia and other end-of-life decisions in minors. *Child: Care, Health and Development* 2009;35(3):349-356.

§ p-value for Chi-square statistic testing for differences between both studies.

#### 4.4. Discussion

We investigated adolescent cancer survivors' attitudes towards end-of-life decisions (ELDs). A large majority of participants thought minor patients should be allowed to request a non-treatment decision (NTD) or intensified alleviation of pain and symptoms (APS) when they are in a terminal situation. Participants were less inclined to find requests for NTD and APS acceptable when a non-terminal situation was concerned.

While a request for euthanasia by a minor patient was generally less acceptable than requests for NTD or APS, more than half of participants found a euthanasia request acceptable in a terminal situation. Almost all participants identified different safeguarding circumstances where the administration of a lethal drug is concerned: the adolescent should agree with the administration of a lethal drug, should be well informed about his/her condition, and the parents' opinion should be asked. The burden caused to parents and illness-induced sadness were found not to be sufficient reasons to permit the administration of a lethal drug, while parental agreement with the adolescent's wish for euthanasia was not a necessity for all participants. Compared with adolescents without a cancer diagnosis, adolescent cancer survivors were more acceptant towards requests for NTD and APS where a terminal situation was concerned.

Patient-reported outcomes are relatively few in number in pediatric oncology (22). By focusing on attitudes of minors with a cancer diagnosis, the present study can help to fill this gap. This study is the first to our knowledge to investigate attitudes towards ELDs in adolescents who recovered from cancer and had thus had experience of a life-threatening illness. Because the questionnaire was similar to a previous study in secondary schools, it was possible to compare the present results with the attitudes of adolescents without a cancer diagnosis. The study also has some shortcomings. Firstly, the response rate was fairly low. Non-response was partly at parent-level, and partly caused by adolescents not wanting to be confronted with their period of illness. It is possible that this caused some bias in the results. However, as it is vital to obtain informed consent, both at parent and adolescent level, when conducting studies on these sensitive topics, potential bias could not be prevented. Secondly, when comparing with the previous study in secondary schools, it cannot be entirely ruled out that some of the participants from the first study had also had a cancer diagnosis in the past. However, as this is probably a very small proportion it is highly unlikely that it has substantially influenced the results of the comparative analyses. Finally, some participants were very young at the time of diagnosis and treatment, whilst others were already nearing adulthood, causing heterogeneity in the degree of illness experience.

The first major finding, that attitudes towards ELDs vary strongly with case characteristics (terminal vs. non-terminal), was in accordance with the previous study (21). Apparently, adolescent cancer survivors also find ELDs more acceptable in situations where treatment is no longer possible and death is imminent than in non-terminal situations. This is not surprising, as adolescents have been shown to be very resilient and perseverant, even in life-threatening situations, making them less likely to accept life-shortening options when death is not imminent (23;24).

The second important finding was that adolescent cancer survivors were more acceptant of requests for NTD and APS in terminal situations than adolescents without cancer a diagnosis. This finding suggests some effect of illness experience on attitudes towards ELDs. We hypothesize that cancer survivors, having lived through the pain and symptoms caused by cancer, are better able to empathize with the cancer patients in the terminal case descriptions, leading to less resistance to a request for an end-of-life

decision that may shorten life. It may have been more difficult for them to identify and empathize with the severely burnt patient in the non-terminal case description. A second hypothesis is possible, based on the specific developmental issues related to adolescence. Psychological literature has identified individuation (identity formation and the development of autonomy) as one of the most important developmental tasks adolescents face, and this is often challenged by the feelings of invincibility which are prominent in adolescence (25;26). As research shows, living or having lived with cancer can influence these developmental processes and outcomes (27;28). It could be hypothesized that adolescent cancer survivors detach more easily from these feelings of invincibility than do adolescents who have not lived through a cancer episode, which causes them to accept life-limiting options, under certain circumstances, more easily. More specific research is needed to explore further the psycho-developmental processes of children who have survived cancer.

Illness experience did not significantly affect attitudes towards requests for euthanasia. This finding suggests that attitudes towards euthanasia, as opposed to other ELDs, are influenced more by stable personal attitudes on eg religion (14), autonomy and self-determination, than they are by experience with chronic illness.

A third striking finding was that almost all adolescent cancer survivors participating in the study identified one or more circumstances in which a physician should hold back from administering a lethal drug to a patient. Involvement of parents in the decision-making process was found to be very important to the participants, although for 40% of cases parental agreement with the child's wish for euthanasia was not required. Also, nearly all cancer survivors agreed that children should have a right to be informed about a terminal prognosis. These results were all in line with the previous study, and show that although they value a certain amount of autonomous decision-making, adolescents do not take these end-of-life issues lightly, and want their parents to be involved (21). The results also accord with a study of American adolescent cancer patients who stressed the relational aspect of the end-of-life decision-making process and valued parental involvement (13).

## **4.5. Conclusion**

The results of the present study show that adolescent cancer survivors, like other adolescents, want to be involved in medical decision-making at the end of life. Not only are they acceptant towards requests for certain ELDs, especially when terminal situations are concerned, but they also value a certain degree of autonomous decision-making, albeit without excluding the parents from the process. The findings further suggest that the experience of living through a life-threatening illness can lead adolescents to become more acceptant towards requests for NTD and APS where a terminal situation is concerned. When trying to involve adolescents and their parents adequately in medical decision-making, age, sex and type of education are factors that

should be taken into account by physicians and caregivers (21). As the present study shows, the adolescent's own illness experience should also be taken into consideration.

#### 4.6. Acknowledgement

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## Chapter 5: Attitudes and practices of physicians regarding physician-assisted dying in minors

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## Abstract:

### Objective

Investigating attitudes towards physician-assisted death in minors of all physicians involved in the treatment of children dying in Flanders, Belgium over an 18-month period, and how these are related to actual medical end-of-life practices.

### Method

Anonymous population-based post-mortem survey among physicians signing death certificates of all patients aged 1 to 17 years who died between June 2007 and November 2008 in Flanders, Belgium. Attitudes towards physician-assisted death in minors and actual end-of-life practices in the deaths concerned were surveyed.

### Results

Response was obtained from 124 physicians for 70.5% of eligible cases (N=149). Sixty-nine percent favor an extension of the Belgian law on euthanasia to include minors, 26.6% think this should be done by establishing clear age-limits. Sixty-one percent think parental consent is required before taking life-shortening decisions. Cluster-analysis yielded a cluster (67.7% of physicians) acceptant of, and a cluster (32.2% of physicians) reluctant about physician-assisted death in minors. Controlling for physician specialty and patient characteristics, acceptant physicians were more likely to engage in practices with the intention of shortening the patient's life than were reluctant physicians.

### Conclusion

A majority of surveyed Flemish physicians appear to accept physician-assisted dying in children under certain circumstances and favor an amendment to the euthanasia law to include minors. The approach favored is one of assessing decision-making capacity rather than setting arbitrary age-limits. These stances, and their connection with actual end-of-life practices, may encourage policy-makers to develop guidelines for medical end-of-life practices in minors that address specific challenges arising in this patient group.

## 5.1. Introduction

It is increasingly recognized that end-of-life decisions with a possible or certain life-shortening effect are frequently taken in relation to minor patients (<18y) (1-4), as they are with adults.(5-8) Whereas non-treatment decisions and intensified alleviation of pain and symptoms are generally accepted as part of sound medical practice(9-11), physician-assisted dying is much more controversial.(12-16) Moreover it is linked with additional problems in minor patients, such as issues about whether it is ethically justified to let a minor with decision-making capacities participate in decisions to use lethal drugs.

In recent years, laws on euthanasia have been enacted only in Belgium, the Netherlands and Luxemburg and physician-assisted suicide has been legally accepted in the Netherlands, Luxemburg, Switzerland and the states of Oregon, Washington and Montana in the US.(17-19) Only in the Netherlands is the law on euthanasia or physician-assisted suicide applicable to minors: they can validly request physician assistance in dying from the age of 12 with the consent of their parents, and from the age of 16 when their parents are informed. In Belgium, minors are excluded from the provisions of the euthanasia act; a debate is currently going on to extend the range of the Act to include minors. This debate, which has resulted in several proposed amendments (20-24), would be well-served by the availability of empirical data.

The attitudes of physicians towards physician-assisted death in minors, and how these may influence their practice, are important issues in this debate. However, until now, research on attitudes towards end-of-life decisions in minors has predominantly focused on non-treatment decisions(25), has mostly been conducted among physicians of specific specialties or in specific settings, and has rarely linked attitudes to actual practices.(26-29). This study aims (1) to investigate the attitudes towards physician-assisted death in minors of all those physicians involved in the treatment of dying minor patients in Flanders, Belgium, no matter their specialty or working environment; and (2) to examine how these attitudes are related to the characteristics of physicians and patients and to the actual end-of-life practices adopted.

## 5.2. Methods

In Flanders, Belgium, all deaths are reported to the Flemish Ministry of Health. All deaths in Flanders of patients residing in Belgium aged one to 17, occurring from June 2007 until November 2008 were included in the study, and an anonymous questionnaire was mailed by the Flemish Ministry of Health to all physicians who signed the death certificates. To enhance response, the Total Design Method was used, with a maximum of three reminders per physician.(30) The anonymity procedure was identical to that of a study on medical end-of-life practices in all deaths in Flanders described

elsewhere.(31) It was possible that a physician reported more than one death during the study period, and thus received more than one questionnaire.

One part of the questionnaire contained 13 statements designed to explore the physician's attitude towards physician-assisted dying. These statements were based on previous studies with a similar study design and designed to reflect relevant aspects of situations in which physician-assisted death may occur in minors.(4;25) The 13 statements are listed in full in Table 2. Physicians were asked to indicate their agreement with the statements on a five point Likert-type scale (totally disagree, disagree, neither agree nor disagree, agree, totally agree). If a physician reported more than one death, and as such received more than one questionnaire, he/she was asked to fill out the attitude-items only once; these answers were then copied anonymously by the researchers onto all questionnaires returned by that physician, so that each death could be linked to the reporting physician's attitudes.

A second part of the questionnaire contained questions designed to identify end-of-life practices, used in previous studies on end-of-life practices in Flanders and the Netherlands.(5-7) Questions were kept descriptive, rather than using value-laden terms such as 'euthanasia'. Physicians were asked whether they had withdrawn or withheld treatment (non-treatment decision), intensified alleviation of pain and symptoms, administered lethal drugs to the patient (physician-assisted death) or sedated the patient continuously and deeply until death. They were further asked whether they performed this practice with no intention, a co-intention, or an explicit intention of shortening the patient's life.

Initially, standard descriptive methods were used to provide a descriptive overview of the physician's answers on the 13 statements. To this end, the answer categories of the attitude-items were recoded into three categories: 'disagreeing/disagreeing totally', "neutral" and "agreeing/agreeing totally". In second instance, a K-means cluster analysis was performed on the 13 dichotomized attitude-items (0 = neutral or (totally) disagreeing; 1 = (totally) agreeing) to investigate whether physicians could be clustered into interpretable attitude-groups. Reporting physicians were the unit of analysis.

To discover whether and if so how these attitudes are related to actual end-of-life practices, the deceased patient was the unit of analysis. Chi-square statistics and Fisher's Exact test were used to investigate the relationship between cluster membership and actual end-of-life practices and to test whether physician specialty and patient characteristics differed between the attitude-clusters. To investigate whether the relationship between attitudes and actual end-of-life practices was confounded by differences in physician specialty or patient characteristics, a multivariate binary logistic regression was used, with end-of-life practices as dependent variables and cluster membership, physician specialty and patient characteristics (gender, age, cause and place of death) were entered in block as independent variables. Adjusted odds ratios and 95% confidence intervals were calculated.

The protocol was approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Ethics Committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

### 5.3. Results

From June 2007 until November 2008, 250 children died between the ages of one and 17 years. These deaths were reported by 206 different physicians. For all 250 deaths, the reporting physician received a questionnaire. An additional survey of non-response yielded that response was not possible for 16 of these cases (eg because the physician had no access to the patient's file). Of 234 eligible cases, which were reported by 191 different physicians, 165 were returned (response-rate 70.5%). These 165 cases were reported by 137 physicians. Thirteen of these physicians, reporting 16 deaths, completed none of the attitude-items. These cases were excluded from analysis. Thus, analyses with physicians as unit of analysis contained 124 cases, while analyses with deaths contained 149 cases. Physician and patient characteristics are presented in Table 1.

Table 1: Physician (N=124) and patient (N=149) characteristics

	N	%		N	%
<b>Patients</b>	<b>149</b>		<b>Physicians</b>	<b>124</b>	
Gender			Specialty		
Male	85	57.0	General practitioner	29	23.4
Female	67	43.0	Emergency medicine	35	28.2
Age			Anesthesiology and intensive care	25	20.2
1-5y	58	38.9	Pediatric	24	19.4
6-11y	30	20.1	Other	11	8.9
12-17y	61	40.9			
Cause of death					
External	61	40.9			
Cancer	24	16.1			
Central Nervous system	15	10.0			
Congenital	14	9.4			
Other	35	23.8			
Place of death					
Home	49	32.9			
Hospital	62	41.6			
Other	38	25.5			

Number of cases and percentages within physicians and patients

Table 2: Description of physicians' answers on the thirteen statements (N=124)

		(totally) disagreeing	neutral	(totally) agreeing
1	The current law on euthanasia should be extended to include minors	16.9	12.9	69.4
2	If the law on euthanasia was extended to include minors, this should be done by establishing clear minimal age limits	50.0	21.8	26.6
3	The task of a physician sometimes implies that he/she must prevent needless suffering in minor patients by hastening the end of life	21.0	17.7	61.3
4	The decision on possible life-shortening acts in children who lack decision-making capacities is the exclusive responsibility of the physician	77.4	10.5	12.1
5	Treatment aimed at prolonging life is not always in the best interests of a severely ill minor patient	8.1	4.8	85.5
6	In minor patients, palliative sedation is always to be preferred to the administration of a lethal drug	21.8	29.0	47.6
7	Adequate pain control and end-of-life care make euthanasia superfluous in minors	43.5	19.4	37.1
8	Consent of parents/representatives is required before taking life-shortening decisions	15.3	24.2	60.5
9	The administration of a lethal drug can be acceptable if parents/representatives of a minor patient who lacks decision-making capacities request it	22.6	23.4	52.4
10	Minors are, where decisions about life and death are concerned, not yet capable of making a rational assessment of their interest	59.7	16.9	21.8
11	Experiencing a chronic condition causes younger minor patients, as compared to healthy peers, to be more capable of assessing their interest	8.1	19.4	72.6
12	Wishes of older minor patients should be taken into consideration to the same degree as the wishes of adult patients	7.3	10.5	82.3
13	A request for life termination of minor patients can be acknowledged if they are capable of making a rational assessment of their interest	16.9	11.3	71.0

Percentage of physicians (totally) disagreeing, neither agreeing/disagreeing (neutral) and (totally) agreeing with thirteen statements. Percentages do not always add up to 100% because of missing values. There were two missing values on statements 2, 5, 6, 9 and 10, and one on statements 1 and 13.

Of all physicians, 69.4% agreed with the statement that the current law on euthanasia should be extended to include minors (see Table 2). However, only 26.6% agreed that this should be done by establishing clear minimal age-limits. Of all items, the statement on the preference of palliative sedation above the administration of a lethal drug involved the highest proportion of physicians with a neutral attitude (29.0%) yet 47.6% of these agreed that palliative sedation is to be preferred. On the statement that

adequate pain control and end-of-life care make euthanasia superfluous in minors, roughly as many agreed (37.1%) as disagreed (43.5%).

Table 3: Classification of physicians into a permissive and a reluctant cluster, based on the answers on the thirteen statements (N=124)

		Total	Permissive cluster	Reluctant cluster	p-value*
	Number of physicians per cluster (%)	124	84 (67.7)	40 (32.3)	
1	The current law on euthanasia should be extended to include minors	69.4	90.5	25.0	<.001
2	If the law on euthanasia was extended to include minors, this should be done by establishing clear minimal age limits	26.6	23.8	32.5	.306
3	The task of a physician sometimes implies that he/she must prevent needless suffering in minor patients by hastening the end of life	61.3	71.4	40.0	.001
4	The decision on possible life-shortening acts in children who lack decision-making capacities is the exclusive responsibility of the physician	12.1	15.5	5.0	.079
5	Treatment aimed at prolonging life is not always in the best interest of a severely ill minor patient	85.5	89.3	77.5	.082
6	In minor patients, palliative sedation is always to be preferred to the administration of a lethal drug	47.6	29.8	85.0	<.001
7	Adequate pain control and end-of-life care make euthanasia superfluous in minors	37.1	11.9	90.0	<.001
8	Consent of parents/representatives is required before taking life-shortening decisions	60.5	56.0	70.0	.135
9	The administration of a lethal drug can be acceptable if parents/representatives of a minor patient who lacks decision-making capacities request it	52.4	71.4	12.5	<.001
10	Minors are, where decisions about life and death are concerned, not yet capable of making a rational assessment of their interest	21.8	11.9	42.5	<.001
11	Experiencing a chronic condition causes younger minor patients, as compared to healthy peers, to be more capable of assessing their interest	72.6	77.4	62.5	.082
12	Wishes of older minor patients should be taken into consideration to the same degree as the wishes of adult patients	82.3	92.9	60.0	<.001
13	A request for life termination of minor patients can be acknowledged if they are capable of making a rational assessment of their interest	71.0	95.2	20.0	<.001

Percentage of physicians agreeing or totally agreeing with the statements, in the total sample and per cluster.

\* p-value for Chi square statistic testing differences in agreement between clusters, per statement.

Sixty point five percent of physicians thought parental consent should be required before taking life-shortening decisions. The administration of a lethal drug to a minor who lacks decision-making capacities was acceptable to 52.4% if the parents requested it. A minority of 21.8% agreed that minors are not capable of making a rational assessment of their interests where decisions about life and death are concerned. Where minors are capable of making a rational assessment of their interests, 71.0% of physicians agreed that a request for life termination can be acknowledged.

A cluster analysis on the answers of physicians on the 13 statements yielded two interpretable clusters (see Table 3). The first cluster contained 67.7% of physicians, and was interpreted as those who tend to regard minor patients as competent decision-makers at the end of life and regard euthanasia and life termination for minor patients as acceptable options under certain circumstances. Physicians in this cluster believe the current Belgian law on euthanasia should be extended to include minors and their attitude was summarized as “acceptant” towards physician-assisted dying. The second cluster contained 32.3% of physicians and was interpreted as those who tend to oppose euthanasia and life-termination in minors, even if requested by a patient with decision-making capacities and/or their parents. They are inclined to prefer palliative sedation above the administration of a lethal drug, and are convinced that adequate pain control and end-of-life care make euthanasia superfluous. Physicians in the second cluster do not want the current Belgian law on euthanasia to be extended, and their attitude was summarized as “reluctant” towards physician-assisted dying.

Table 4: Relation between cluster and actual end-of-life practices (N=149)

	Acceptant cluster	Reluctant cluster	p-value*
	N=98	N=51	
Sudden and unexpected death	48.0	54.9	.421
All end-of-life practices	42.9	33.3	.259
Non-treatment decisions without intention	31.6	25.5	.435
Non-treatment decisions with intention	16.3	5.9	.070
Alleviation of pain and symptoms without intention	22.4	21.6	.902
Alleviation of pain and symptoms with co-intention	17.3	2.0	.006
Physician assisted death	13.3	0.0	.003
No end-of-life practice	9.2	11.8	.619
Continuous deep sedation§	29.6	11.8	.015
without intention	18.4	9.8	.170
with (co-)intention	8.2	0.0	.032

Percentage of cases in which different types of end-of-life practices occurred, per cluster to which the reporting physician belongs. Different end-of-life practices may have co-occurred.

\* p-value for Chi-square statistic testing differences in occurrence of end-of-life practices between clusters and per end-of-life practice, or Fisher’s Exact test if expected cell count was smaller than 5.

§ Data on intention was missing for 3 cases.



Physician specialty and patient characteristics of deaths reported by physicians from the acceptant cluster did not differ significantly from those reported by physicians from the reluctant cluster (data not shown in tables). Significant relations were found between a physician's cluster-membership and actual end-of-life practices (see Table 4). Physicians from the acceptant cluster were more likely to have intensified the alleviation of pain and symptoms with a co-intention of hastening the patient's death (17.3%) and to have practiced physician-assisted death (13.3%) than those from the reluctant cluster (2.0% and 0.0% respectively). Sedation with an intention or co-intention of hastening the patient's death was more frequent among physicians from the acceptant cluster (8.2%) as opposed to the reluctant cluster (0.0%).

The multivariate binary logistic regression showed that, controlling for specialty and patient characteristics (gender, age, cause and place of death), physicians from the acceptant cluster had significantly higher chances of implementing non-treatment decisions with a life-shortening intention (OR: 4.8; 95% CI: 1.1-21.0), intensified alleviation of pain and symptoms (OR: 71.5; 95% CI: 5.0-1023.5) and continuous deep sedation (OR: 4.7; 95% CI: 1.4-15.2) than those from the reluctant cluster (data not shown in tables).

## 5.4. Discussion

Most Flemish physicians caring for a dying child accept physician-assisted death as a possible intervention at the end of minor patients' lives. About seven in ten would like to see the application of the current Belgian law on euthanasia extended to include minors. Based on their attitudes, two thirds of physicians could be considered as quite acceptant and about one third as quite reluctant towards physician-assisted death. Although they had been confronted with similar patients, physicians with a acceptant attitude towards physician-assisted death, no matter what their specialty, were more likely to engage in acts with a co-intention of hastening the patient's death, than were their colleagues with a reluctant attitude.

The present study is to our knowledge only the second worldwide to focus on end-of-life decisions in minors aged between one and 17 years across patient groups and care settings(1) and the first to link attitudes to actual behavior. The study is based on all deaths of minors over a considerable time-span (18 months). The method used has been successfully applied in previous studies.(31) A shortcoming of the study is the relatively small sample of physicians, due to the relative rarity of death in minors over one year of age. However, the sample of physicians was representative for all physician specialties covering the deaths of children, as they were the signatories of all death certificates of minors during an 18-month period. Also, it can not be completely ruled out that some participating physicians filled in the death certificate, but were not closely involved in the treatments and end-of-life discussions and decision-making.

A first major finding of the study is that 68% of studied physicians have an acceptant attitude towards physician-assisted dying in minors. A majority acceptance in principle of euthanasia in older minors and under certain conditions, including parental consent, was also found in a study in the Netherlands.(25) However, the level of acceptance is remarkably high when compared with the general acceptance of physician-assisted dying in most other countries.(32-35) It seems plausible that in Belgium and the Netherlands the context of legal euthanasia under strict due care conditions (even though minors are explicitly excluded from the euthanasia law in Belgium) and the ensuing experience with the euthanasia laws has coincided with a change in attitudes of physicians involved in children's end-of-life care. In particular the lack of salient abuse of the legal framework in both countries may have contributed to Flemish physicians having a less reluctant attitude towards the practice. Conversely, it should be noted that Belgian and Dutch physicians already had a higher acceptance of physician-assisted dying prior to the legalization of euthanasia(36;37), making it impossible to state conclusively that changing legislation will result in changing attitudes of physicians in countries where euthanasia is still illegal.

Interestingly, while seven in ten would like to see the application of the current Belgian law on euthanasia extended to include minors, half of the Flemish physicians surveyed disagree with achieving this by establishing clear age limits. However, the amendments under discussion in Belgium do not propose fixing age limits, as does the Dutch law, but advance casuistic criteria, referring to "the required discriminatory capacity"(20) and "judgmental capacity".(23) The physicians in the present study appear to support similar casuistic criteria. Concordantly, a Dutch study found that about half of all pediatricians disagreed with the Dutch law and felt that age limits are arbitrary and that each case should be considered individually.(25) It is not surprising that physicians support these casuistic criteria, as minor patients' decision making capacity is a crucial and necessary standard in determining whether they can make decisions autonomously. By focusing on the minor patients' decision making capacity rather than their age, discrimination on the sole basis of chronological age can be prevented. A casuistic approach will also protect children who lack decision-making capacities from the undue burden of making high impact choices and decisions autonomously. It is important to notice that an extended application of the Belgian law on euthanasia should reflect this reality. Any proposed amendments should thus be cautiously formulated to prevent age discrimination and to adequately protect children who lack decision-making capacities.

Physicians appear to put a high premium on parental consent. Although 60% believe that minors are capable of making a rational assessment of their own interests in life-and-death-matters, an equal proportion think that consent of parents is required before making end-of-life decisions. Respect for parental consent was also found in the belief of half the physicians that parental requests for the administration of a lethal drug in a minor who lacks decision-making capacities may justify granting that request. We hypothesize that a majority of physicians observe a shared responsibility ethic with respect to the life-ending of minors; the decisional capacities of minors with decision-making capacities are recognized, but checked by respect for parental authority and

interests. This was in line with a model of shared decision-making, which is generally the preferred decision making model in medicine, as it seems best suited to safeguard patients' best interests.(38,39) If euthanasia is ever to be legalized for minors in Belgium, or in other countries, the legal framework should not ignore the crucial role of parents as partners in end-of-life decision-making.

Although physicians from both attitude-clusters had been confronted with similar patients and although physician specialty did not differ between attitude-clusters, actual end-of-life practices were related significantly to the attitude of the physicians. In the group of physicians demonstrating acceptance of euthanasia in minor patients there were not only more cases of physician-assisted dying, as might be expected, but also of intensified alleviation of pain and symptoms and continuous deep sedation with a co-intention of shortening life. Euthanasia in minors still being illegal, physicians acceptant of euthanasia possibly rely on intended or co-intended life-shortening practices such as intensified alleviation of pain and symptoms (eg by strongly increasing doses of opiates), or continuous deep sedation, as alternatives to euthanasia. These practices involve no risk of prosecution, and are probably more concordant with institutional policies.

## **5.5. Conclusion**

A large majority of surveyed physicians appear to accept physician-assisted dying in children under certain circumstances and favor a model of shared decision-making. Moreover, a large majority of these physicians seem to favor an amendment to the euthanasia law to include minor patients, not so much by the setting of an arbitrary age-limit as by taking a decision-making capacity approach. These stances, and their connection with actual end-of-life practices, may encourage Belgian legislators, and policy-makers in other countries, to develop guidelines for medical end-of-life practices in minor patients, not limited to euthanasia, that would address specific challenges arising in this patient group, including how children and parents should be involved in the decision-making process.

## **5.6. Acknowledgement**

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## **Chapter 6: Medical end-of-life decisions in children in Flanders, Belgium: a population-based post-mortem survey**

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## Abstract:

### Objectives

To estimate the prevalence of end-of-life decisions, and to describe their characteristics and the preceding decision-making process, in minors in Belgium.

### Design

Population-based post-mortem anonymous survey among all physicians signing the death certificates of all patients aged 1 to 17 years who died between June 2007 and November 2008 in Flanders, Belgium. Prevalence and characteristics of end-of-life decisions and the preceding decision-making process were measured.

### Results

During the study period, 250 children died. For 165 of these a questionnaire was returned. The response-rate was 70.5%. In 36.4% death was preceded by an end-of-life decision. Drugs were administered to alleviate pain and symptoms with a possible life-shortening effect in 18.2% of all deaths, non-treatment decisions in 10.3% and the use of lethal drugs without the patient's explicit request in 7.9%. No cases of euthanasia, i.e. the use of drugs with the explicit intention to hasten death at the patient's explicit request, were reported. Poor clinical prospects (84.6%) and low quality of life expectations (61.5%) were important reasons for the physicians to engage in end-of-life decisions. Parents were involved in decision-making in 85.2% of these decisions, patients in 15.4%.

### Conclusions

Medical end-of-life decisions are frequent in minors in Flanders, Belgium. Whereas parents were involved in most end-of-life decisions, the patients themselves were much less so, even where life-ending was intended. At the time of decision-making, patients were often comatose or were deemed incompetent or too young to be involved by the physician.



## 6.1. Introduction

Medical end-of-life decisions with a possible or certain life-shortening effect have become frequently-used options at the end of a patient's life and the prevalence of these have been extensively studied in adults.(1-4) In minors (<18y) they have received less attention, and studies have mostly been limited to specific care settings or patient groups (5-12). However, end-of-life decisions in minors pose specific clinical and ethical challenges for professional caregivers. As parents function as advocates for their child, they are the primary partners in communication with professional caregivers.(13) The involvement of minor patients in the decision-making process is not always straightforward, and depends on their age, level of competence, the nature of the decisions concerned and experience with chronic illness.(14;15) The three-way interaction between caregivers, parents and patients makes decision-making complex.(16) Furthermore, on an ethical level, the interplay between the parents' representative function and the patient's decision-making capacity raises important questions about the rights of minors to self-determination, the limits of parental advocacy and the balancing of best interest considerations with the wishes of the minor patient.(17)

Whereas non-treatment decisions and of the administration of drugs to alleviate pain and symptoms with a possible life-shortening effect are generally regarded as part of common and sound medical practice, physician-assisted death, i.e. the administration, prescription or supply of drugs, by a physician, with the explicit intention of ending the patient's life, is much less so.(18-20) If drugs are administered by a physician to end a patient's life, at the patient's explicit request, the decision is termed 'euthanasia' in the three countries where laws on this practice have been enacted in recent years: Belgium, the Netherlands and Luxemburg. In other countries, this practice is commonly referred to as 'voluntary euthanasia'. Additionally, physician-assisted suicide, i.e. lethal drugs provided by a physician, but administered by the patient, has been legally accepted in the Netherlands, Luxemburg, Switzerland and the states of Oregon, Montana and Washington in the US.(21-23) Only in the Netherlands is the law on euthanasia or physician assisted suicide applicable to minors: they can legitimately request assistance in dying from the age of 12 with parental consent and from the age of 16 when parents are informed. For neonates, the Groningen protocol was developed to facilitate reporting of cases for legal control and to enhance quality of decision-making.(24) Debates are taking place in Belgian society and politics to extend the application of the law on euthanasia to include minors, and legal propositions on the subject are under consideration.(25;26) However, little empirical evidence on these end-of-life decisions is available in minors, and in Belgium no population-based data have so far been collected.

This study aims to: (1) estimate prevalence of end-of-life decisions with a possible or certain life-shortening effect in minors across care settings in Flanders (Belgium), (2) describe clinical and demographic characteristics of patients involved, (3) describe

characteristics of end-of-life decisions (estimated life-shortening effect, reasons for deciding to perform an end-of-life decision), and (4) describe the decision-making process preceding these end-of-life decisions.

## 6.2. Methods

In Flanders, the largest region of Belgium with approximately six million inhabitants, all deaths are to be reported to the Flemish Ministry of Health. From June 2007 until November 2008 (18-month period), 250 patients residing in Belgium aged one to 17 years died in Flanders. The focus was on patients from this age group, because these had not been previously studied in Flanders, and only once in the Netherlands.<sup>(11)</sup> An anonymous questionnaire was mailed by the Flemish Ministry of Health to all physicians who signed the death certificates in each of these cases. There was generally a two to three month delay between death of the patient and receipt of the questionnaire. Some physicians signed more than one death certificate, but no physician signed more than five during the 18-month study period. To enhance response, the Total Design Method was followed, with a maximum of three reminders per case.<sup>(27)</sup> A complex mailing procedure, separating data collection and data analyses, with a lawyer as intermediary between physicians and the Flemish Ministry of Health, was used to ensure strict anonymity of both physician and patient. As an appendix to the questionnaire, physicians were informed about the mailing procedure. The anonymity procedure was identical to that of a study on medical end-of-life decisions in all deaths in Flanders described elsewhere.<sup>(28)</sup>

The questionnaire was similar to those used in previous studies in adults and neonates (1-3;6;7;11), but adapted to fit pediatric practice by including questions on the decision-making capacity of patients and the involvement of parents. All questions were closed and contained different answer categories where one or more answers were possible.

If, according to the physician, a death had not been sudden and unexpected, they were asked about end-of-life decisions assessed to have had a possible or certain life-shortening effect. Instead of using terms with different connotation, like 'euthanasia', descriptions of the decisions concerned were used: withholding or withdrawing treatment (non-treatment decisions); administration of drugs to alleviate pain and symptoms (taking a possible hastening of death into account) and the administration, prescription or supply of drugs by the physician with the explicit intention of hastening the patient's death (physician-assisted death). The latter was further divided according to the person administering the drugs and the presence of an explicit patient request: if the drugs were administered by the physician at the patient's explicit request, we categorized the decision as 'euthanasia'; if the drugs were administered by the patient him/herself, the decision was categorized as 'physician-assisted suicide'; a final category contained cases where drugs were administered by someone else than the patient, with the explicit intention of hastening the patient's death, without explicit patient request. The exact wordings of the questions are described

elsewhere.(28) If more than one decision was made for one patient, the decision with the most explicit life-shortening intention was used to classify the decision. If different decisions with a similar intention co-occurred, the administration of drugs prevailed over the withdrawal or withholding of treatment.

Further questions were aimed at gathering information on the characteristics of these end-of-life decisions (estimated life-shortening effect, main reasons for the decision) and the care provided (length and goal of treatment for terminal illness). Others focused on the decision-making process preceding the end-of-life decision: discussion with patient, parents or other professional caregivers and the reasons that the decision was not discussed with the patient. Clinical and demographic information as recorded on the death certificate (age, gender, cause and place of death) was provided by the Flemish Ministry of Health. The lawyer linked data from the questionnaires case-per-case to clinical and demographic information of the corresponding deaths, after which the data were made anonymous.

The study, including the anonymity procedure, was approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel and the Ethics Committee of Ghent University Hospital, and positive recommendations were received from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

Standard descriptive statistics (frequencies, 95% confidence intervals corrected for finite population size (N=250)) were used to analyze the data. Chi square statistics were used to investigate representativeness of the response sample for the population and the relation between patient characteristics and end-of-life decisions. SPSS 15.0 was used for all analyses. Level of significance was set at  $p < .05$ .

### **6.3. Results**

In sixteen of the 250 cases, the physician received the questionnaire but was unable to provide information, according to an additional non-response survey, because the patient could not be identified or because they had not been involved in the treatment of the patient themselves and the treating physician was not known and/or could not be reached. For 165 of the 234 remaining cases a questionnaire was returned (response-rate 70.5%).

Of the 165 studied deaths, 92 patients were male (55.8%), 71 died at ages 12 to 17 (43.0%), external causes of death were the most frequent (eg traffic accidents and suicide, 44.8%), 25 patients died from cancer (15.2%) and hospital was the most frequent place of death (40.0%). The response sample did not differ from the non-response sample for gender, age and cause of death. The proportion of hospital deaths was significantly higher in the response sample than in the non-response sample (56.5% vs. 40.0%). When the response sample was compared to the total population, demographic and clinical characteristics did not differ (data not shown in tables).

Table 1: Frequencies of medical end-of-life decisions (N=165)

	Observed	%	95% C.I.
Sudden and unexpected death*	88	53.3	48.8-57.8
Non-sudden death, no end-of-life decision	17	10.3	7.9-13.4
Total end-of-life decisions	60	36.4	32.2-40.8
withholding or withdrawing of life-sustaining treatment	17	10.3	7.9-13.4
without intention of shortening the patient's life	6	3.6	2.3-5.7
with intention of shortening the patient's life	11	6.7	4.7-9.3
alleviation of pain and symptoms with a possible life-shortening effect	30	18.2	15.0-21.9
without intention of shortening the patient's life	27	16.4	13.3-20.0
with co-intention of shortening the patient's life	3	1.8	0.9-3.5
use of drugs with the explicit intention of hastening the patient's death	13	7.9	5.8-10.7
euthanasia	0	0.0	-
physician-assisted suicide	0	0.0	-
life-ending acts without explicit patient request	13	7.9	5.8-10.7
Total	165	100	-

Number of observed cases, percentage and 95% confidence intervals calculated via complex samples procedure (Monte Carlo) and corrected for finite population size (N=250);

\* Including cases where the physician's first contact was after the child's death.

Of all 165 deaths studied, 53.3% were indicated by the physician to have been sudden and unexpected, thus an end-of-life decision was not possible (Table 1). In 10.3% of all deaths, death was expected, but no end-of-life decision was made. In total, 36.4% of all deaths were preceded by an end-of-life decision. Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect were the most frequent, involving 18.2% of all deaths. Non-treatment decisions were made in 10.3% of all deaths. Physicians administered, prescribed or supplied drugs with an explicit intention to hasten the patient's death in 7.9% of all deaths (13 cases), and all occurred without an explicit patient request. These lethal drugs were muscle relaxants (Curare) combined with barbiturates in one case, morphine in eight cases (as sole drug in three and in combination with benzodiazepine in five cases) and barbiturates in four cases (as sole drug in two and in combination with benzodiazepine in two). The drugs were administered by the attending physician in seven of 13 cases, by a nurse in three instances, and by both in three cases. Physicians estimated that death had been hastened by one week or less in 90.4% of cases. In eight of 13 cases, the main goal of treatment in the last week of life was comfort, in five of 13 cases an expert in palliative care was consulted by the physician. In six of 13 cases, the physician had been treating the patient for the fatal illness for more than a year, in two cases for one week or less. Patients died aged younger than six in seven of 13 cases, three patients were 12 or older.

Table 2: Type of medical end-of-life decision according to patient characteristics (N=165)

	Study sample	Non-treatment decisions	Alleviation of pain and symptoms†	Physician-assisted death	All end-of-life decisions
Total	165	17	30	13	60
Total percentage	100	10.3	18.2	7.9	36.4
	N (%)	%	%	%	%
Gender					
Male	92 (55.8)	58.8	60.0	53.8	58.3
Female	73 (44.2)	41.2	40.0	46.2	41.7
	p-value*	.788	.605	.885	.615
Age					
1-5	62 (37.6)	41.2	46.7	53.8	46.7
6-11	32 (19.4)	29.4	26.7	23.1	26.7
12-17	71 (43.0)	29.4	26.7	23.1	26.7
	p-value*	.394	.130	.301	.005
Cause of death					
Cancer	25 (15.2)	11.8	33.3	30.8	26.7
External (eg traffic accidents and suicide)	74 (44.8)	41.2	10.0	15.4	20.0
Diseases of the central nervous system	16 (9.7)	11.8	16.7	15.4	15.0
Congenital diseases	14 (8.5)	0.0	13.3	15.4	10.0
Other	36 (21.8)	35.3	26.7	23.1	18.3
	p-value*	.483	<.001	.179	<.001
Place of death§					
Home	53 (32.1)	11.8	43.3	30.8	31.7
Hospital	66 (40.0)	82.4	40.0	69.2	58.3
Other	46 (27.9)	5.9	16.7	0.0	10.0
	p-value*	.001	.213	.031	<.001

Percentages are column percentages.

\* p-value for Chi square statistic testing differences between patient groups in incidence of end-of-life decisions. Fisher's Exact test was used when expected cell counts were less than five.

† Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.

End-of-life decisions were relatively more frequent in children younger than 12 (46.8% vs. 22.5% in children aged 12-17), children dying from other than external causes and children dying in hospital (53.0% hospital vs. 35.8% home and 13.0% other) (Table 2).

Table 3: Characteristics of end-of-life decisions (N=60)

	Non-treatment decisions	Alleviation of pain and symptoms†	Physician-assisted death	All end-of life decisions
Total number of cases	17	30	13	60
Estimated shortening of life:				
more than 1 week	13.3	7.7	9.1	9.6
1-7 days	26.7	7.7	45.5	21.2
<24 hours	20.0	19.2	45.5	25.0
no shortening	40.0	65.4	0.0	44.2
Reason for end-of-life decision:*				
no improvement to be expected	87.5	78.3	92.3	84.6
low expected quality of life	56.3	52.2	84.6	61.5
not needlessly prolonging life	25.0	39.1	76.9	50.0
(severe) symptoms of patient	25.0	17.4	69.2	44.2
expected suffering of the patient	43.8	47.8	61.5	44.2
wish of parents	18.8	52.2	61.5	32.7
Time treated for fatal illness:				
1-7 days	47.1	13.3	15.4	23.3
1-4 weeks	5.9	13.3	15.4	11.7
1-12 months	5.9	16.7	23.1	15.0
more than 1 year	41.2	56.7	46.2	50.0
Main goal of treatment in last week:				
cure	47.1	13.3	30.8	26.7
prolonging of life	5.9	3.3	7.7	5.0
comfort	47.1	83.3	61.5	68.3

Number of observed cases and percentages. Percentages do not always add up to 100 because of rounding;

Data were missing for 2 to 8 cases for estimated shortening of life and reason for end-of-life decision;

\* Multiple answers were possible, percentages may add up to more than 100.

† Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.

Estimated life-shortening was less than 24 hours in 69.2% of cases where an end-of-life decision was performed and less than 24 hours in 45.5% of physician-assisted death cases (Table 3). No improvement prospects and low quality of life expectations were the most frequent reasons cited by physicians in all three end-of-life decisions. Not needlessly prolonging life, severe symptoms, expected suffering and the wish of the parents were other frequently cited reasons in cases of physician-assisted death, but were less frequent in non-treatment decisions and administration of drugs to alleviate pain and symptoms with a possible life-shortening effect. In 50% of cases where an end-of-life decision was performed, the patient had been in treatment for the terminal illness for more than one year. The main goal of treatment in the last week of life was

comfort in 47.1% of cases of non-treatment decisions and 83.3% in cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.

Table 4: Decision-making process preceding end-of-life decisions (N=60)

	Non-treatment decisions	Alleviation of pain and symptoms†	Physician-assisted death	All end-of-life decisions
Total number of cases	17	30	13	60
Decision discussed with parents	100.0	68.0	100.0	85.2
Discussion with parents was aimed at:*				
reaching a decision together	66.7	82.4	84.6	77.8
obtaining parental consent	6.7	17.6	23.1	15.6
informing parents of a decision	13.3	11.8	7.7	11.1
Decision requested by parents	33.3	30.4	75.0	41.2
Decision discussed with patient	12.5	21.7	7.7	15.4
Decision requested by patient	0.0	4.3	0.0	1.9
Reasons for not discussing with patient:*				
patient was comatose	92.3	41.2	66.7	64.3
patient was too young	38.5	76.5	58.3	59.5
patient was mentally handicapped	30.8	35.3	50.0	35.7
Patient was found competent	0.0	0.0	7.7	2.1
Decision discussed with other caregivers*				
Physicians	75.0	69.6	92.3	76.9
Nurses	43.8	43.5	84.6	53.8
Other	6.3	26.1	7.7	15.4
Not discussed with other caregivers	12.5	8.7	0.0	7.7

Number of observed cases and percentages. Percentages do not always add up to 100 because of rounding;

Data were missing for 3 (Reasons for not discussing with patient), 6 (Discussion with parents), 8 (Discussion with patient and other caregivers), 9 (Request by parents) and 13 cases (Patient competence);

\* Multiple answers were possible, percentages may add up to more than 100.

† Administration of drugs to alleviate pain and symptoms with a possible life-shortening effect.

All non-treatment decisions and cases of physician-assisted death were discussed with the parents, as were 68.0% of cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect (Table 4). Discussion with parents was aimed at reaching a joint decision in 77.8% of cases. The decision was requested by the parents in 30.4% of non-treatment-decisions, in 33.3% of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect and in 75% of cases of physician-assisted death. Decisions were discussed with the patient in 7.7% of cases of physician-assisted death, 12.5% of non-treatment decisions and 21.7% of cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening

effect. Where an end-of-life decision was made, patients were found not to have decision-making capacity by the physician at the time of decision-making in all cases but one. As reasons for not discussing the decision with the patient, physicians most frequently cited the patient being comatose (64.3%) or too young (59.5%). Decisions were discussed with other professional caregivers in 92.3% of cases. Rates of involvement of other physicians (92.3%) and nurses (84.6%) were highest in cases of physician-assisted death.

## 6.4. Discussion

Medical end-of-life decisions preceded 36.4% of all deaths of minors aged one to 17 years in Flanders, Belgium. If sudden and unexpected deaths were excluded, end-of-life decision preceded 78% of deaths. The administration of drugs to alleviate pain and symptoms with a possible life-shortening effect was the most frequent end-of-life decision. Non-treatment decisions were less frequent. The prevalence of physician-assisted death was high. No case of euthanasia, i.e. the use of drugs with the explicit intention to hasten death at the patient's explicit request, was reported. Poor clinical prospects and low quality of life expectations were important reasons for the physicians to make an end-of-life decision. Shared decision-making with parents was reached in 85.2% of cases, but patients were seldom involved in the process themselves. Physicians reported the patient being comatose or too young as the most important reasons for not involving them.

To our knowledge this study was only the second in the world to investigate end-of-life decisions in children across different care settings and causes of death.(11) However slightly lower than studies in the Netherlands where response rates of 75% (11) to 78% (3) were reported and a study in neonates in Flanders were a response-rate of 87% was reported(6), a good response-rate of 70.5% was attained, and patients in the response group were representative of the total population. The method used has been successfully applied in previous studies and allows for making reliable estimates of end-of-life decisions.(1-3;6;7;11) However, only the physician's perspective was studied; the valuable perspective of parents was not included. The present study was retrospective and descriptive, thus less suitable for providing in-depth explanations of its findings.

Medical end-of-life decisions are frequent in children dying in Flanders, as could be expected from previous studies in limited patient groups (eg. neonates) and settings (eg. intensive care units), where medical end-of-life decisions were also frequent.(5-10) The overall prevalence of end-of-life decisions in the present study was lower than in Flemish adults (48%)(4) and in neonates in Flanders and the Netherlands(6;7), but consistent with the only comparable population-based study in children aged one to 17 in the Netherlands in 2001 (36%).(11) However, the finding that Flemish physicians frequently intended to hasten death (in 7.9% of all deaths) was remarkable, and different from findings in the US, where hastening of death is rather a foreseen but unintended side-effect of medical end-of-life decisions.(5) The prevalence was higher



than the prevalence of physician-assisted death in Flemish adults (3.8%), and was rather at the level found in Flemish neonates (7%).(4;6) The prevalence of physician-assisted death in children is notably higher in Belgium than in the Netherlands (7.9% vs. 2.7%), but in Belgium there was no case where the decision was explicitly requested by the patient (euthanasia), as compared to five cases per year in the Netherlands.(11) The finding that life-ending without patient request was more frequent in Belgium than in the Netherlands is consistent with findings of previous studies among adults.(2;3) This may be caused by differences in actual practices of Flemish and Dutch physicians, where Flemish physicians in fact acted more often with an explicit life-shortening intention than their Dutch colleagues, as well as by differences in reported intentions, where physicians may have acted in a similar way in both countries, but Flemish physicians ascribed a more explicit life-shortening intention to their acts than their Dutch colleagues. The present findings further suggest that physician-assisted death is not a stand-alone practice in Flanders, but is part of a broader process of care and symptom control. In this study, physician-assisted death mostly occurs after a long period of illness, often by increasing dosages of morphine in discussion with the parents, and - given the limited estimated life-shortening effect - often at the very last moments of life.

All non-treatment decisions and physician-assisted death cases were previously discussed with the parents of the minors, and physicians mostly indicated that they reached a decision together with the parents, indicating that physicians predominantly followed a model of shared decision-making in these decisions. Unfortunately, the study does not allow for comparison of physician and parental perspectives on this matter, which could have provided a more in depth understanding. The results concur with the results from the nationwide study in the Netherlands, where end-of-life decisions were always discussed with the parents of the child,(11) and with the findings in Flemish neonates, where decisions were discussed with parents in 84% of cases.(29) In cases of administration of drugs to alleviate pain and symptoms with a possible life-shortening effect, discussion with parents occurred less often. It may be that physicians find it less necessary to discuss this decision with the parents, considering it a duty and part of standard practice to relieve the suffering of their patient irrespective of the opinion of others, even if a possible life-shortening side-effect cannot be precluded.(30;31) On the other hand, administration of drugs to alleviate pain and symptoms with a possible life-shortening effect was relatively more often discussed with or requested by the patient. It seems more often to be patient-initiated, possibly by the patient indicating to the physician a worsening of his/her symptoms. Non-treatment decisions and physician-assisted death generally occurred in different clinical circumstances from administration of drugs to alleviate pain and symptoms with a possible life-shortening effect, with poorer clinical prospects for the patient, which make it more difficult to discuss the decisions with them. Given the clear life-shortening effect of both decisions, it is thus not surprising that parents were consulted in all of these cases.

End-of-life decisions were generally not discussed with minor patients and only one patient was considered to have decision-making capacity by the attending physician.

This was in line with a Dutch interview study, where pediatricians found minor patients incompetent for end-of-life decision-making in 12% of cases, and consequently did not discuss the decision with minor patients in 84% of cases.<sup>(11)</sup> In about two thirds of cases, the patient's comatose condition was cited by the physician as a reason for not discussing the end-of-life decision. These patients did no longer have decision-making capacity, which obviously precluded any discussion with the patient at that time. In nearly 60% of cases, physicians deemed the patients too young to discuss possible end-of-life decisions. These patients were younger than six in more than 70% of cases. In seven of ten cases where a decision was not discussed with a patient aged 12 or older, the patient was comatose. These reasons were the same as the reasons for not discussing a decision with a minor patient reported by Dutch pediatricians: in 71% were patients unconscious or deemed too young.<sup>(11)</sup> The present data are limited in providing a full understanding of which factors determine physicians' assessment of minor patients' decision-making capacity. Further research is needed to comprehend why decisions are not discussed with minor patients, and how their decision-making capacity is assessed by physicians.

## **6.5. Conclusions**

Medical end-of-life decisions are frequent in minors in Flanders, Belgium. Although the legal representatives of the minors were involved in most end-of-life decisions, patients themselves were involved very rarely, even when life-ending was intended. At the time of decision-making, patients were often comatose or were deemed incompetent or too young to be involved by the physician.

## **6.6. Acknowledgement**

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## **Chapter 7: Continuous deep sedation at the end of life of children in Flanders, Belgium**

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## Abstract:

### Objectives

This study estimates the incidence of continuous deep sedation in minor patients (aged 1-17), and describes the characteristics of, and the decision-making process prior to, continuous deep sedation.

### Methods

An anonymous population-based post-mortem survey was mailed to all physicians signing the death certificates of all patients aged 1 to 17 years who died between June 2007 and November 2008 in Flanders, Belgium. The questionnaire concerned whether or not continuous deep sedation was used at the end-of-life, and measured characteristics of sedation and the decision-making process preceding it.

### Results

Response rate was 70.5% (N=165). Of all children, 21.8% had been continuously and deeply sedated at the end-of-life. Duration of sedation was one week or less in 72.4% of cases and artificial nutrition and hydration were administered until death in 54.3% of cases. Benzodiazepines were used as sole drug for sedation in 19.4% of cases, benzodiazepines combined with morphine in 50%, and morphine as sole drug in 25%. In 23.5% of cases physicians had the explicit or co-intention of hastening death. Only 3.0% of patients requested sedation, and 6.1% consented. Parents consented in 77.8% of cases, and requested sedation in 16.7%.

### Discussion

Minor patients were commonly kept in continuous deep sedation or coma until death in Flanders, Belgium. Given the high incidence of the practice, and indications that it is often used without involving the patient - and sometimes with a life-shortening intention - the development of specific guidelines for sedation in children might contribute to due-care practice.



## 7.1. Introduction

Continuous deep sedation is an acceptable last resort option to alleviate refractory symptoms in terminally ill patients.(1) Nationwide studies in European countries show that the practice precedes between 2.5% and 16.5% of all adult deaths and that it has become more widespread in recent years.(2-6) Mono-centric studies exist which suggest that sedation is frequently used in pediatric end-of-life practice(7-9), although this has not been confirmed at population level.

Continuous deep sedation at the end-of-life poses clinical and ethical challenges to practitioners.(10) To help them deal with these, several guidelines and recommendations have been put forward (11-16), including indications for palliative sedation, whether or not artificial food and fluids should be administered, and whether life-shortening should be intended. Although some people argue that continuous deep sedation can have a life-shortening effect, this is still debated. This is one reason why its practice should respect strict due-care requirements.(17-20) In minor patients, decision-making is further complicated by a limited capacity to make autonomous decisions due to still-developing mental competence, by legal restraints on decision-making by minors, and by the involvement of parents as a third party in the process.

Given these important clinical and ethical challenges, it is striking that few guidelines have yet been put forward for pediatric practice and that empirical data on the practice of continuous deep sedation in minors is rare.(21;22) This study aimed to estimate the incidence of continuous deep sedation in minor patients (aged 1-17) in Flanders, Belgium, and to describe the characteristics of, and the decision-making process leading up to, its practice.

## 7.2. Methods

During an 18-month period from June 2007 until November 2008, an anonymous, self-administered questionnaire was mailed by the Flemish Ministry of Health to all physicians who signed the death certificates of all 250 patients residing in Belgium who had died in Flanders at age one to 17 years within that period. To enhance response, the Total Design Method was followed, with a maximum of three reminders per case.(23) A complex mailing procedure, with a lawyer as intermediary between physicians and the Flemish Ministry of Health, was used to ensure anonymity of both physician and patient.(24) A one-page non-response survey was mailed to physicians who did not respond after three reminders.

The questionnaire was similar to those used in previous studies in adults and neonates (2;4;25;26), albeit slightly adapted to fit pediatric practice by including questions on the involvement of parents and minor patients. When death had not been sudden and unexpected according to the physician, he or she was asked “Was the patient

continuously kept in deep sedation or coma until death, by means of one or more drugs?” This implies that, regardless of whether sedation was initiated by the physician or a consequence of disease progression, only patients who were kept in coma by means of drugs could be considered continuously and deeply sedated until death. Further questions were aimed at eliciting the characteristics of continuous deep sedation: administration of artificial food/fluids until death, drugs used, duration of sedation, consent or request by parents and/or patient, alternatives to sedation and the physician’s life-shortening intention when engaging in sedation. The Flemish Ministry of Health provided clinical and demographic information as recorded on the death certificate (age, gender, cause and place of death) which the lawyer linked case-by-case to data from the questionnaires. Afterwards the data were made anonymous. Standard descriptive statistics were used to analyze the data. Chi square statistics were used to investigate differences between cases where continuous deep sedation was used and other non-sudden deaths where no continuous deep sedation was used. SPSS 15.0 was used for all analyses. Level of significance was set at  $p < .05$ .

The study was approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel and the Ethics Committee of Ghent University Hospital, and positive recommendations were received from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

### **7.3. Results**

In sixteen of the 250 cases, the physician received the questionnaire but was unable to provide information, according to an additional non-response survey, due to lack of access to the patient’s medical file or patient identification. For 165 of the 234 remaining cases a completed questionnaire was returned (response-rate 70.5%). For 88 of 165 cases, the physician estimated that death had been sudden and unexpected.

Of all patients, 36 had been continuously and deeply sedated at the end of life. This was 21.8% of all studied deaths and 46.8% of non-sudden deaths. Patient characteristics are presented in Table 1. Benzodiazepines were used as the sole drug for sedation in seven patients (19.4%), benzodiazepines combined with morphine in 18 (50.0%), and in nine patients (25.0%) morphine was used as the sole drug (see Table 2). One patient had been sedated for more than two weeks while most were sedated for one week or less (72.4%). Artificial nutrition and hydration were administered until death in more than half of cases (54.3%) and were withdrawn during sedation in eight (22.9%). The proportion of patients receiving artificial nutrition or hydration during sedation differed according to place of death: 44.4% of patients receiving continuous deep sedation at home received artificial nutrition and hydration at some point during sedation, compared with 91.3% of patients in hospital (data not shown in table). Physicians indicated having had the explicit or co-intention of hastening death in eight cases (25.0%). When artificial food and fluids were administered until death, 17.6% of physicians reported an explicit or co-intention of hastening death, while 37.5% and 33.3% did so when artificial

food and fluids were withdrawn during sedation or withheld. In 27 cases (84.4%) physicians indicated that there was no alternative to continuous deep sedation for treating the patient's symptoms (see Table 2).

Table 1: Demographic characteristics, cause of death and treatment duration of patients who were continuously and deeply sedated at the end of life (N=36), other non-sudden deaths (N=41)

	Non-sudden deaths†		Sudden deaths
	Continuous deep sedation	No continuous deep sedation	
	N (%)	N (%)	N (%)
Number of deaths	36	41	88
% of all deaths	21.8	24.8	53.3
Gender			
Male	22 (61.1)	22 (53.7)	48 (54.5)
Female	14 (38.9)	19 (46.3)	40 (45.5)
	p-value*		
	.510		
Age			
1-5	18 (50.0)	17 (41.5)	27 (30.7)
6-11	8 (22.2)	11 (26.8)	13 (14.8)
12-17	10 (27.8)	13 (31.7)	48 (54.5)
	p-value*		
	.752		
Cause of death			
External	7 (19.4)	7 (17.1)	60 (68.2)
Cancer	11 (30.6)	11 (26.8)	3 (3.4)
Central Nervous System	4 (11.4)	6 (14.6)	6 (6.8)
Congenital	3 (8.3)	6 (14.6)	5 (5.7)
Cardiovascular	2 (5.6)	0 (0.0)	6 (5.7)
Other	9 (25.0)	11 (26.8)	9 (8.0)
	p-value*		
	.655		
Place of death			
Home	10 (27.8)	15 (36.6)	28 (31.8)
Hospital	23 (63.9)	18 (43.9)	25 (28.4)
Other	3 (8.3)	8 (19.5)	35 (39.8)
	p-value*		
	.168		
Time in treatment			
1-7 days	9 (25.0)	9 (22.5)	-\$
1 week – 6 months	12 (33.3)	3 (7.5)	-\$
> 6 months	15 (41.7)	28 (70.0)	-\$
	p-value*		
	.010		

Number of observed cases (percentage). Percentages do not always add up to 100 because of rounding.

\* p-value for Chi-square statistic testing differences in the distribution of described characteristics between cases of CDS and non-sudden deaths without CDS

§ Information on time in treatment was not available for sudden deaths.

† Cases were categorized as Sudden when the physician indicated that death had been sudden and completely unexpected and when the physician indicated that the first contact with the patient was after the child's death

Table 2: Characteristics of continuous deep sedation and decision-making process (N=36)

	N	%
Total	36	100
Drugs used		
only benzodiazepines	7	19.4
benzodiazepines and morphine	13	36.1
benzodiazepines, morphine and other	5	13.9
only morphine	9	25.0
morphine and other drug	2	5.6
Duration of sedation*		
0-48 hours	12	41.4
2-7 days	9	31.0
1-2 weeks	7	24.1
>2 weeks	1	3.4
Artificial nutrition and hydration*		
administered until death	19	54.3
withdrawn during sedation	8	22.9
withheld	8	22.9
Intention of hastening death*		
no intention	9	28.1
taking into account possible hastening of death	15	46.9
co-intention	4	12.5
explicit intention	4	12.5
Alternatives to continuous deep sedation*		
none	27	84.4
only ending the patient's life	3	9.4
unspecified other alternatives	2	6.3
Main goal of care in the last week before death		
cure	14	38.9
prolongation of life	3	8.3
comfort	19	52.8
Patient request for or consent to continuous deep sedation *§		
request	1	3.0
consent	2	6.1
no†	30	90.9
Parental request for or consent to continuous deep sedation §		
request	6	16.7
consent	28	77.8
no†	6	16.7

Number of observed cases and percentages. Percentages do not always add up to 100 because of rounding

\* Data were missing for 7 cases (duration of sedation), 4 cases (alternatives), 3 cases (patient request/consent), 4 cases (physician's intention) and 1 case (artificial food or fluids)

§ Multiple answers were possible, total percentage may add up to more than 100

† No information was available on whether consent was solicited for by the physician or not.

The decision to use continuous and deep sedation was made without patient involvement in most cases: one patient requested sedation (3.0%) and two patients consented (6.1%).(see Table 2) No patient dying at age 11 or younger consented with or requested to be sedated. In 70% of patients dying at age 12 and older, there was no request for or consent with sedation (data not shown in table). Parents consented in most cases (77.8%) and requested sedation in six cases (16.7%). In six cases (16.7%) there was no request or consent from the parents.

## 7.4. Discussion

Minor patients were commonly kept in continuous deep sedation or coma until death (21.8% of all deaths and 46.8% of non-sudden deaths) in Flanders, Belgium. Most sedation started one week or less before death and artificial nutrition and hydration were administered until death in more than half of cases. Physicians had the explicit or co-intention of hastening death in a quarter of cases. Parents consented with sedation in most cases, while the patients were seldom involved in decision-making.

The present study is, to our knowledge, the first to investigate the practice of continuous deep sedation in minors across different patient groups and care settings. A good response rate was attained. The method used has been successfully applied in previous studies and allows the making of reliable estimates of end-of-life practices.(2;4;25) However, only the physician's perspective was studied; the perspective of parents was not included. The present study was retrospective and descriptive, thus less suitable for providing in-depth explanations of its findings.

The incidence of continuous deep sedation in our study in minor patients was higher than the incidences found in recent population-wide studies in adult patients in Belgium (14.5%).(5;6) The high incidence may partly be related to a lack of appropriate optimal pain control in children due to the barriers to using sufficiently high doses of drugs and to the limited capacity of young children to express their symptom burden verbally.(27) Despite recent advances in pediatric pain relief, providing optimal symptom relief remains challenging for caregivers. To make sure that total symptom control is attained, physicians caring for minor patients may therefore be more easily inclined to resort to sedation. In most cases, physicians indicated that sedation was used where there were no options left to alleviate symptoms and only when death was imminent. Further studies on optimal dosages of pain medication for pediatric use, and improved training in palliative care and aggressive symptom control may help physicians to resort to sedation less easily.

At least four different types of sedation may occur at the end of life. The total proportion of 22% observed in our study is thus a combination of different practices. A first type is "palliative" or "terminal" sedation, which is used as a last resort option to treat refractory symptoms in imminently dying patients. This type of sedation has been

investigated frequently for the population of adult patients, and guidelines for good clinical practice have been formulated.(11-16) A second type of sedation is used to calm patients in order to facilitate certain treatments, such as ventilation after surgery. However, the patient's condition may worsen while under sedation, and it may consequently become irreversibly impossible to bring the patient back to consciousness. This second type of sedation is used when the main goal of treatment is curative, and the intention of professional caregivers is still to preserve the patient's life. Our finding that artificial food and fluids were administered until death in just over half of cases of sedation may indicate that this type of sedation occurred in our study. A third type of sedation is an unintended consequence of a gradual increase in pain medication. In our study, a quarter of physicians reported that they had only used morphine to sedate the patient. Finally, sedation may also sometimes be used as a covert form of life-ending, which was reported as their intention or co-intention by a quarter of physicians. The types of sedation described above would all be interpreted as continuous deep sedation until death by the physician, but the conditions under which sedation was started may have been entirely different. Unfortunately, the study design did not allow for clearly distinguishing between different types of sedation. Further prospective studies may help to clarify this issue.

According to Art. 12 § 2 of the Belgian Law on the Rights of the Patient (2002), which implicitly applies to continuous deep sedation, minor patients who are thought to be capable of judging their own interests may exercise their medical rights autonomously. In the great majority of cases studied here, the decision to sedate was taken with parental consent, but strikingly, patients themselves were seldom involved in the decision-making, if they died at age 12 or older. Of course, discussion would have been impossible in cases where sedation was an unintended side-effect of pain and symptom control. The findings may indicate that physicians make these decisions, in consultation with parents, in the patient's stead in their best interests, sometimes because patients are judged to be too young and sometimes possibly because of their diminished consciousness at the time of the decision. However, such circumstances cannot always justify the exclusion of minors from the decision-making process. If possible, some kind of discussion should perhaps be initiated early enough in the disease process. Moreover, in cases where there was neither parental request nor consent it is possible that patients and parents missed farewell opportunities. As the present data were limited in providing a full explanation of the finding, further studies are needed to clarify whether the decision-making process preceding sedation in minors is indeed less than optimal, and if so, whether this affects bereavement outcomes.

However, contrary to existing guidelines, physicians intended or co-intended life-shortening in one quarter of cases of continuous deep sedation in the present study. Almost half of physicians reported that they had taken possible hastening of death into account when engaging in sedation. These physicians may have observed the principle of double effect in these cases: they accept that sedation has two effects (symptom relief and shorter longevity), the physicians only intend the good effect, and accept the negative effect as a necessary but unintended side-effect. However, our results do not

preclude the use of sedation where euthanasia might otherwise have been chosen if it were legal in minors. Further studies in other populations are needed to establish whether this finding can be generalized to other countries, where the legal framework surrounding euthanasia is different from Belgium, and physicians hold less permissive attitudes towards the practice.

## **7.5. Conclusion**

The present study indicates that minor patients were commonly kept in continuous deep sedation or coma until death in Flanders, Belgium. Given the high incidence of the practice, and indications that it is sometimes used with a life-shortening intention without involving the patient, the development of specific guidelines for sedation in children appears to be appropriate in order to guide physicians and to guarantee the practice of due care. These guidelines should be formulated with adequate attention for ethical and legal decision-making. Further in-depth research is warranted to improve understanding of how decisions are made, why minor patients are seldom involved in them, and how sedation relates to acts with an explicit life-shortening intention.

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## Chapter 8: General discussion and conclusion

### 8.1. Summary of the main findings

#### 8.1.1. Place of death

In our study of 3.328 death certificates of children who died at age one to 17 in six European countries (Belgium, the Netherlands, Italy, Norway, Wales and England) described in Chapter 2, 1.037 (31.2%) died of a complex chronic condition. The proportion of home deaths differed between countries, and ranged between 19.6% in Italy and 28.6% in the Netherlands. Children dying from complex chronic conditions had higher chances of dying at home in all studied countries than children dying from other causes. The proportion of home deaths for children dying from complex chronic conditions varied between 21.7% in Italy and 50% in the Netherlands. Sub analyses among children dying from complex chronic conditions demonstrated that home death was more likely for chronically ill children dying from cancer and for children dying at age 11 or older. Differences in the proportion of home deaths between countries were significant, and remained significant after controlling for potentially related clinical and socio-demographic factors. As compared to Italy, significantly higher proportions of home deaths among children dying from complex chronic conditions were recorded in Belgium and the Netherlands.

#### 8.1.2. Attitudes of Flemish adolescents and physicians towards end-of-life decisions

The study on attitudes towards end-of-life decision of 1.769 Flemish adolescents showed that 61% found a request for euthanasia acceptable, 60% a request for intensified alleviation of pain and symptoms and 69% a request for a non-treatment decision when a terminally ill 14-year-old patient would request it. This was significantly higher than the 18% acceptance for euthanasia and 50% acceptance of intensified alleviation of pain and symptoms when requested by a non-terminally ill minor patient. Rates of acceptance of requests for end-of-life decisions varied significantly among participants. Boys, participants older than 14 years and participants from the general type of education were more acceptant towards end-of-life decisions than were girls, participants aged 14 and younger and participants from technical and vocational education. Participants cited different circumstances that should hold back a physician from administering a lethal drug. The child not agreeing (76%), the child being badly informed about his/her condition (68%) or the opinion of

the parents not having been sought (66%) were the most frequently cited reasons. For 40%, the lack of agreement of the parents with the child's death wish was a circumstance that should hold back a physician from administering a lethal drug. Ninety percent of participants thought a minor has the right to be informed about terminal prognosis of a disease, while 78% would like to be informed themselves. Agreement with the right to be informed about a terminal prognosis and the willingness to be informed themselves was highest among female participants and students older than 14 years. Agreement with the right to be informed about terminal prognosis was lowest for students from vocational education as compared to students from general and technical education.

A second study in adolescents tried to establish the influence of experience with chronic illness on end-of-life attitudes. To this end, 83 adolescents who were treated for cancer at least two years prior to the study were interviewed with questions similar to the first study so that results of both studies could be compared. The response-rate was 42%. Where a terminally ill cancer patient was concerned, 90.4% of participants found a request for a non-treatment decision acceptable and 84.3% a request for intensified alleviation of pain and symptoms, which was significantly higher than among the adolescents of the first study. The level of acceptance of a request for euthanasia by a terminally ill cancer patient was 63.9%, which did not differ significantly between both studies. Request for a non-treatment decision and euthanasia were found acceptable by respectively 69.9% and 56.6% of adolescent cancer survivors when a terminally ill non-cancer patient was concerned. Acceptance of requests for end-of-life decisions by non-terminally ill patients did not differ between the two studies and was, among the cancer survivors, 27.7% for requests for a non-treatment decision, 38.6% to 47.0% for a request for intensified alleviation of symptoms and 10.8% to 20.5% for a request for euthanasia. A majority of 92% thought a physician should not be allowed to administer a lethal drug when the child is not well informed about his or her condition, when the child wants to die because of the burden he or she causes to the parents, and when the parents' opinion is not asked by the physician. Fewer participants thought that a physician should not administer a lethal drug to a child when the parents do not agree with their child's wish to die. Almost all participants agreed that a terminally ill minor should have the right to be informed about the terminality of his or her condition; while slightly fewer, but still 86%, indicated that they would want to be informed themselves if they were ever faced with a similar situation. We will further discuss these findings below.

In our study of physician attitudes towards physician-assisted dying in minors, a 70.5% response rate was obtained. The attitude-items of the questionnaire were completed by 124 physicians. Sixty-nine percent agreed that the Belgian law on euthanasia should be extended to include minors, but only 26.6% thought this should be done by establishing clear age limits. The role of parents was clearly valued by the participating physicians: 60.5% thought parental consent is required before taking life-shortening decisions and 52.4% that the administration of a lethal drug can be acceptable if parents/representatives of a non-competent minor patient request for it. Only 21.8% of physicians agreed that minors are not yet capable of making a rational assessment of

their interests where decisions about life and death are concerned. Seventy-three percent acknowledged that experiencing a chronic condition causes younger minor patients to be better capable of assessing their interest as compared to healthy peers and 82.3% that the wishes of older minor patients should be taken into consideration to the same degree as those of adult patients. Opinions were divided where alternatives to physician-assisted death were concerned. While 46.7% agreed, 29.0% remained neutral as to whether palliative sedation is always to be preferred above the administration of a lethal drug in minor patients. About as many physicians agreed as disagreed that adequate pain control and end-of-life care make euthanasia superfluous in minors. The physicians could be clustered in two groups, based on their attitudes. About two thirds of physicians belonged to the “permissive” cluster: they are more likely to regard minor patients as competent decision-makers at the end of life, and to see euthanasia and life termination for minor patients as acceptable options under certain circumstances. Physicians in this cluster believe that the current Belgian law on euthanasia should be extended to include minors. The remaining third of physicians belonged to the “reluctant” cluster: they oppose euthanasia and life-termination in minors, even if requested for by a competent minor patient and/or parents. They tend to prefer palliative sedation above the administration of a lethal drug, and believe that adequate pain control and end-of-life care make euthanasia superfluous. These physicians do not want the current Belgian law on euthanasia to be extended. The physicians’ cluster membership was significantly related to their actual end-of-life practices. Permissive physicians were more likely to engage in intensified alleviation of pain and symptoms with a co-intention of shortening the patient’s life, in physician-assisted death, and in continuous deep sedation with a (co-)intention of shortening the patient’s life.

### **8.1.3. Incidence and characteristics of end-of-life decisions and sedation in minors in Flanders, Belgium**

A 70.5% response rate was obtained in our mortality follow-back study. Detailed information was collected on 165 deaths in minors aged between one and 17 years. Fifty-three percent of patients died sudden and unexpected. An end-of-life decision preceded death in 36.4% of cases, of which 10.3% were a non-treatment decision, 18.2% intensified alleviation of pain and symptoms and 7.9% physician-assisted death. All cases of physician-assisted death occurred without an explicit patient request, but in three quarters of cases the decision was requested by the parents. The most frequently cited reasons for performing an end-of-life decision were: no improvement to be expected (84.6%), low expected quality of life (61.5%) and not needlessly prolonging life (50.0%). Half of patients where an end-of-life decision was made had been in treatment for their terminal illness for more than a year. End-of-life decisions were generally discussed with the parents (85.2%), and discussion was mostly aimed at reaching a decision together with them. The decision was discussed with the patient in only 15.4%

of cases, mainly because the patient was comatose, too young or mentally disabled. In our study, only one patient was found to be competent by the physician.

In 21.8% of cases, the patient was continuously and deeply sedated until death. Benzodiazepines were used to sedate the patient in a majority of cases, yet in 25% of cases only morphine was used. Patients were sedated for 48 hours or less in 41.8% of cases and longer than two weeks in only 3.4% of cases. In a majority of cases, artificial nutrition was administered until death. In a quarter of cases, the physician indicated having had the intention or a co-intention of shortening the patient's life. Patients did not request or consent with sedation in 90.9% of cases. Parents however were involved in decision-making in most, but not all, cases of sedation.

## **8.2. Strengths and limitations of the study designs**

To help readers to appreciate the general discussion of the findings below, we summarize and elaborate on the methodological strengths and shortcomings of the study designs used.

### **8.2.1. Death certificate study on place of death**

The use of death certificates for studying place of death on a population level has been demonstrated to be a feasible study design.<sup>(1)</sup> Advantages of the design include the accuracy of the data, the inclusion of deaths across all care settings and places of death, the inclusion of patients across all causes of death and the exclusion of non-response on a patient level. Our study was, to our knowledge, the first to study place of death of children on a population-level in Europe, and the first to provide international comparisons. The detailed information on death certificates allowed us to distinguish the group of children who died from complex chronic illness, a relevant group where planning of place of death is more likely than for children dying from external causes.

The study, however, had some limitations. First, not all deaths were included in all countries. For Italy and Belgium, not all regions were included in the study, which may obscure some of the variance in place of death and associated factors in these countries. Second, while a comparison was made between six countries, a lot of European countries remain to be studied. Third, for some variables, estimates had to be made in some countries because detailed information was missing. This was the case for cause of death in Italy, age in Norway and socio-economic status in all countries. The estimates for cause of death in Italy may have been imperfect, which may have led to false positives or false negatives when selecting children who died from complex chronic conditions. The lack of detailed information on age in Norway led to Norway being excluded from the multivariate binary logistic regression. More detailed

information on age would have allowed for a more complete model. Fourth, while studying death certificates is a feasible study design, inaccuracies and errors cannot be entirely excluded.<sup>(2)</sup> Finally, some information, which is relevant for studying place of death, is not available on death certificates, and was thus missing. There was, for instance, no information on patient or parent preference for place of death, a factor which has been demonstrated to be relevant for pediatric end-of-life care. However, collecting population-wide data via death certificates precludes collecting more detailed information, which was not the primary aim of the study.

### **8.2.2. Questionnaire study among secondary school students**

The questionnaire study among secondary school students was, to our knowledge, the first to study systematically the attitudes of minors towards end-of-life decisions in minors. The study design, using concise case descriptions and touch screen units, attempted to appeal to the participating adolescents' sphere of interest. The sampling procedure allowed for students and schools from different religious backgrounds to participate in the study. Because students were sampled by the school principals, there was also no non-response at student level. This precluded any selection bias at participant level. Moreover, because computerized touch screen units were used to administer the survey, there were no missing values on any of the questions. By informing the participants about the scope of the study only in general terms beforehand, there was no risk of class consensus being formed.

On the other hand, the fact that classes of participating pupils were proposed by the school principals also carried some risk of selection bias. However, we estimated that it was not likely that this had a significant and systematic effect on the data, as the selection bias could have gone either way: principals may have proposed their most accepting students as well as their least accepting students. A second limitation of the study was that the short case description and limited answer categories may not have given enough information and response options to the participants to express their opinions with as much nuance as they would have liked. An additional limitation was that we had to use a student's membership of a school network as an approximation of the individual life stance. This may have been an imprecise estimation, as students and parents no longer primarily opt for a certain school on the basis of its life stance, but rather on the basis of social, academic or practical arguments. It would have been interesting to have more precise information on the students' individual life stances, a factor which has already been shown to be related to attitudes towards end-of-life matters.<sup>(3)</sup>

### **8.2.3. Interview study among cancer survivors**

As the design of the study among cancer survivors was similar to the study in secondary school students, most strengths and limitations are also similar. An additional strength of the study among cancer survivors was that it used interviews to survey the adolescents, which allowed the researchers to support the participants if any of the questions would prove to be burdensome for the participants. A second additional strength was the focus on a group of minors who had been treated for cancer in the past, a group which had not yet been studied. This met the need for more patient reported outcomes, one of the principal needs of research in pediatric oncology.(4)

A specific limitation of the study in cancer survivors was its relatively low response rate of 42%. The non-response was partly caused by parents refusing consent for their child to participate in the study. Non-response was also partly at participant level, where parents consented but the adolescents did not. We can thus not preclude that there may have been some selection bias. Non-response may have been systematic to some extent. Parents and adolescents who had less positive experiences with the care received may have been less inclined to consent to participation in research. Adolescents who did not participate in the study often indicated that the study subject was still too confrontational for them. However, we deem it implausible that this non-response, even if it were systematic, significantly biased the results on adolescent's attitudes towards end-of-life decisions. We see few reasons to suspect that only the adolescents with the most distinct positive or negative attitudes have participated in the study.

### **8.2.4. Mortality follow-back study on end-of-life practices**

A retrospective post-mortem physician survey is a study design that has been shown to be feasible for studying end-of-life practices on a population level, and has been successfully used several times in the past for making epidemiological estimates of end-of-life practices.(5-9) Our study was based on these previous studies, which allowed for putting the findings in perspective with findings in the Netherlands and in adults. The design is well suited to investigate deaths across care settings and causes of death, and the opportunity to link the survey data to case-wise death certificate data adds detail to the findings. Our study was, next to a study in the Netherlands, only the second to focus on deaths of minors dying between the age of one and 17, and the first to do so in a country where euthanasia was legal.(10) Moreover, our study was the first worldwide to study the practice of continuous deep sedation at the end-of-life systematically, at the end-of-life in minors. Furthermore, our study did not use a sample of death certificates. Instead, all deaths of minor patients in an 18-month period from June 2007 until November 2008 were included. The response-rate of 70.5% was satisfying, although somewhat lower than in previous studies.(10;11) The response-group was



representative for the total group of 250 deaths in the study period. An additional strength of the study was the inclusion of attitude-items in the questionnaire. This not only made it possible to study physicians' attitudes towards physician-assisted dying in minors, a rarely studied topic, but also to relate their attitudes to their actual reported end-of-life practices. Our study is, to our knowledge, the first to do so in minor patients other than neonates.

The study also had some shortcomings. Inherent to the study design was the retrospective nature of the survey. This may have induced some recall bias in the physicians' responses. This problem was present in similar previous studies.<sup>(5;7;8;12;13)</sup> We do however expect this recall bias to have played a smaller role in the present study. As physicians were surveyed on the death of minor patients, we would expect them to recall these cases more clearly, because of the rarity of child deaths, and the powerful impact the event has on families and caregivers. A second shortcoming was the fact that only the physician's perspective was studied. The valuable perspective of the parents and other professional caregivers thus remained unstudied. Including these perspectives in the study would of course have added to the richness of the data and interpretation, but was ultimately beyond the scope of the study and impossible because deceased patients were anonymous – not only for the researchers, but also for the Flemish Ministry of Health who collected the data. A third shortcoming was the limited potential of our survey to fully capture the complex decision-making process prior to end-of-life decisions in minors. It would have been useful to gather more detailed information on minor patients' competence to be involved in decision-making, the way this was assessed, what were the main reasons for deeming the patient incompetent, etcetera. Unfortunately, including these questions would have considerably lengthened the survey, and would possibly have reduced the response rate. A compromise between length and detail of the questionnaire had to be made. Of course, as noted above, a complete picture of decision-making is hard to achieve by studying only the physician's perspective. A final limitation of the study was that the group of physicians who completed the attitude items was relatively small (N=124). However, while the group was small, they nevertheless represented a very relevant sample of physicians. They were in fact all the physicians who certified the death of a minor patient during an 18-month period in Flanders, Belgium. Because they represent the physicians caring for dying children in Flanders, their attitudes are the most relevant of all physicians.

### **8.3. General discussion and implications**

#### **8.3.1. Place of death of children**

Our death certificate study on place of death in children in six European countries demonstrated a low rate of home deaths in all countries studied, varying between 20%

and 29%. As only few population-based studies on place of death in children are available, it is not easy to frame these results in an international context. Comparison with similar population-based studies in the US suggests that our findings are largely concordant with findings in the US, where also a large majority of children died in hospital.(14;15) The high proportion of hospital deaths is of course linked to the pattern of causes of death. A lot of children die from external causes, where there are no opportunities to plan end-of-life care, and attempts to keep children alive are logically maximized in emergency or intensive care units.

In order to come to meaningful interpretations, a focus on children dying from complex chronic diseases was necessary, and we found that chronically ill children died more often at home than did children dying from other causes. This was, again, concordant with Feudtner's population-based studies in the US.(14;15) This result was to be expected, as end-of-life care is easier to plan when a child suffers from chronic disease and has longstanding relationships with professional caregivers. When death is an imminent outcome, and frequent contacts with professional caregivers occur, it appears plausible that parents more frequently get a chance to articulate their preference concerning place of end-of-life care and death to health professionals. Although our study did not provide information on parental preferences, previous studies lead us to expect that a majority of parents will have preferred to care for their child at home.(16-23) The fact that most children, even when dying from a chronic condition, did not die at home in the studied countries, suggests that a considerable gap exists between preferences and outcomes regarding place of end-of-life care and death.

In this context, it is important to notice the significant differences between countries, even after controlling for patient characteristics and socio-demographic variables. Children dying from chronic disease in Italy had significantly lower chances of dying at home than their Belgian and Dutch counterparts. In Chapter 2, we have elaborated on some possible cultural and structural explanations for this finding. To understand why Italian chronically ill children had low chances of dying at home, we hypothesized some cultural factors to be in play. In Italy, we expected parents and professional caregivers to hold strong attitudes towards preserving the lives of children, which may ultimately even lead to therapeutic obstinacy. Knowledge of such cultural factors is in principle needed to fully understand the results, as home death may not be a desirable outcome for a lot of Italian parents. Further research should try to take these factors into account.

A marked finding was that home death was more likely for children dying from cancer in four out of six countries studied, even when compared with children dying from other chronic diseases. This was not a novel finding, as previous studies in the US and the UK already suggested higher chances of home death in children dying from cancer.(14;24) However, the finding was important, in that understanding the mechanisms which facilitate home death in children dying from cancer may lead to factors being uncovered which can improve rates of home death in children dying from other diseases. A factor that will evidently play a role in the higher rate of home death among cancer patients is the more predictable course of the illness, which makes it

easier for parents and professional caregivers to plan end-of-life care.(25-28) This factor however provides little indication of how to improve the rate of home deaths in other patient groups, as we cannot just change the predictability of illness trajectories.

A second factor which undoubtedly improves the rate of home death among cancer patients in Belgium, is the availability of palliative home care teams in three of four academic hospitals in Flanders. These teams operate from pediatric oncology settings, and still reach predominantly cancer patients – although aiming to care for all terminally ill children. Within the “Koester”-project in Ghent, for instance, 84% of patients between 1996 and 2005 had malignant pathologies.(29) It is logical that palliative care teams for terminally ill children originate in oncology settings, as professional caregivers operating in these settings are relatively experienced in the care of dying children. The care models of “Koester” in Ghent and “KITES” in Leuven are aimed at providing palliative home care for their patients. This is done by providing a liaison between caregivers in the home situation (including the general practitioner, the parents and home nurses) and the hospital.(29) This link between hospital and home allows for good continuity of care. It is reassuring for families that the specialists in hospital keep track of the progression of their child’s condition, and that they can admit their child to hospital more easily if home care can no longer be managed. The experienced caregivers of the specialized pediatric palliative home care teams do not only organize and coordinate home care, they also train and instruct the less experienced caregivers in the home situation. By doing this, the scarce expertise in children’s end-of-life care is shared efficiently with other professional caregivers such as home nurses or general practitioners, who generally have little or no experience with pediatric end-of-life care. As we outlined in the introduction to this dissertation, the limited level of experience and expertise of professional caregivers is one of the principal challenges and barriers in pediatric end-of-life care.(30-35) Additionally, the fact that these home care teams are hospital-based and provide outreach to the home setting allows them to cover a relatively large geographical area, and adds to their cost efficiency.

Unfortunately, the home care teams have depended on fund raising and charity for a long time. Only recently, a first structural financing was made available for pediatric palliative home care.(36) Given the expertise and efficiency of the existing home care teams, we recommend extending structural financing for these services in the future. With extra resources, the teams can elaborate their services and focus more on children dying from diseases other than cancer, a group where our study clearly indicates that the most progress is still to be made. By doing so, other dying children may in the future also benefit from the end-of-life care expertise available in pediatric oncology settings. Of course, further studies are needed to monitor the quality of care delivered by these pediatric palliative home care teams. Parents should feel confident that reliable support is readily available and that continuity of care is guaranteed.(17;37;38) Results in other countries already suggest that palliative home care, although not yet accessible to all children, can indeed be successfully organized.(19;39-45)

### 8.3.2. Attitudes towards end-of-life decisions in children

Our studies on attitudes of adolescents towards end-of-life decisions show a similar pattern of acceptance of requests for different kinds of end-of-life decisions as in adults.(3;46-48) They generally accept requests for a non-treatment decision more easily than requests for intensified alleviation of pain and symptoms, and the latter more easily than a request for euthanasia. All requests were generally more accepted when formulated by a terminally ill minor patient than when formulated by a non-terminally ill minor patient. When we assume that adults, in general, think rationally about end-of-life decisions, and adolescents show a similar pattern of attitudes, the findings suggest a certain degree of “outcome rationality” in adolescents. The data do not allow for establishing whether the adolescents in fact formed their opinion in a rational and competent way, but the outcome of their thinking suggests that they did. This was to be expected, based on the literature on adolescents’ competence for medical decision making, which indicates that adolescents from the age of 14 years on are generally competent decision-makers, and no less than adults.(49) Additionally, adolescents indicated that they do not want to be left alone with end-of-life decisions. This was in line with previous studies.(50-52) Parental input was generally highly valued by the participants, in that they found the administration of a lethal drug to a minor patient unacceptable if the parents’ opinions were not asked. However, the final decisional authority should, according to the participants, lie with the adolescents.

There was a considerable degree of variance in attitudes according to the participants’ characteristics. Experience with chronic illness appeared to have some influence, but the general pattern of results was generally similar between both studies. The main implication of this finding for professional caregivers is that adolescents generally think that requests for end-of-life decisions by minors are acceptable under certain circumstances, and that they generally want to be informed about a terminal prognosis, but that the variance in the results urges professionals to assess preferences and needs case by case when faced with adolescents at the end of their life. Our studies provided some guidance as to which adolescents are most likely to be open to end-of-life decisions: males, adolescents older than 14, with a general education and with experience with chronic illness. It is important to notice that our studies did not provide information on adolescents currently living with cancer. Their attitudes may be different from those with chronic illness experience or those who have been clear of cancer treatment for at least two years, but further study is needed to clarify this issue.

The findings are hard to put into an international context. Not only because comparable studies are scarce, but also because in Belgium, unlike in other countries, end-of-life decisions in minors can be openly discussed - even the more controversial

physician-assisted death. It is thus possible that acceptance towards requests for end-of-life decisions is lower in other countries, where a less open culture of debate exists. Studies among other groups already indicate that people in Belgium hold generally more positive attitudes towards physician-assisted dying than do people in a lot of other countries.(53) Further research would be needed to investigate whether adolescents in other countries hold similar attitudes to the Flemish adolescents. A repeat study of the survey in Flemish secondary schools would also be interesting, as it would provide a first measure of adolescents' attitudes after the Belgian law on euthanasia came into effect. Although minors are excluded from the law, it is possible that the debates around it have changed adolescents' opinions.

The results of our study on attitudes of physicians towards end-of-life decisions in minors showed a clear majority of Flemish physicians favorable to physician-assisted death in minors. This is an important finding, especially in the context of societal and political debate concerning the adaptation of the current law to extend its application to minors.(54-59) Nearly 70% of surveyed Flemish physicians involved in the care of dying children agreed with the thesis that the Belgian law on euthanasia should be extended. This result was even more distinct than previous findings among Flemish physicians involved in the care of dying infants and neonates, where 58% favored a law which would make termination of life possible in some cases.(60) This study was however conducted before the euthanasia law was enacted in Belgium, a process which may have influenced physicians' attitudes.

Physicians surveyed in our study generally did not favor an adaptation of the Belgian law on euthanasia by establishing clear age limits. This accords with most of the submitted bills to supplement the law on euthanasia, where generally no age limits are proposed.(55-59) Only one proposal put forward age limits, not to determine which minors would be eligible for euthanasia, but rather to determine when parental consent is needed.(54) In this proposal, the age limits determining the degree of parental involvement were modeled on the Dutch law on euthanasia, where parental consent is needed if the child has not yet reached the age of 16, and parents need only to be informed of their child's wish if the child is 16 or older.(61) The Dutch euthanasia law additionally formulates an age limit for minors to validly request euthanasia: minors need to have reached the age of 12 in order to do so. This is of course an attractive way of formulating a law, and it has the advantage of providing objectively assessable criteria for the evaluation commissions. However, an age limit always remains arbitrary and raises the question why, for instance, a request for euthanasia by a competent 11-year old cannot be granted, whereas a request by an equally competent 12-year old would be granted if all other evaluation criteria are met. Formulating a clear age limit thus does not take away all age discrimination, which is still one of the main reasons for including minors in a law on euthanasia. Clearly, the surveyed Flemish physicians are opposed to age limits if the Belgian law on euthanasia is ever to be extended. This was in line with Dutch pediatricians, of whom a majority do not agree with the existing age-limits in the Dutch law on euthanasia.(62) Our findings suggest to policy makers that there is support for an extension of the Belgian law among Flemish physicians involved in the care of dying children, albeit not by formulating age limits

but by focusing on competence. The current and past bills to supplement the law all included the competence of the patient as a prerequisite to formulating a valid request.(54-59) It is important for policy makers to understand the attitudes of physicians involved in the care of dying children, as these physicians will be a principal party in the decision-making process if euthanasia is ever to be legalized for minors in Belgium. Parents and children would be the other two principal parties in the process. While we have presented data above on how adolescents view the issue of euthanasia in children, many questions remain unanswered, such as how younger children and parents view these issues. From our attitude studies, we have already learnt that physicians and adolescents clearly value and appreciate parents as partners in decision-making.

An additional striking finding from our survey among Flemish physicians was that attitudes were significantly linked to actual end-of-life practices. This link was already reported in other studies, but our study was the first to demonstrate it in minors.(3;63) Notably, a positive attitude towards physician-assisted death was also positively related to continuous deep sedation. This already suggests that physician-assisted death and sedation are not two perfectly separated practices. Below we will go into these more deeply. It was important to see that physicians' decision-making in end-of-life situations is not only determined by the clinical characteristics of the patient's condition, but also by their own attitudes and opinions on end-of-life decisions. This may have implications for clinical practice. If physicians do not communicate their own attitudes towards these issues to parents and patients, there is a possibility that major conflicts arise between all parties involved as to whether or which end-of-life decisions are to be taken at a certain point. While we have no indications from our data that major conflicts arose, we suggest that physicians articulate their attitudes towards end-of-life decisions to parents and patients early enough. By doing so, parents and patients get a chance to learn what they can and cannot expect from their physician if end-of-life decisions are ever considered. If parents or patients foresee that major conflicts may arise, they can prevent this by openly discussing the differences in opinions beforehand or even by seeking a second opinion, instead of being faced with a fait accompli. In any case, if attitudes are linked to actual practices, they cannot be disregarded by policy makers in the current debates on euthanasia in children.

### **8.3.3. End-of-life decisions and decision-making**

As could be expected based on the existing body of literature, albeit often in limited settings and patient groups(64-78), our population-wide study demonstrated that end-of-life decisions are also frequently taken in minors. Our study was only the second population-wide account of end-of-life decisions in children dying after infancy. The findings were remarkably similar to the only previous study in the Netherlands, where 36% of all deaths in minors dying at age one to 17 in 2001 were also preceded by an end-of-life decision.(10) When only non-sudden deaths are taken into consideration, the

proportion of end-of-life decisions was even higher in Flanders than in the Netherlands (78% vs. 66%). This difference could indicate a higher frequency of end-of-life decisions in Flanders than in the Netherlands, but it is more plausible that a time effect is influential: the frequency of end-of-life decisions in the total population rose significantly in Flanders between 2001 and 2007.<sup>(8)</sup> Flemish physicians strongly take expected quality of life into consideration as an argument for engaging in end-of-life decisions in children. The young age of children can be an important factor when weighing quality and quantity of life. While chronically ill patients in very old age are already approaching death, chronically ill children may still face a long life of agony and unbearable suffering if no intervention is made. Therefore, it is easy to understand why the expected quality of life plays an important role in a physician's considerations.

While the general pattern of end-of-life decisions in children in Flanders resembled the pattern found in the Netherlands (intensified alleviation of pain and symptoms was the most frequent, physician-assisted death the least frequent), there were some marked differences in the proportion of physician-assisted death.<sup>(10)</sup> In Flanders, nearly eight percent of all deaths were preceded by a decision which was explicitly intended to shorten the patient's life, whereas a proportion of 2.7% was recorded in the Netherlands, and 3.8% among adults in Flanders.<sup>(10;79)</sup> Meanwhile, there were no cases of euthanasia recorded among children in Flanders, as compared to 0.7% (or an annual five cases) in the Netherlands. It is not surprising that euthanasia was more frequent in the Netherlands, where the practice is legal for minors from the age of 12 on.<sup>(80)</sup> It was nonetheless striking that euthanasia did not occur in children in Flanders during an 18-month period. The fact that the practice is still illegal in Flanders does not preclude that it is used in practice. This was a novel and important finding, and should inform policy-makers who are debating the extension of the Belgian law on euthanasia. If an amendment to the law would be principally aimed at regulating existing practices among physicians, in order to protect them legally, our data suggest that an amended law would not substantially add to the actual legal protection of physicians, since they are apparently rarely or never faced with requests for euthanasia by minors. Evidently, a law should not necessarily be aimed at regulating existing practices. The amended law on euthanasia could also aim to eliminate age discrimination which is present in the existing law. To this end, it is irrelevant whether euthanasia occurs frequently or not, more important is that minors are no longer denied a privilege purely on the basis of an age criterion, without taking their competence into account.

More pertinent to everyday pediatric end-of-life practice in Flanders than euthanasia seems to be the practice of life-ending without patient request. Physicians appear to take these decisions with more caution: they discuss the decision more often with other professional caregivers, and take more reasons into consideration when engaging in this practice than they do in other practices. This indicates that this kind of decision is also very hard for physicians to take. That does not take away the fact that, by engaging in the practice of life-ending without patient request, physicians expose themselves to legal prosecution. It is hard to see how an amended law on euthanasia could ever reassure physicians in this kind of practice. Characteristic to the practice is the absence of a valid request, which represents exactly one of the underlying principles of the law

on euthanasia: the right to self-determination. Apparently, requests for life-termination do not occur among Flemish children. We can only hypothesize as to why these requests do not occur. Possibly, Flemish children are very resilient and prefer to fight for their lives until the very end.(81;82) Alternatively, the lack of a legal framework for children to validly request euthanasia may impede them from requesting it. It is possible that if the application of the Belgian law on euthanasia is extended, Flemish children will also request euthanasia, because they then have the opportunity to legally do so. Notably, physician-assisted death was requested by the parents in three quarters of cases, possibly because it is too hard for them to see their child suffering unbearably. In any case, the data suggest that pain control and palliative care are not always sufficient alternatives in end-of-life care for physicians and parents in Flanders.

One may wonder whether the intentional life-ending of a patient who did not explicitly request it can ever be ethically justified. In answering this question, the four principles of ethics will have to be taken into consideration: respect for autonomy, beneficence, non-maleficence and justice.(83) The active life-ending of a hopelessly and unbearably suffering patient can be regarded as an act of non-maleficence, with a compassionate intention of ending the patient's suffering. By doing this, a physician would intend to safeguard a patient from a life full of unbearable pain and suffering, which fits the "primum non nocere" precept of the Hippocratic Oath. Additionally, prolonging the life of a patient, when only a life full of agony is to be expected can be regarded as an infliction of the principle of beneficence. However, physicians will always need to be careful not to violate the patient's autonomy. Different ethical principles can conflict with each other, and physicians can face dilemmas in how to prioritize one of the principles in a particular situation. In assessing the ethical justifiability of an act of life-ending, a distinction will have to be made between competent and incompetent patients. In incompetent patients, the principle of autonomy will understandably have a lower priority than the principles of beneficence and non-maleficence. Incompetent patients cannot make their own autonomous decisions, which makes it morally justifiable for physicians to act paternalistically on their behalf, albeit with respect for the patient's best interests and parental rights. In incompetent patients, it can thus be ethical to terminate life without the patient's explicit request, insofar as the principles of beneficence and non-maleficence are respected.(84) The situation is different where competent patients are concerned. In competent patients, the principle of autonomy will have a much higher priority, and it is hard to see how life-ending can ever be justified when it violates the patient's autonomy, even when the principles of beneficence and non-maleficence are respected.

Decision-making was shared with parents in most cases of all end-of-life decision. This is in accordance with most guidelines on pediatric end-of-life care, which recommend that parents should be involved in decision-making, and the Belgian law on patient rights which states that parents act as representatives of their minor children.(85-90) It also accords with the findings from our attitude studies described above, in which adolescents and physicians put a high premium on parental involvement in decision-making. Discussion with parents however varied according to the type of end-of-life



decision concerned: in all cases of non-treatment decisions and physician-assisted death the decision was discussed with the parents, but in only 68% of cases of intensified alleviation of pain and symptoms. In Chapter 6 we hypothesized that this lower rate of discussion with parents when pain and symptom alleviation was intensified can be related to the fact that life-shortening is less certain in these cases. In non-treatment decisions and physician-assisted death, life-shortening is a necessary effect of the decision, and it is a reassuring part of quality decision-making that all these high impact decisions were indeed discussed with the parents.

Minor patients, on the other hand, were seldom involved in decision-making themselves. This is in contradiction with existing guidelines and legal frameworks, which prescribe that minors should be involved in decision-making as much as possible, and in function of their maturity and competence. We found no evidence in our data that decision-making at the end-of-life in children fits a model of shared decision-making, which is however the recommended model.(38;91;91-97) Only a few studies are available on minor patients' involvement in end-of-life decisions, but the 15% involvement found in our study was parallel to the 16% found in a Dutch interview study among pediatricians.(10) In order to understand whether minor patient's involvement was in fact less than optimal, it is necessary to know whether patients were competent or not at the time that decisions had to be made. Our findings suggest that minor patients were almost never deemed competent by the physician, compared with almost 13% in the Dutch interview study.(10) As in the Netherlands, the estimated lack of competence appeared to be related in our study to young age and a comatose condition in the patient. The first factor, very young age, is evidently a factor which complicates patient involvement. When patients are for instance too young to speak, it is hard to see how they can be involved in any meaningful way in decision-making. The ability to communicate is acknowledged to be a prerequisite for competence.(83) However, when children have acquired the skills to speak and to express themselves, a phase of development exists where meaningful discussion would be possible in principle, but would require extensive efforts by physicians to adapt their information to the developmental level of the child.(95;98-100) Using age as a criterion for not involving children in decision-making therefore seems to be an inadequate argument - at least when dealing with children who are already verbally skilled. Training health professionals to communicate better with children, to adapt the information to the developmental level of their minor patient, may not only improve the skills of health providers in fostering competence in their patients, but may also ultimately improve minor patient's involvement in end-of-life decision making. This is a recommendation for existing training for pediatricians and nurses, as we know from studies in other countries that pediatricians and nurses currently still feel inadequately trained to face these end-of-life situations.(31;32;35;40;101-105)

The second reported factor for not involving children in decision-making, the patients' comatose condition, of course precludes any meaningful involvement. However, it remains possible that children were competent enough to be involved in decision-making at some point before they became comatose. Unfortunately, our data were too limited to fully understand why children were not involved in decision-making, and

why they were found to be not competent. The findings suggest less than optimal involvement by minor patients, but further studies are required to investigate whether this was really the case. Prospective studies could help to better understand the physician's consideration. An aspect of decision-making that remained unstudied in our survey was the complex interaction between physicians, parents and children. In this triad, parents may make an appeal on physicians to conceal information from the child/patient. In order to sketch a complete and detailed image of decision-making, these complex interactions should be included in future studies.

#### **8.3.4. Continuous deep sedation**

The proportion of continuous deep sedation at the end-of-life of children was, at 22% of all deaths, remarkably high. Although previous limited studies already suggested that sedation may be frequently used at the end of children's lives, the proportion found across all settings and patient groups in Flanders was striking.(106-110) The proportion even surpassed that found in Flemish adults in 2007, which had already significantly increased since 2001.(8;111) This upward trend was also demonstrated in the Netherlands.(7) Our findings represented the first detailed account of continuous deep sedation at the end-of-life of children, where information about characteristics and the decision-making process was available.

In Chapter 7 we have already tried to seek explanations for the high incidence of sedation in minors. In order to make clear interpretations about what role sedation plays at the end of children's lives, it is necessary to make a distinction between different types of continuous deep sedation. At least four different types of sedation may occur at the end of life. The total proportion of 22% observed in our study is thus a combination of different practices, and the data suggest that all the different types have occurred in our study. A first type is "palliative" or "terminal" sedation, which is used as a last resort option to treat refractory symptoms in imminently dying patients. This type of sedation has been investigated frequently for the population of adult patients, and guidelines for good clinical practice have been formulated.(112-122) A second type of sedation is used to calm patients in order to facilitate certain treatments, such as ventilation after surgery. This second type of sedation is used when the main goal of treatment is curative, and the intention of professional caregivers is still to preserve the patient's life. Our finding that artificial food and fluids were administered until death in just over half of cases of sedation may reflect this type of sedation. When cure is still the main goal of treatment, it is of course necessary to administer food and fluids to the patient. However, the patient's condition may worsen while under sedation, and it may consequently become irreversibly impossible to bring the patient back to consciousness. A third type of sedation is an unintended consequence of a gradual increase in pain medication. Fourth, sedation may also sometimes be used as a covert form of intentional life-ending. In retrospect, the types of sedation described above would all be interpreted as continuous deep sedation until

death, but the conditions under which sedation was started may have been entirely different. Unfortunately, our study design did not allow for clearly distinguishing between different types of sedation. This, of course, complicates the interpretation of the findings.

Besides being mostly used as a last resort option for symptom control, patients in our study were mostly sedated for one week or less. This was in line with previously formulated guidelines.(121;123-125) Yet, in more than a quarter of cases, patients were sedated for a week or longer. It is to be recommended that the duration of sedation be kept as short as possible, as the situation can be very distressing for the parents (see below). The drugs used were not always in line with recommendations. While benzodiazepines are recommended, minor patients appeared to be sedated by means of only morphine or morphine in combination with drugs other than benzodiazepines in about 30% of cases. The use of non-recommended drugs holds a risk of less than optimal sedation. However, as noted above, the cases where sedation was initiated by means of morphine may reflect situations where the doses of morphine were gradually increased in the context of intensified symptom control, and lowered conscience was an inevitable and unintended side-effect. This finding suggests that specific guidelines for sedation in children are necessary, or that existing guidelines in adults should become better known among pediatricians.

While all guidelines on terminal or palliative sedation recommend that life-shortening should not be intended when engaging in sedation at the end of life(115;120;126;127), physicians indicated having at least co-intended to shorten the patient's life in a quarter of cases in our study. This was slightly higher than the 17% life-shortening intention observed in Flemish adults who were continuously and deeply sedated until death in 2007.(128) Moreover, sedation was frequently terminated by physician-assisted death, which was mostly requested by the parents, possibly because it is hard for parents to witness their child deeply sedated with no prospect of regaining conscience. Decisions to sedate patients at the end-of-life indeed have a profound impact on the families, as the patient is made unconscious and further communication between child and parents is rendered impossible. Under these circumstances, it is vital that decisions are made with great care and caution, and that practice and communication by physicians is optimized. Specific guidelines can help to further improve the practice in the future. The current findings on life-shortening intentions appear to contradict existing guidelines, and rather support the hypothesis that sedation is sometimes also used as a form of "slow euthanasia" in children.(129;130) This is an important and interesting finding, and warrants further study of the practice of continuous deep sedation at the end-of-life of children.

Decision-making was comparable in continuous deep sedation and end-of-life decisions. In over 90% of cases, continuous deep sedation was neither consented to nor requested by the minor patients themselves. As noted above, our data are too limited to conclude unequivocally that decision-making was less than optimal, but the data suggest that it was. In other end-of-life decisions, the patient's comatose condition was one of the main reasons why decisions were not discussed with the patient. This reason

seems not to suffice when physicians consider sedating a patient, as it can be reasonably expected that the patient was still conscious prior to the administration of sedatives. As with other end-of-life decisions, more research is needed to clarify the reasons for not involving minor patients in decision making where sedation is concerned.

As in other end-of-life decisions, parents were involved in most cases; however they requested the sedation themselves in only 17% of cases. This suggests that the decision to sedate the patient is mostly physician-initiated. This is a reasonable expectation, as physicians indicated in nearly 85% of cases that there were no alternatives other than sedation to treat the patient's symptoms. When patients suffer from refractory symptoms, physicians propose sedation as a last resort option for symptom control. This is in line with existing guidelines.(121;124;125;131) As the incidence of sedation is higher in children than in adults, one can wonder whether refractory symptoms are more frequent in children. We hypothesize that this is not necessarily the case, but that other factors come into play. A possible explanation is that physicians are more easily urged to resort to sedation, as probabilities for suboptimal symptom control are higher in children than in adults, as (especially young) children lack skills to verbalize their symptom burden and drugs are often less thoroughly tested for use in pediatric populations.(108;132-139) Physicians will then, understandably, prefer to treat symptoms maximally by means of sedation, rather than risking suboptimal pain control.

#### 8.4. References

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## Chapter 9: Nederlandstalige samenvatting “Zorg en beslissingen aan het levenseinde van minderjarigen: studies naar attitudes en praktijk”

### 9.1. Situering en onderzoeksvragen

Het overlijden van een kind is in moderne ontwikkelde samenlevingen een zeldzame gebeurtenis geworden. Ouders worden gemiddeld genomen zelden geconfronteerd met deze ingrijpende gebeurtenissen, maar blijven door het gedaalde geboortecijfer wel vaker kinderloos achter. De impact van het overlijden van een kind voor ouders, maar ook voor alle andere betrokkenen en nabestaanden, kan dan ook nauwelijks overschat worden. Doordat het overlijden van een kind zo zeldzaam is geworden, krijgen zorgverleners relatief weinig kansen om specifieke expertise op te bouwen in het begeleiden van terminaal zieke kinderen en hun families.

Zorgverleners die werken met terminaal zieke kinderen worden daarenboven geconfronteerd met heel wat specifieke uitdagingen. Zo is het door de ontwikkelende competentie van minderjarigen moeilijk om correct in te schatten in welke mate zij betrokken kunnen of moeten worden bij beslissingen aan het levenseinde, en moet dit afgewogen worden tegen de beslissingsbevoegdheid van de ouders die optreden als vertegenwoordiger van hun kind.

Deze uitdagingen komen zeer uitgesproken tot uiting wanneer beslissingen overwogen worden om het leveneinde te bespoedigen, waaronder: niet-behandelbeslissingen, opgedreven pijn- en symptoombestrijding en levensbeëindiging. Levensbeëindiging kan verder onderverdeeld worden in hulp bij zelfdoding, euthanasie (wanneer de patiënt er expliciet om verzoekt) en levensbeëindiging zonder verzoek. In België is euthanasie, hoewel wettelijk geregeld voor volwassenen, niet mogelijk voor minderjarigen. Dat neemt niet weg dat er hevig gedebatteerd wordt, zowel in de politiek als in de maatschappij, over het al dan niet uitbreiden van de huidige Belgische euthanasiewet. Opvallend genoeg zijn deze beslissingen, en de attitudes van de belangrijkste betrokken partijen, tot op heden nauwelijks onderzocht in Vlaanderen, waardoor de debatten niet ondersteund konden worden door empirische gegevens.

Een bijkomende uitdaging voor zorgverleners is de planning van de plaats van levenseindezorg voor kinderen. Ouders verkiezen doorgaans om hun kind thuis te kunnen verzorgen aan het levenseinde, alsook om het thuis te laten overlijden. Dit is gerelateerd aan positievere rouwuitkomsten bij ouders en nabestaande broertjes en zusjes. Voor Vlaanderen en Europa zijn er echter geen onderzoeksgegevens beschikbaar over de plaats van overlijden van kinderen.

In deze doctoraatsthesis hebben we daarom geprobeerd om een antwoord te vinden op volgende onderzoeksvragen:

- Waar sterven kinderen, en met welke factoren hangt dit samen?
- Hoe staan minderjarigen tegenover levenseindebeslissingen?
- Speelt ervaring met chronische ziekte een rol in de attitudes van jongeren ten opzichte van levenseindebeslissingen?
- Hoe staan artsen tegenover levensbeëindiging bij minderjarigen en een aanpassing van de Belgische wet betreffende euthanasie naar minderjarigen toe?
- Hoe vaak worden levenseindebeslissingen, waaronder continue diepe sedatie, genomen bij minderjarigen in Vlaanderen, België?
- Wat zijn de kenmerken van deze beslissingen, en hoe worden ze genomen?

## 9.2. Methode

Om bovenstaande onderzoeksvragen te beantwoorden, werd gebruik gemaakt van verschillende onderzoeksmethodes.

De eerste onderzoeksvraag werd benaderd door gebruik te maken van een database die informatie bevat van overlijdenscertificaten van alle kinderen die tussen 1 en 17 jaar overleden in negen Europese landen. Binnen deze database werden de landen geselecteerd waarvoor de data toelieten om eenduidig thuis van andere plaatsen van overlijden te onderscheiden. Er werden zes landen behouden in de dataset: België (Vlaanderen en Brussel), Nederland, Italië (de regio's Toscane en Emilia Romagna en de stad Milaan), Noorwegen, Wales en Engeland. Standaard beschrijvende statistieken werden gebruikt om de proportie thuissterfte te beschrijven. Chi-kwadraat statistieken en multivariate binomiale logistische regressies werden gebruikt om na te gaan welke factoren de kans op thuisoverlijden beïnvloeden voor kinderen die overlijden aan een complexe chronische aandoening.

Om de tweede onderzoeksvraag te beantwoorden, werd gebruik gemaakt van de gegevens van een studie uit 2000-2001 bij 1.769 Vlaamse jongeren uit het tweede en vierde leerjaar van het secundair onderwijs uit 20 scholen. Hypothetische gevalsbeschrijvingen werden voorgelegd aan deze jongeren. Alle gevallen beschreven een situatie waar een 14-jarige leed aan een terminale of aan een niet-terminale ziekte. Aan de deelnemers werd gevraagd of de patiënt de arts mocht verzoeken om verschillende levenseindebeslissingen. Daarnaast werden de deelnemers bevraagd naar hun mening over het recht van minderjarigen om geïnformeerd te worden over een terminale prognose, en of zij zelf zouden willen geïnformeerd worden wanneer ze zich in een gelijkaardige situatie zouden bevinden. Beschrijvende statistieken werden gebruikt om de attitudes van de deelnemers te beschrijven, en Chi-kwadraat statistieken om te testen of attitudes en patiëntkenmerken gerelateerd zijn.

Een gelijkaardige methode werd gehanteerd om de derde onderzoeksvraag te beantwoorden. Er werden gegevens gebruikt van een interviewstudie uit 2004 bij 83

jongeren die minstens twee jaar voor aanvang van de studie behandeld werden voor kanker. Tijdens de interviews werden gelijkaardige gevalsbeschrijvingen voorgelegd aan de deelnemers, waarbij gelijkaardige vragen gesteld werden. Naast het beschrijven van de attitudes van deze jongeren, werden Chi-kwadraat toetsen gebruikt om na te gaan of de attitudes van deze jongeren verschilden van de jongeren uit de eerste studie.

De overige onderzoeksvragen werden beantwoord aan de hand van een bevraging van alle artsen die gedurende een periode van 18 maanden overheen 2007 en 2008 het overlijden van een minderjarige hadden vastgesteld die in Vlaanderen overleed op een leeftijd van 1 tot en met 17 jaar. Naar de artsen die een dergelijk overlijden vaststelden werd een anonieme vragenlijst gestuurd, die handelde over levenseindebeslissingen, waaronder continue diepe sedatie, en het beslissingsproces voorafgaand aan de beslissing. Daarnaast werden de artsen aan de hand van 13 stellingen bevraagd over hun attitudes ten opzichte van euthanasie en levensbeëindiging bij minderjarigen. Om de anonimiteit van de artsen strikt te garanderen, werd een complexe verzendingsprocedure opgezet, met een advocaat als tussenpersoon tussen het Vlaamse Ministerie van Gezondheid die de vragenlijsten verstuurde en de onderzoekers, die de vragenlijsten pas ontvingen nadat ze volledig anoniem gemaakt waren door de advocaat. Om de respons te verhogen, werd de Total Design Method gebruikt, met een maximum van drie herinneringsbrieven voor artsen die niet antwoordden. Standaard beschrijvende statistieken werden gebruikt om de incidentie, kenmerken en het beslissingsproces bij levenseindebeslissingen te beschrijven. De attitudes van de artsen werden beschreven en daarnaast geclusterd in een K-means cluster analyse. Het behoren tot een bepaalde attitude-cluster werd gebruikt om na te gaan of attitudes en feitelijke handelwijzen gerelateerd waren aan elkaar.

## **9.3. Resultaten**

### **9.3.1. Plaats van overlijden**

In onze studie van 3.328 overlijdenscertificaten van kinderen die overleden tussen een en 17 jaar in zes Europese landen (België, Nederland, Italië, Noorwegen, Wales en Engeland) overleden er 1.037 (31.2%) ten gevolge van een complexe chronische aandoening (Hoofdstuk 2). De proportie thuissterfte verschilde tussen landen, en varieerde tussen 19.6% in Italië en 28.6% in Nederland. Kinderen die overleden ten gevolge van een complexe chronische aandoening hadden in alle bestudeerde landen een grotere kans om thuis te sterven dan kinderen die ten gevolge van andere oorzaken overleden. Ook hier verschilde de proportie thuissterfte tussen landen, en varieerde tussen 21.7% in Italië en 50.0% in Nederland. Subanalyses voor de groep van kinderen die ten gevolge van een complexe chronische aandoening overleden toonden aan dat thuissterfte waarschijnlijker was voor kinderen die aan kanker overleden en voor kinderen die stierven toen ze 11 jaar of ouder waren. De verschillen in proporties

thuissterfte tussen landen waren significant, en bleven significant nadat gecontroleerd werd voor mogelijk gerelateerde klinische en socio-demografische factoren. In vergelijking met Italië, stierven kinderen die aan een complexe chronische aandoening overleden in België en Nederland significant vaker thuis.

### **9.3.2. Attitudes van Vlaamse jongeren en artsen ten opzichte van beslissingen aan het levenseinde**

De studie over attitudes ten opzichte van beslissingen aan het levenseinde van 1.769 Vlaamse jongeren (Hoofdstuk 3) toonde aan dat 61% van hen een verzoek voor euthanasie aanvaardbaar zou vinden, 60% een verzoek voor opgedreven pijn- en symptoombestrijding en 69% een verzoek voor een niet-behandelbeslissing, wanneer een terminaal zieke 14-jarige patiënt erom zou verzoeken. Dit was significant hoger dan de 18% aanvaarding voor euthanasie en 50% aanvaarding van opgedreven pijn- en symptoombestrijding wanneer een niet-terminaal zieke minderjarige erom zou verzoeken. De mate van aanvaarding van verzoeken om levenseindebeslissing varieerde significant tussen de deelnemers: jongens, deelnemers ouder dan 14 jaar en deelnemers uit het algemeen secundair onderwijs, waren meer aanvaardend dan meisjes, deelnemers van 14 jaar of jonger en deelnemers uit technisch en beroeps secundair onderwijs. De deelnemers haalden verschillende omstandigheden aan die een arts ervan zouden moeten weerhouden om een dodelijk middel toe te dienen. De vaakst aangehaalde redenen waren dat het kind het niet wil (76%), dat het kind slecht geïnformeerd is over zijn/haar toestand (68%) en dat de mening van de ouders niet gevraagd werd (66%). Voor 40% van de deelnemers was het ontbreken van instemming van de ouders met de doodswens van hun kind een omstandigheid die een arts ervan zou moeten weerhouden een dodelijk middel toe te dienen. Negentig percent van de deelnemers vond dat een minderjarige het recht heeft om geïnformeerd te worden over de terminale prognose van een ziekte, terwijl 78% zelf wou willen ingelicht worden. Ook hier varieerden de attitudes naargelang de deelnemerskenmerken. Vrouwelijke deelnemers en deelnemers ouder dan 14 jaar vonden vaker dat minderjarigen het recht hebben om geïnformeerd te worden, en zij wilden ook vaker zelf geïnformeerd worden over een terminale prognose. Jongeren uit het algemeen en uit het technisch secundair onderwijs waren meer geneigd om te vinden dat jongeren het recht hebben om geïnformeerd te worden dan jongeren uit het beroeps secundair onderwijs.

In een tweede studie bij jongeren (Hoofdstuk 4) probeerden we na te gaan of ervaring met chronische ziekte een verschil maakt voor levenseinde-attitudes. Hiertoe werden 83 jongeren die minstens twee jaar voor de studie in behandeling waren geweest voor kanker geïnterviewd met vragen die vergelijkbaar waren aan de eerste studie. De responsgraad was 42%. Wanneer de casus handelde over een terminaal zieke patiënt vond 90.4% van de deelnemers een verzoek voor een niet-behandelbeslissing aanvaardbaar, en 84.3% een verzoek voor opgedreven pijn- en symptoombestrijding,

wat significant hoger was dan bij de jongeren uit de eerste studie. Bijna 64% van de geïnterviewde jongeren vond een verzoek om euthanasie van een terminaal zieke minderjarige aanvaardbaar, wat niet significant verschilde van de eerste studie. De aanvaarding van verzoeken om levenseindebeslissingen door niet-terminaal zieke jongeren verschilde niet significant tussen de twee studies, en was bij de geïnterviewde jongeren 27.7% voor een verzoek om een niet-behandelbeslissing, 38.6% tot 47.0% voor verzoeken om opgedreven pijn- en symptoombestrijding en 10.8% tot 20.5% voor een verzoek om euthanasie. Een ruime meerderheid van 92% van de geïnterviewden vond dat een arts geen dodelijk middel mag toedienen aan een kind dat niet goed geïnformeerd is over zijn/haar aandoening, wanneer het kind wil sterven omwille van de last die hij/zij vormt voor de ouders en wanneer de mening van de ouders niet gevraagd werd. Minder deelnemers vonden dat de ouders ook akkoord moeten gaan met de doodswens van hun kind. Bijna alle deelnemers waren het ermee eens dat een minderjarige het recht zou moeten hebben om geïnformeerd te worden over een terminale prognose. Zesentachtig percent gaf aan dat ze zelf zouden geïnformeerd willen worden wanneer ze met een gelijkaardige situatie geconfronteerd zouden worden.

In onze studie van attitudes van artsen ten opzichten van levensbeëindiging bij minderjarigen (Hoofdstuk 5) werd een responsgraad van 70.5% bereikt. De attitude-items van de vragenlijst werden ingevuld door 124 artsen. Negenenzestig percent van de artsen was het ermee eens dat de Belgische wet betreffende euthanasie zou moeten uitgebreid worden zodat ze ook betrekking heeft op minderjarigen, hoewel slechts 26.6% vond dat dat zou moeten gebeuren door duidelijke leeftijdsgrenzen vast te leggen. De deelnemende artsen schatten de rol van de ouders duidelijk naar waarde: 60.5% vond dat instemming van de ouders noodzakelijk is wanneer er beslissingen rond levensbeëindiging genomen worden en 52.4% vond dat het toedienen van een dodelijk middel aanvaardbaar kan zijn wanneer de ouders van een niet-competente minderjarige erom verzoeken. Slechts 21.8% van de artsen vond dat minderjarigen nog niet in staat zijn tot het een redelijke beoordeling van hun belangen wanneer het gaat om beslissingen rond leven en dood. Drieënzeventig percent van de artsen erkende dat het ondergaan van een chronische aandoening jongere minderjarigen beter in staat kunnen zijn om hun belangen redelijk te beoordelen dan hun gezonde leeftijdsgenoten. Tweeëntachtig percent vond dat met de wensen van oudere minderjarigen evenveel rekening moet gehouden worden als met die van volwassenen. De meningen waren verdeeld wanneer het over alternatieven voor levensbeëindiging ging: terwijl 47% het ermee eens was, bleef 29% van de artsen neutraal op de stelling dat palliatieve sedatie altijd verkozen moet worden boven de toediening van een lethaal middel bij kinderen. Ongeveer evenveel artsen waren het eens als oneens met de stelling dat goede pijncontrole en levenseindezorg euthanasie overbodig maken bij minderjarigen. Op basis van hun profiel van antwoorden, konden de artsen onderverdeeld worden in twee attitude-clusters. Twee derde van de artsen behoorde tot de "permissieve" cluster: zij waren meer geneigd om minderjarigen te beschouwen als competente beslissers aan hun levende en beschouwen euthanasie en levensbeëindiging als aanvaardbare opties aan het levende, onder bepaalde voorwaarden. Artsen uit deze cluster vonden

dat de Belgische euthanasiewet moet uitgebreid worden. Het overblijvende derde van artsen behoorde tot de “terughoudende” cluster: zij zijn eerder tegen euthanasie en levensbeëindiging bij minderjarigen, zelfs wanneer een competente minderjarige en/of de ouders erom zouden verzoeken. Zij zijn eerder geneigd om palliatieve sedatie te verkiezen boven de toediening van een lethaal middel, en zijn ervan overtuigd dat adequate pijncontrole en levenseindezorg euthanasie overbodig maken. Artsen uit deze cluster willen niet dat de Belgische euthanasiewet wordt uitgebreid. Het behoren tot de eerste of tweede cluster bleek significant gerelateerd aan de feitelijke praktijken van de bevraagde artsen. Artsen die tot de permissieve cluster behoorden namen vaker beslissingen om pijn- en symptoombestrijding op te drijven met een co-intentie om het leven van de patiënt te verkorten, alsook levensbeëindiging en continue diepe sedatie met een (co-)intentie om het leven van de patiënt te verkorten.

### **9.3.3. Incidentie en kenmerken van beslissingen aan het levenseinde en sedatie bij minderjarigen in Vlaanderen, België**

In onze sterfgevallenstudie (Hoofdstuk 6) werd een responsgraad van 70.5% bereikt. Er werd gedetailleerde informatie verzameld voor 165 sterfgevallen van minderjarigen die overleden tussen de leeftijd van 1 en 17 jaar. Drieënvijftig percent van de patiënten overleed plots en geheel onverwacht. Het overlijden werd voorafgegaan door een levenseindebeslissing in 36.4% van alle sterfgevallen, waarvan 10.3% een niet-behandelbeslissing was, 18.2% opgedreven pijn- en symptoombestrijding en 7.9% levensbeëindiging. Alle gevallen van levensbeëindiging gebeurden zonder dat de minderjarige patiënt er zelf om verzocht, maar in drie vierde van deze gevallen was er een verzoek van de ouders. De vaakst aangehaalde redenen om een levenseindebeslissing te nemen waren: er kon geen verbetering meer verwacht worden (84.6%), lage verwachte levenskwaliteit (61.5%) en het niet onnodig verlengen van het leven (50.0%). De helft van de patiënten waar een levenseindebeslissing werd genomen waren meer dan een jaar behandeld voor de ziekte die tot hun overlijden had geleid. Levenseindebeslissingen werden in het algemeen besproken met de ouders (85.2%), waarbij de bespreking er doorgaans op gericht was om samen tot een beslissing te komen. In slechts 15.4% van de gevallen werd de beslissing besproken met de minderjarige patiënt, voornamelijk omdat deze comateus, te jong of mentaal gehandicapt was. In onze studie werd er slechts één patiënt competent gevonden door de arts.

In 21.8% van de gevallen werd de patiënt continu en diep gesedeerd tot aan het overlijden (Hoofdstuk 7). In een meerderheid van deze gevallen werden benzodiazepines gebruikt om de patiënt te sederen, hoewel in een kwart van de gevallen enkel morfine gebruikt werd. Patiënten werden doorgaans maar gedurende 48u of minder gesedeerd, en slechts in 3.4% van de gevallen langer dan twee weken. In een meerderheid van de gevallen werden vocht en voeding kunstmatig toegediend tot aan het overlijden. In bijna een kwart van de gevallen gaf de arts aan de intentie of co-

intentie te hebben gehad om het leven van de patiënt te verkorten. In 90.9% van de gevallen was er geen verzoek voor of instemming met sedatie vanwege de patiënt. De ouders werden echter wel betrokken in het beslissingsproces in de meeste, maar niet alle, gevallen.

## **9.4. Bespreking van de resultaten en implicaties**

In Hoofdstuk 8 worden de belangrijkste resultaten besproken en wordt ingegaan op de implicaties van de bevindingen voor de praktijk en verder onderzoek. Hieronder worden de belangrijkste elementen van deze bespreking kort samengevat.

### **9.4.1. Plaats van overlijden van kinderen**

Uit onze studie bleek dat slechts een minderheid van 20 à 30% van alle kinderen thuis overlijdt in de zes onderzochte Europese landen. Kinderen die overleden ten gevolge van een complexe chronische ziekte stierven weliswaar vaker thuis, maar ook hier is er nog veel ruimte voor het verhogen van de proportie thuissterfte bij kinderen. De verschillen in thuissterfte tussen landen waren significant. Culturele en zorgorganisatorische factoren kunnen aan de basis liggen van deze verschillen.

Uit de resultaten komt verder naar voor dat kankerpatiënten doorgaans hogere kansen hebben om thuis te sterven dan kinderen die aan een andere chronische ziekte sterven. Deze bevinding is waarschijnlijk deels gerelateerd aan het beter voorspelbare ziekteverloop van kanker (waardoor planning van levenseindezorg beter mogelijk is), maar deels ook aan de expertise met levenseindezorg bij zorgverleners in kinder-oncologische settings. Wanneer men de proportie thuissterfte bij kinderen in de toekomst verder wil verbeteren, zullen zorgverleners uit kinder-oncologische settings een belangrijke rol te spelen hebben. De bestaande pediatrie palliatieve thuiszorginitiatieven in Vlaanderen zijn reeds opgebouwd vanuit deze settings. Het verder structureel ondersteunen van deze initiatieven zal nodig zijn om palliatieve thuiszorg en thuisoverlijden mogelijk te maken, ook voor kinderen die aan andere aandoeningen dan kanker overlijden. Verder onderzoek is nodig om de evolutie van de proportie thuisoverlijden bij kinderen in Europa op te volgen, alsook om na te gaan in welke mate kwaliteitsvolle levenseindezorg kan gerealiseerd worden in de thuisomgeving van stervende kinderen.

### 9.4.2. Attitudes ten opzichte van beslissingen aan het levenseinde bij kinderen

Uit onze studies van attitudes bij jongeren bleek dat jongeren over het algemeen genuanceerd denken over levenseindebeslissingen. Zij maken onderscheid naargelang het een terminale situatie betreft en naargelang het type levenseindebeslissing, op een gelijkaardige manier als volwassenen dat doen, wat lijkt te wijzen op een “uitkomstationaliteit” in de manier hoe jongeren nadenken over levenseindebeslissingen. Ervaring met chronische ziekte had weliswaar enig effect op de attitudes, maar het algemene resultatenpatroon van de jongeren uit beide studies was vergelijkbaar. De deelnemende jongeren zouden over het algemeen geïnformeerd willen worden over een terminale prognose. Zij zien echter ook een belangrijke rol voor de ouders in het beslissingsproces bij levenseindebeslissingen. Hoewel de rol van de ouders erg gewaardeerd wordt door de jongeren, willen zij de uiteindelijke beslissingsbevoegdheid zelf dragen. Deze bevindingen schetsen een beeld van jongeren die gesteld zijn op hun autonomie wanneer het over levenseindebeslissingen gaat, maar passend in een beslissingsmodel van “shared decision-making”.

De studie over attitudes van artsen toonde aan dat een meerderheid van Vlaamse artsen die betrokken waren bij levenseindezorg van minderjarigen, voorstander is van een uitbreiding van de huidige Belgische euthanasiewet zodat ze ook betrekking heeft op minderjarigen. Bovendien vonden de deelnemende artsen dat een wetsuitbreiding best niet kan gebeuren door strikte leeftijdsgrenzen vast te leggen, eerder waren zij voorstander van een aanpak gericht op competentie van de patiënt. Dit was een belangrijke bevinding, die de actuele debatten rond een eventuele wetsuitbreiding empirisch kan onderbouwen. Uit de antwoorden van de artsen bleek eveneens dat zij, net zoals jongeren dat doen, de rol van ouders bij het nemen van levenseindebeslissingen naar waarde schatten.

Opvallend was verder dat de attitudes van artsen gerelateerd waren aan hun beslissingen in de praktijk. Dit gegeven kan belangrijke implicaties hebben voor de betrokken ouders en patiënten, aangezien beslissingen niet enkel gestuurd worden door de klinische situatie en de evolutie van de aandoening van de patiënt, maar ook door de houding van de arts. Ten einde conflicten tussen de betrokken partijen te vermijden aan het levenseinde, kan het aangewezen zijn voor artsen om met patiënt en ouders te communiceren over deze attitudes. Op die manier krijgen ouders en patiënt de kans om een realistisch verwachtingspatroon op te bouwen over welke beslissingen al dan niet overwogen kunnen worden.

### 9.4.3. Beslissingen aan het levenseinde en beslissingsproces

Medische beslissingen met een mogelijk levensverkortend effect worden frequent genomen bij kinderen tussen 1 en 17 jaar in Vlaanderen. De incidentie van 36% kwam overeen met de incidentie die eerder in Nederland gevonden werd, maar



levensbeëindiging was frequenter in Vlaanderen (7.9%) dan in Nederland (2.7%). Opvallend was dat euthanasie, i.e. levenbeëindiging op expliciet verzoek van de patiënt, niet voorkwam in Vlaanderen. In drie vierde van deze gevallen was er wel een verzoek van de ouders. Deze bevinding is belangrijk in de context van de debatten rond uitbreiding van de Belgische euthanasiewet. Het is moeilijk om te zien hoe een aangepaste euthanasiewet de artsen meer juridische zekerheid zou kunnen geven, wanneer zij levensbeëindigend handelen zonder een verzoek van de patiënt. Het verzoek van de patiënt is immers één van de fundamentele voorwaarden van de euthanasiewet, en laat toe om de autonomie van de patiënt te verhogen aan het levenseinde. Het reguleren van de bestaande praktijk zal dan ook niet de voornaamste beweegredenen kunnen zijn van voorstellen tot wetsuitbreiding. Het opheffen van een bestaande leeftijdsdiscriminatie kan dan wel zijn.

Ouders werden meestal betrokken in het beslissingsproces voorafgaand aan levenseindebeslissingen. De minderjarigen zelf werden daarentegen eerder zelden betrokken. Dit lijkt in te gaan tegen bestaande richtlijnen van diverse verenigingen, alsook van de Belgische wet betreffende de patiëntenrechten, die aanbevelen dat minderjarigen in functie van hun leeftijd en maturiteit dienen betrokken te worden bij beslissingen aan het levenseinde. Uit onze studie bleek dat slechts één minderjarige patiënt competent werd bevonden door de arts, en dat de jonge leeftijd en een comateuze toestand van de patiënt vaak aangehaalde redenen waren om beslissingen niet te bespreken met de minderjarige patiënt. Deze redenen kunnen soms valide redenen zijn om minderjarigen niet te betrekken, toch blijft de mogelijkheid bestaan dat enige bespreking mogelijk was indien ze aangepast werd aan het ontwikkelingsniveau van de patiënt (bij jonge kinderen), of in een vroeg stadium van het ziekteproces werd aangevat (bij comateuze patiënten). Onze studie was echter te beperkt om ondubbelzinnig na te gaan of de betrokkenheid van minderjarigen in realiteit onvoldoende was. Het verder uitklaren van de betrokkenheid van minderjarigen, en de rol die competentie en competentiebeoordeling hierin speelt, is dan ook een van de meest noodzakelijke aanbevelingen voor vervolgonderzoek die op basis van onze bevindingen naar voor geschoven kunnen worden. Verder onderzoek kan ook nagaan of artsen die werken met terminaal zieke kinderen zich voldoende opgeleid en ervaren voelen om te communiceren met kinderen, op een aangepast ontwikkelingsniveau, en of verdere verbeteringen aan de opleiding van pediaters de huidige praktijk zou kunnen verbeteren.

#### **9.4.4. Continue diepe sedatie**

Continue diepe sedatie, een praktijk die recent meer en meer aandacht krijgt, bleek eveneens vaak voor te komen bij kinderen in Vlaanderen. Dit is, voor zover wij weten, de allereerste studie die deze praktijk systematisch onderzocht heeft bij minderjarigen. Verschillende types van sedatie leken voor te komen in onze studie. Een eerste type is “terminale” of “palliatieve” sedatie, die gebruikt wordt als een laatste redmiddel voor

onbehandelbare symptomen. Een tweede type van sedatie wordt gebruikt wanneer de behandeling van de patiënt nog gericht is op genezing. Sedatie kan dan soms gebruikt worden om bepaalde ondersteunende ingrepen, zoals beademing, mogelijk te maken. Een derde vorm van sedatie is een onbedoeld gevolg van een geleidelijke toename van de pijn- en symptoombestrijding. Ten vierde kan sedatie soms ook worden gebruikt als een verdoken vorm van opzettelijke levensbeëindiging. Terugkoppeland naar bestaande richtlijnen voor volwassenen, zagen we dat sedatie meestal in overeenstemming met deze richtlijnen gebeurde: artsen gaven aan dat er geen andere alternatieven waren om de symptomen te bestrijden en patiënten werden zelden langer dan twee weken geseedeerd. Anderzijds werden niet in alle gevallen de aanbevolen middelen gebruikt en gaven artsen in een vierde van de gevallen aan dat ze een intentie hadden om het levenseinde te bespoedigen. De gegevens laten dus niet toe om uit te sluiten dat sedatie bij kinderen soms aangewend wordt als een verdoken vorm van levensbeëindiging. De betrokkenheid van ouders en minderjarigen bij het beslissingsproces volgde hetzelfde patroon als bij de andere levenseindebeslissingen: ouders werden meestal betrokken, maar de minderjarige patiënten veel minder. Het patroon van resultaten leidt ons ertoe te suggereren dat specifieke richtlijnen over sedatie bij kinderen nuttig kunnen zijn om de praktijk in de toekomst te verbeteren. Meer onderzoek is echter nodig om na te gaan op welke punten eventuele richtlijnen zouden moeten verschillen van de bestaande richtlijnen, alsook om uit te klaren hoe vaak sedatie in de praktijk wordt aangewend als een palliatieve optie, dan wel als een ondersteuning om bepaalde curatieve en supportieve ingrepen te faciliteren.

## Appendices

### Appendix 1 - Questionnaire "Attitudes of secondary school students" (Chapter 3)

#### Vragenlijst attitude-onderzoek Vlaamse minderjarige scholieren 2000-2001

<b>Q1</b>	Doe je even mee? Druk met je vinger op start.	
<b>Q2</b>	Femke is een veertienjarig meisje met botkanker. Ze heeft veel pijn. Ook de behandelingen die ze ondergaat zijn erg pijnlijk. Iedereen, ook zijzelf, weet dat ze in het beste geval nog maar een paar jaar te leven heeft. Femke kan de pijn niet meer verdragen en wil graag doodgaan. Vind jij dat ze aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor haar leven beëindigd wordt?	ja
		neen
		ik weet het niet
<b>Q3</b>	Vind jij dat ze mag vragen om de behandelingen stop te zetten? Haar leven wordt daardoor wel verkort.	ja
		neen
		ik weet het niet
<b>Q4</b>	Vind jij dat ze mag vragen om de pijnmedicatie te verhogen? Daardoor wordt haar leven misschien verkort.	ja
		neen
		ik weet het niet
<b>Q5</b>	Pieter is veertien jaar en heeft kanker. Door zijn ziekte is hij afhankelijk geworden van andere mensen. Hij moet zich aan iedereen letterlijk en figuurlijk blootgeven. Pieter kan bijvoorbeeld niet meer alleen naar het toilet gaan. Dat is dan een heel gedoe met vuilniszakken onder bed leggen, handschoenen omdoen, ... Pieter beseft dat hij niet lang meer zal leven en hij verdraagt niet langer dat hem al zijn eer wordt ontnomen. Hij wil graag sterven. Vind jij dat hij aan de dokter mag vragen om zijn levenseinde te versnellen?	ja
		neen
		ik weet het niet
<b>Q6</b>	Thomas is veertien jaar en heeft een spierziekte, waardoor hij langzaam aan het aftakelen is. Thomas vreest dat hij als een plant zal eindigen. Hij kan gerust nog meer dan tien jaar leven, maar toch wil hij niet meer verder leven. Vind jij dat hij aan de dokter mag vragen om zijn levenseinde te versnellen?	ja
		neen
		ik weet het niet
<b>Q7</b>	Nathalie, veertien jaar, is ernstig verbrand over heel haar lichaam en gezicht. Ze heeft veel pijn en door de vele brandwonden kan ze zich niet meer goed bewegen. Nathalie wil zo niet verder leven, hoewel ze een normale levensverwachting heeft. Vind jij dat ze aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor haar leven beëindigd wordt?	ja
		neen
		ik weet het niet
<b>Q8</b>	Vind jij dat ze mag vragen op de pijnmedicatie te verhogen? Daardoor wordt haar leven misschien verkort.	ja
		neen
		ik weet het niet

<b>Q9</b>	Kevin, veertien jaar, heeft een ernstig accident gehad met de fiets. Hij is daardoor beide benen verloren. Bovendien moet hij ook nog zware en pijnlijke operaties ondergaan om in leven te blijven. Kevin wil niet blijven leven zonder benen. Vind jij dat hij aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor zijn leven beëindigd wordt?	ja
		neen
		ik weet het niet
<b>Q10</b>	Mag hij weigeren de operaties te ondergaan?	ja
		neen
		ik weet het niet
<b>Q11</b>	Katrien is veertien jaar en heeft een ziekte waardoor ze niet lang meer zal leven. Iedereen in haar omgeving weet dat ze binnenkort zal sterven. Katrien heeft reeds herhaaldelijk gevraagd of ze zal dood gaan, maar niemand wil het haar vertellen. Vind jij dat Katrien mag weten dat ze zal doodgaan?	ja
		neen
		ik weet het niet
<b>Q12</b>	Zou jij het willen weten?	ja
		neen
		ik weet het niet
<b>Q13</b>	Vanaf welke leeftijd mag de dokter het kind een spuitje met een dodelijk middel geven, in de veronderstelling dat het kind het zelf wil.	0 tot 8 jaar
		9 tot 12 jaar
		13 tot 15 jaar
		16 tot 17 jaar
		ouder dan 17 jaar
		eender welke leeftijd
		nooit
ik weet het niet		
<b>Q14</b>	Wanneer mag volgens jou de dokter GEEN spuitje met een dodelijk middel geven?	het kind is stervende, maar wil geen spuitje met een dodelijk middel
		het kind is niet goed ingelicht over zijn toestand
		het kind wil niet blijven leven als het door zijn ziekte zijn ouders tot last is
		de ouders zijn het niet eens met de doodswens van het kind
		de dokter heeft de mening van de ouders niet gevraagd
		het kind wil alleen maar dood omdat het door zijn ziekte verdrietig is
<b>Q15</b>	Je bent...	een jongen
		een meisje
<b>Q16</b>	Je bent...	jonger dan 12 jaar
		12 jaar
		13 jaar
		14 jaar
		15 jaar
		16 jaar
		17 jaar
ouder dan 17 jaar		

## Appendix 2 - Questionnaire "Attitudes of cancer survivors" (Chapter 4)

Mijn geboortedatum is	.....
Ik ben	1 Een jongen 2 Een meisje
Ik ga naar school	1 In het Algemeen Secundair Onderwijs 2 In het Buitengewoon Secundair Onderwijs
Toen de diagnose van kanker gesteld werd, was ik	..... jaar oud
De precieze diagnose die gesteld werd, was	.....
Femke is een veertienjarig meisje met botkanker. Ze heeft veel pijn. Ook de behandelingen die ze ondergaat zijn erg pijnlijk. Iedereen, ook zijzelf, weet dat ze in het beste geval nog maar een paar jaar te leven heeft. Femke kan de pijn niet meer verdragen en wil graag doodgaan. Vind jij dat ze aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor haar leven beëindigd wordt?	1 Ja 2 Neen 3 Ik weet het niet
Vind jij dat ze mag vragen om de behandelingen stop te zetten? Haar leven wordt daardoor wel verkort.	1 Ja 2 Neen 3 Ik weet het niet
Vind jij dat ze mag vragen om de pijnmedicatie te verhogen? Daardoor wordt haar leven misschien verkort.	1 Ja 2 Neen 3 Ik weet het niet
Pieter is veertien jaar en heeft kanker. Door zijn ziekte is hij afhankelijk geworden van andere mensen. Hij moet zich aan iedereen letterlijk en figuurlijk blootgeven. Pieter kan bijvoorbeeld niet meer alleen naar het toilet gaan. Dat is dan een heel gedoe met vuilniszakken onder bed leggen, handschoenen omdoen, ... Pieter beseft dat hij niet lang meer zal leven en hij verdraagt niet langer dat hem al zijn eer wordt ontnomen. Hij wil graag sterven.  Vind jij dat hij aan de dokter mag vragen om zijn levenseinde te versnellen?	1 Ja 2 Neen 3 Ik weet het niet
Thomas is veertien jaar en heeft een spierziekte, waardoor hij langzaam aan het aftakelen is. Thomas vreest dat hij als een plant zal eindigen. Hij kan gerust nog meer dan tien jaar leven, maar toch wil hij niet meer verder leven. Q: Vind jij dat hij aan de dokter mag vragen om zijn levenseinde te versnellen?	1 Ja 2 Neen 3 Ik weet het niet
Nathalie, veertien jaar, is ernstig verbrand over heel haar lichaam en gezicht. Ze heeft veel pijn en door de vele brandwonden kan ze zich niet meer goed bewegen. Nathalie wil zo niet verder leven, hoewel ze een normale levensverwachting heeft. Q: Vind jij dat ze aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor haar leven beëindigd wordt?	1 Ja 2 Neen 3 Ik weet het niet

Vind jij dat ze mag vragen op de pijnmedicatie te verhogen? Daardoor wordt haar leven misschien verkort.	1 Ja 2 Neen 3 Ik weet het niet
Kevin, veertien jaar, heeft een ernstig accident gehad met de fiets. Hij is daardoor beide benen verloren. Bovendien moet hij ook nog zware en pijnlijke operaties ondergaan om in leven te blijven. Kevin wil niet blijven leven zonder benen. Q: Vind jij dat hij aan de dokter een spuitje met een dodelijk middel mag vragen, waardoor zijn leven beëindigd wordt?	1 Ja 2 Neen 3 Ik weet het niet
Mag hij weigeren de operaties te ondergaan?	1 Ja 2 Neen 3 Ik weet het niet
Katrien is veertien jaar en heeft een ziekte waardoor ze niet lang meer zal leven. Iedereen in haar omgeving weet dat ze binnenkort zal sterven. Katrien heeft reeds herhaaldelijk gevraagd of ze zal dood gaan, maar niemand wil het haar vertellen. Vind jij dat Katrien mag weten dat ze zal doodgaan?	1 Ja 2 Neen 3 Ik weet het niet
Zou jij het willen weten?	1 Ja 2 Neen 3 Ik weet het niet
Vanaf welke leeftijd mag de dokter het kind een spuitje met een dodelijk middel geven, in de veronderstelling dat het kind het zelf wil.	1 Vanaf ..... jaar 2 Eender welke leeftijd 3 nooit 4 Ik weet het niet
Evelien is stervende, maar wil geen spuitje met een dodelijk middel. Vind jij dat de dokter een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet
Mieke is niet goed ingelicht over haar toestand. Vind jij dat de dokter een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet
Johan wil niet blijven leven als hij door zijn ziekte zijn ouders tot last is. Vind jij dat de dokter een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet
De ouders zijn het niet eens met de doodswens van het kind. Vind jij dat de dokter een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet
De dokter heeft de mening van de ouders niet gevraagd. Vind jij dat hij een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet
Sander wil dood omdat hij door zijn ziekte verdrietig is. Vind jij dat de dokter een spuitje met een dodelijk middel mag geven?	1 Ja 2 Neen 3 Ik weet het niet

## Appendix 3: Questionnaire “End-of-life decisions in children” (Chapter 5-7)

Algemeen	
1 U was met betrekking tot dit sterfgeval werkzaam als...	<input type="checkbox"/> specialist (of specialist in opleiding) <input type="checkbox"/> welk specialisme? <input type="text"/> <input type="checkbox"/> huisarts (of huisarts in opleiding) <input type="checkbox"/> andere <input type="text"/>
2 Van wanneer dateerde uw eerste contact met de patiënt?	<input type="checkbox"/> vóór of tijdens het overlijden <input type="checkbox"/> na het overlijden → <b>door naar vraag 33</b>
3 Ging het om een <u>plotseling en geheel onverwacht</u> overlijden?	<input type="checkbox"/> ja → <b>door naar vraag 30</b> <input type="checkbox"/> neen
4 Probeer de gezinssituatie van de patiënt te omschrijven.	<input type="checkbox"/> samenwonende ouders/vertegenwoordigers <input type="checkbox"/> alleenstaande ouder/vertegenwoordiger <input type="checkbox"/> andere <input type="text"/>
Medische handelwijzen	
5 Heeft u of een andere arts één of meer van de volgende handelwijzen uitgevoerd of doen uitvoeren, <u>rekening houdend</u> met de mogelijkheid dat deze handelwijze het levenseinde van de patiënt zou bespoedigen? – <i>zowel a, b als c beantwoorden</i> –	
a. Het niet instellen van een behandeling*?  Zo ja, welke behandeling(en) betrof dit?	<input type="checkbox"/> ja <input type="checkbox"/> neen <input type="text"/> <input type="text"/>
b. Het staken van een behandeling*?  Zo ja, welke behandeling(en) betrof dit?	<input type="checkbox"/> ja <input type="checkbox"/> neen <input type="text"/> <input type="text"/>
c. Het intensiveren van pijn- en/of symptoombestrijding d.m.v. één of meer middelen?  Zo ja, welk(e) middel(en) werd(en) gebruikt? - <i>meerdere antwoorden mogelijk</i> -	<input type="checkbox"/> ja <input type="checkbox"/> neen → <b>door naar vraag 7</b> <input type="checkbox"/> morfine of ander opiaat <input type="checkbox"/> benzodiazepine <input type="checkbox"/> ander middel <input type="text"/>
* onder 'behandeling' wordt ook de kunstmatige toediening van vocht en/of voeding verstaan.	
6 Was het bespoedigen van het levenseinde <u>mede het doel</u> van het intensiveren van pijn- en/of symptoombestrijding?	<input type="checkbox"/> ja <input type="checkbox"/> neen
7 Was het overlijden het gevolg van één of meer van de volgende handelwijzen, waartoe door u of een andere arts is besloten <u>met het uitdrukkelijke doel</u> het levenseinde van de patiënt te bespoedigen? – <i>zowel a als b beantwoorden</i> –	
a. Het niet instellen van een behandeling*?  Zo ja, welke behandeling(en) betrof dit?	<input type="checkbox"/> ja <input type="checkbox"/> neen <input type="text"/> <input type="text"/>
b. Het staken van een behandeling*?  Zo ja, welke behandeling(en) betrof dit?	<input type="checkbox"/> ja <input type="checkbox"/> neen <input type="text"/> <input type="text"/>
* onder 'behandeling' wordt ook de kunstmatige toediening van vocht en/of voeding verstaan.	
8 Was het overlijden het gevolg van het gebruik van een middel dat door u of een andere arts werd voorgeschreven, verstrekt of toegediend <u>met het uitdrukkelijke doel</u> het levenseinde van de patiënt te bespoedigen (of de patiënt in staat te stellen zelf het leven te beëindigen)?	<input type="checkbox"/> ja <input type="checkbox"/> neen

	Naam	Toedieningswijze	Dosis
Zo ja, welk(e) middel(en) betrof dit? – meerdere antwoorden mogelijk –	<input type="checkbox"/> spierslapper (curare of gelijkaardig middel)		
	<input type="checkbox"/> barbituraat		
	<input type="checkbox"/> benzodiazepine		
	<input type="checkbox"/> morfine of ander opiaat		
	<input type="checkbox"/> ander middel		
Zo ja, door wie is (zijn) dit (deze) middel(en) toegediend? – meerdere antwoorden mogelijk –	<input type="checkbox"/> de patiënt zelf		
	<input type="checkbox"/> u of een andere arts		
	<input type="checkbox"/> verpleegkundige		
	<input type="checkbox"/> iemand anders		
Indien het (de) middel(en) niet door een arts werd(en) toegediend, was u of een andere arts aanwezig bij de toediening?	<input type="checkbox"/> ja		
	<input type="checkbox"/> neen		

Indien 'ja' is geantwoord op één van de onderdelen van de vragen 5 tot en met 8 → door naar vraag 9

Indien op geen enkel onderdeel van de vragen 5 tot en met 8 'ja' is geantwoord → door naar vraag 23

### De laatstgenoemde handelwijze

Let op: de vragen 9 tot en met 22 hebben betrekking op de laatstgenoemde handelwijze, dit wil zeggen op het laatst gegeven 'ja'-antwoord bij de vragen 5 tot en met 8

9 Met hoeveel tijd is het leven van de patiënt naar uw schatting verkort door de laatstgenoemde handelwijze?	<input type="checkbox"/> meer dan een half jaar <input type="checkbox"/> één tot zes maanden <input type="checkbox"/> één tot vier weken <input type="checkbox"/> één tot zeven dagen <input type="checkbox"/> minder dan 24 uur <input type="checkbox"/> heeft waarschijnlijk geen verkorting van de levensduur gegeven
10 Heeft u of een andere arts de (mogelijke) bespoediging van het levenseinde besproken met ouder(s)/vertegenwoordiger(s) voordat werd besloten tot de laatstgenoemde handelwijze?  Welk doel had de bespreking? - meerdere antwoorden mogelijk -	<input type="checkbox"/> ja <input type="checkbox"/> patiënt had geen ouder(s)/vertegenwoordiger(s) → <b>door naar vraag 13</b> <input type="checkbox"/> neen → <b>door naar vraag 12</b> <input type="checkbox"/> samen tot een beslissing te komen <input type="checkbox"/> verkrijgen van toestemming <input type="checkbox"/> op de hoogte brengen van de reeds genomen beslissing <input type="checkbox"/> anders
11 Is de beslissing over de laatstgenoemde handelwijze genomen na een uitdrukkelijk verzoek van ouder(s)/vertegenwoordiger(s)?	<input type="checkbox"/> ja → <b>door naar vraag 13</b> <input type="checkbox"/> neen → <b>door naar vraag 13</b>
12 Om welke reden(en) is de (mogelijke) bespoediging van het levenseinde door de laatstgenoemde handelwijze <u>niet</u> met de ouder(s)/vertegenwoordiger(s) besproken? -meerdere antwoorden mogelijk-	<input type="checkbox"/> patiënt had geen ouder(s)/vertegenwoordiger(s) → <b>door naar vraag 13</b> <input type="checkbox"/> emotioneel te belastend voor ouder(s)/vertegenwoordiger(s) <input type="checkbox"/> te weinig tijd <input type="checkbox"/> ouder(s)/vertegenwoordiger(s) was/waren niet bereikbaar <input type="checkbox"/> patiënt wilde niet dat dit met ouder(s)/vertegenwoordiger(s) besproken werd <input type="checkbox"/> de beslissing over (mogelijke) bespoediging van het levenseinde komt toe aan de patiënt, en niet aan de ouders(s)/vertegenwoordiger(s) <input type="checkbox"/> andere reden
13 Heeft u of een andere arts de (mogelijke) bespoediging van het levenseinde door die laatstgenoemde handelwijze besproken met de patiënt?	<input type="checkbox"/> ja <input type="checkbox"/> neen → <b>door naar vraag 17</b>
14 Achtte u de patiënt <u>tijdens deze bespreking</u> in staat zijn of haar situatie te overzien en daarover op adequate wijze een besluit te nemen?	<input type="checkbox"/> ja <input type="checkbox"/> neen



<p><b>15</b> Is de beslissing over de laatstgenoemde handelwijze genomen na een uitdrukkelijk verzoek van de patiënt?</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> ja, na een mondeling verzoek</li> <li><input type="checkbox"/> ja, na een schriftelijk verzoek</li> <li><input type="checkbox"/> ja, na een mondeling én een schriftelijk verzoek</li> <li><input type="checkbox"/> neen → <b>door naar vraag 20</b></li> </ul>
<p><b>16</b> Achtte u de patiënt <u>tijdens dit verzoek</u> in staat zijn of haar situatie te overzien en daarover op adequate wijze een besluit te nemen?</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> ja → <b>door naar vraag 20</b></li> <li><input type="checkbox"/> neen → <b>door naar vraag 20</b></li> </ul>
<p><b>17</b> Achtte u de patiënt in staat zijn of haar situatie te overzien en daarover op adequate wijze een besluit te nemen?</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> ja</li> <li><input type="checkbox"/> neen</li> </ul>
<p><b>18</b> Om welke reden is de (mogelijke) bespoediging van het levenseinde door de laatstgenoemde handelwijze niet met de patiënt besproken? – <i>meerdere antwoorden mogelijk</i> –</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> de patiënt was te jong</li> <li><input type="checkbox"/> de patiënt was niet in staat om de handelwijze adequaat te beoordelen</li> <li><input type="checkbox"/> de patiënt was subcomateus of buiten bewustzijn</li> <li><input type="checkbox"/> de patiënt was verstandelijk gehandicapt</li> <li><input type="checkbox"/> de patiënt had een psychiatrische stoornis</li> <li><input type="checkbox"/> de laatstgenoemde handelwijze was duidelijk het beste voor de patiënt</li> <li><input type="checkbox"/> de bespreking zou de patiënt meer schaden dan goed doen</li> <li><input type="checkbox"/> andere reden</li> </ul>
<p><b>19</b> Had de patiënt, voor zover u bekend, ooit een wens tot bespoediging van het levenseinde kenbaar gemaakt?</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> ja, uitdrukkelijk</li> <li><input type="checkbox"/> ja, maar niet uitdrukkelijk</li> <li><input type="checkbox"/> neen</li> </ul>
<p><b>20</b> Heeft u of een andere arts de (mogelijke) bespoediging van het levenseinde met andere professionele zorgverleners besproken voordat werd besloten tot de laatstgenoemde handelwijze? – <i>meerdere antwoorden mogelijk</i> –</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> ja, met collega-arts(en)</li> <li><input type="checkbox"/> ja, met verpleegkundige(n)</li> <li><input type="checkbox"/> ja, met anderen</li> <li><input type="checkbox"/> neen</li> </ul>
<p><b>21</b> Wat was (waren) de belangrijkste reden(en) om te besluiten tot de laatstgenoemde handelwijze? – <i>meerdere antwoorden mogelijk</i> –</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> de patiënt had (ernstige) pijn</li> <li><input type="checkbox"/> de patiënt had andere (ernstige) symptomen</li> <li><input type="checkbox"/> verzoek of wens van ouder(s)/vertegenwoordiger(s)</li> <li><input type="checkbox"/> verzoek of wens van de patiënt</li> <li><input type="checkbox"/> verwacht (verder) lijden van de patiënt</li> <li><input type="checkbox"/> er was geen uitzicht op verbetering</li> <li><input type="checkbox"/> het leven niet onnodig verlengen</li> <li><input type="checkbox"/> geringe verwachte levenskwaliteit</li> <li><input type="checkbox"/> situatie werd ondraaglijk voor de naasten</li> <li><input type="checkbox"/> verlies van waardigheid</li> <li><input type="checkbox"/> andere reden, desgewenst toelichten bij vraag 32</li> </ul>
<p>Indien <u>zowel</u> het verzoek van de ouders als het verzoek van de patiënt werd aangeduid: welk had het meeste invloed op de uiteindelijke besluitvorming?</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> verzoek van ouder(s)/vertegenwoordiger(s)</li> <li><input type="checkbox"/> verzoek van de patiënt</li> <li><input type="checkbox"/> beide verzoeken even veel</li> </ul>
<p><b>22</b> Welke term past volgens u <u>het best</u> bij de laatstgenoemde handelwijze? – <i>slechts één antwoord mogelijk</i> –</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> niet-behandelbeslissing</li> <li><input type="checkbox"/> symptoombestrijding</li> <li><input type="checkbox"/> palliatieve of terminale sedatie</li> <li><input type="checkbox"/> levensbeëindiging uit compassie</li> <li><input type="checkbox"/> euthanasie</li> <li><input type="checkbox"/> hulp bij zelfdoding</li> <li><input type="checkbox"/> andere</li> </ul>

<b>Zorg en behandeling</b>																																																																																																																																																													
<p><b>23</b> Hoe lang is de patiënt in behandeling geweest voor de aandoening die tot zijn of haar overlijden heeft geleid?</p>	<input type="checkbox"/> één tot zeven dagen <input type="checkbox"/> één tot vier weken <input type="checkbox"/> één tot drie maanden <input type="checkbox"/> drie tot zes maanden <input type="checkbox"/> zes maanden tot een jaar <input type="checkbox"/> meer dan een jaar																																																																																																																																																												
<p><b>24</b> Waar was de behandeling tijdens de <u>laatste week</u> vóór het overlijden in hoofdzaak op gericht?</p>	<input type="checkbox"/> genezing <input type="checkbox"/> levensverlenging <input type="checkbox"/> comfort																																																																																																																																																												
<p><b>25</b> Is er een bespreking geweest met zorgverleners gespecialiseerd in levenseindezorg?                      – meerdere antwoorden mogelijk –</p>	<input type="checkbox"/> ja, met LevensEinde Informatie Forum-arts(en) (LEIF) <input type="checkbox"/> ja, met palliatieve zorg-arts(en) <input type="checkbox"/> ja, andere <input type="text"/> <input type="checkbox"/> neen																																																																																																																																																												
<p><b>26</b> In welke mate waren naar uw schatting de volgende symptomen of verschijnselen bij de patiënt aanwezig tijdens de <u>laatste 24 uur</u> vóór het overlijden - ondanks eventuele behandeling?</p>																																																																																																																																																													
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<p><b>27</b> Werd de patiënt tot aan het overlijden continu in diepe sedatie of coma gehouden d.m.v. één of meer middelen?</p> <p>Welk(e) middel(en) werd(en) daartoe gebruikt?                      – meerdere antwoorden mogelijk –</p> <p>Hoe lang vóór het overlijden werd gestart met het continu diep sederen van de patiënt?</p> <p>Kreeg de patiënt daarbij kunstmatig vocht en/of voeding toegediend?</p> <p>Is de beslissing over het continu diep sederen genomen met instemming en/of op verzoek van de patiënt?                      - meerdere antwoorden mogelijk -</p> <p>Is de beslissing over het continu diep sederen genomen met instemming en/of op verzoek van de naasten?                      - meerdere antwoorden mogelijk –</p> <p>Waren er naast continue diepe sedatie alternatieven om de symptomen te behandelen?                      - meerdere antwoorden mogelijk -</p> <p>Deze wijze van diep sederen, al dan niet in combinatie met het kunstmatig toedienen van vocht en/of voeding, werd uitgevoerd...</p>	<input type="checkbox"/> ja <input type="checkbox"/> neen → <b>door naar vraag 28</b> <input type="checkbox"/> midazolam <input type="checkbox"/> ander benzodiazepine <input type="checkbox"/> morfine of ander opiaat <input type="checkbox"/> ander middel <input type="text"/> <input type="text"/> uren <input type="text"/> dagen <input type="text"/> weken <input type="checkbox"/> ja, continu tot aan het overlijden <input type="checkbox"/> ja, maar niet tot aan het overlijden <input type="checkbox"/> neen <input type="checkbox"/> ja, met instemming van de patiënt <input type="checkbox"/> ja, op verzoek van de patiënt <input type="checkbox"/> neen <input type="checkbox"/> ja, met instemming van de naasten <input type="checkbox"/> ja, op verzoek van de naasten <input type="checkbox"/> neen <input type="checkbox"/> neen <input type="checkbox"/> ja, symptoombestrijding zonder continue diepe sedatie <input type="checkbox"/> ja, maar alleen levensbeëindiging <input type="checkbox"/> ja, andere <input type="text"/> <input type="checkbox"/> wetende dat dit het levenseinde niet zou bespoedigen <input type="checkbox"/> rekening houdend met de mogelijke bespoediging van het levenseinde <input type="checkbox"/> mede met het doel het levenseinde te bespoedigen <input type="checkbox"/> met het uitdrukkelijke doel het levenseinde te bespoedigen																																																																																																																																																												

**28** Heeft de patiënt morfine en/of een ander opiaat toegediend gekregen tijdens de laatste 24 uur vóór het overlijden?

Naam van het (de) middel(en) en dosering in de laatste 24 uur vóór het overlijden?  
 – meerdere antwoorden mogelijk –

Is een hogere dosis gegeven dan nodig was om pijn en/of andere symptomen te bestrijden?

Hoe lang vóór het overlijden werd gestart met het toedienen van de morfine en/of een ander opiaat?

Welke figuur geeft het beste het beloop van de dosering van de morfine en/of een ander opiaat weer in de laatste 3 dagen vóór het overlijden van de patiënt?

<input type="checkbox"/> ja			
<input type="checkbox"/> neen → <b>door naar vraag 29</b>			Dosering (laatste 24u)
	Middel		
Pleisters	<input type="checkbox"/> fentanyl (o.a. Durogesic®)		µg/uur
	<input type="checkbox"/> buprenorfine (o.a. Transtec®)		µg/uur
Pomp	<input type="checkbox"/> morfine		mg
	<input type="checkbox"/> tramadol		mg
	<input type="checkbox"/> fentanyl		mg
Injecties	<input type="checkbox"/> morfine		mg
	<input type="checkbox"/> piritramide (o.a. Dipidolor®)		mg
Drank	<input type="checkbox"/> morfine		mg
Tabletten	<input type="checkbox"/> morfine retard (o.a. MS Contin®)		mg
	<input type="checkbox"/> morfine (o.a. MS Direct®)		mg
	<input type="checkbox"/> tramadol		mg
	<input type="checkbox"/> gabapentine (o.a. Neurontin®)		mg
Druppels	<input type="checkbox"/> tramadol (o.a. Tramal®)		mg
Anders	<input type="checkbox"/> middel _____		mg
	toedieningswijze _____		

ja  
 neen

\_\_\_\_\_ uren  
 \_\_\_\_\_ dagen  
 \_\_\_\_\_ weken

geen verhoging     geleidelijke verhoging     sterke verhoging laatste dag

3 2 1 0                      3 2 1 0                      3 2 1 0

**29** Heeft de patiënt benzodiazepine(s) toegediend gekregen tijdens de laatste 24 uur vóór het overlijden?

Naam van het (de) middel(en), toedieningswijze en dosering in de laatste 24 uur vóór het overlijden?

<input type="checkbox"/> ja			
<input type="checkbox"/> neen → <b>door naar vraag 30</b>			Dosering (laatste 24u)
	Naam	Toedieningswijze	
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____

**30** Hebben de patiënt en/of de ouders een uitdrukkelijk verzoek om levensbeëindiging gedaan dat niet werd ingewilligd?

Om welke reden(en) werd dit verzoek niet ingewilligd?  
 – meerdere antwoorden mogelijk –

- ja, namelijk
  - (een van) de ouder(s)
  - de patiënt
  - beiden
- neen → **door naar vraag 31**
- de patiënt overleed voordat het tot inwilliging kon komen
- de patiënt was niet terminaal ziek
- het lijden was niet ondraaglijk
- de medische toestand was niet uitzichtloos
- het was geen weloverwogen verzoek
- het was geen vrijwillig verzoek
- ontbreken van instemming van de patiënt
- ontbreken van instemming van ouders/vertegenwoordigers
- de patiënt trok het verzoek weer in
- vanwege instellingsbeleid
- vanwege principiële bezwaren tegen levensbeëindiging in het algemeen
- vanwege principiële bezwaren tegen levensbeëindiging bij minderjarigen
- uit vrees voor juridische consequenties
- andere reden, desgewenst toelichten bij vraag 32



## Curriculum Vitae

Geert Pousset was born in Sint-Truiden, Belgium, on 9 January 1983 as half of a monozygotic twin and son of Marcel Pousset and Ella Dekeyzer. He currently lives in Hasselt with his girlfriend Liesbeth Theelen. Geert attended primary school in Gingelom and Landen, and secondary school at the Sint-Gertrudis Institute of Katholiek Onderwijs Landen where he graduated in economics-maths in 2000. He continued his education at the Catholic University of Leuven where he graduated as a master of clinical child psychology in 2005. After working as a child psychologist at the Children's Psychiatric Unit of Sancta Maria Psychiatric Hospital in Sint-Truiden and as a supervisor of a group of adolescents at the Reception, Orientation and Observation Centre of CIDAR in Kortenberg, he started working as a junior researcher at the Bioethics Institute Ghent of Ghent University and the End-of-life Care Research Group of the Vrije Universiteit Brussel in September 2006. Conducting research and publishing in the field of children's end-of-life care, with a specific interest in end-of-life decisions, Geert obtained his PhD degree in Moral Sciences at Ghent University in 2010, under the supervision of promoter Prof. Freddy Mortier and co-promoters Prof. Johan Bilsen and Prof. Luc Deliens. As of September 2010, Geert will be working in his family's business Huishoudhulp. In his leisure time, Geert enjoys studying the underestimated work of popular philosophers Bruce Springsteen and Rocky Balboa, as well as playing futsal with his Magic Bullet team, playing tennis and squash and playing his guitar and harmonica.

## List of publications and presentations

### *Peer reviewed publications*

Chambaere K, Bilsen J, Cohen J, Pousset G, Onwuteaka-Philipsen B, Mortier F, Deliens L. A post-mortem survey on end-of-life decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. *BMC Public Health* 2008;1(8):299.

Pousset G, Bilsen J, De Wilde J, Deliens L, Mortier F. Attitudes of Flemish secondary school students towards euthanasia and other end-of-life decisions in minors. *Child: Care, Health & Development* 2009;35(3):349-356.

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Pousset G, Bilsen J, De Wilde J, Deliens L, Mortier F. Houding van Vlaamse leerlingen uit het secundair onderwijs ten opzichte van euthanasie en andere beslissingen aan het levenseinde bij minderjarigen.[in Dutch] *Tijdschrift voor Jeugdrecht en Kinderrechten* 2009(4-5):282-292.

Pousset G, Bilsen J, Cohen J, Addington-Hall J, Miccinesi G, Onwuteaka-Philipsen B, Kaasa S, Mortier F, Deliens L. Deaths of children occurring at home in six European countries. *Child: Care, Health & Development* 2010;36(3):375-384.

Pousset G, Bilsen J, Cohen J, Deliens L, Mortier F. Medical end-of-life decisions in children in Flanders, Belgium: a population-based post-mortem survey. *Archives of Pediatrics and Adolescent Medicine* 2010;164(6):547-553.

Pousset G, Bilsen J, Cohen J, Mortier F, Deliens L. Continuous deep sedation at the end of life of children in Flanders, Belgium. *Journal of Pain and Symptom Management*. *In press*.

Pousset G, Mortier F, Bilsen J, Cohen J, Deliens L. Attitudes and practices of physicians regarding physician-assisted dying in minors. *Archives of Disease in Childhood*. *In press*.

### *Published abstracts*

Pousset G, De Wilde J, Bilsen J, Mortier F. Attitudes of Flemish secondary school students towards end-of-life decisions. 9th Public Health Symposium: Public Health at the End of life, Jette, Belgium, 14 December 2007. *Archives of Public Health* 65(Suppl 1):42.

Chambaere K, Bilsen J, Cohen J, Pousset G, Mortier F, Deliens L. Studying medical end-of-life decisions via death certificates in Flanders and Brussels, Belgium: a research protocol. 9th Public Health Symposium: Public Health at the end of life, Brussels, Belgium, 14 December 2007. Archives of Public Health 65(Suppl 1):12.

Pousset G, Bilsen J, De Wilde J, Deliens L, Mortier F. Attitudes of Flemish secondary school students towards end-of-life decisions in minors. 5th Research Forum of the European Association of Palliative Care, Trondheim, Norway, 29-31 May 2008. Palliative Medicine 22(4):421.

Chambaere K, Bilsen J, Cohen J, Pousset G, Mortier F, Deliens L. A post-mortem survey on end-of-life decisions using a representative sample of death certificates: a research protocol for a study in Flanders and Brussels, Belgium. 5th Research Forum of the European Association for Palliative Care, Trondheim, Norway, 29-31 May 2008. Palliative Medicine 22(4):551-552.

Pousset G, Bilsen J, Cohen J, Addington-Hall J, Miccinesi G, Onwuteaka-Philipsen B, Kaasa S, Mortier F, Deliens L. Home death for children dying in six European countries. 11th Congress of the European Association for Palliative Care, Vienna, Austria, 7-10 May 2009. European Journal of Palliative Care: 51.

Pousset G, Mortier F, Bilsen J, Cohen J, Deliens L. Physicians' attitudes and actual practices concerning physician-assisted dying in minors: a nationwide survey. European Journal of Palliative Care. *In press*.

#### *Book chapter*

Pousset G, Deliens L. De levenseindeproblematiek bij minderjarigen. In: Cornelis G (Eds). Boek voor de VUB-Lezingenreeks over kinderen, jongeren en beslissingen rond het levenseinde. *In press*.

#### *Master's thesis*

Co-promoter of Imler I, Palliative home care for minors: a study of experiences of parents and caregivers with the palliative home care team of Leuven University Hospital.[in Dutch] Thesis for Master of Psychology, Vrije Universiteit Brussel, 2008-2009, Promoter: Prof. dr. Johan Bilsen.

#### *Presentations*

Pousset G. Attitudes of Flemish secondary school students towards end-of-life decisions in minors. 9th Public Health Symposium: Public Health at the End of life, Jette, 14/12/2007.

Pousset G. Attitudes of Flemish secondary school students towards end-of-life decisions in minors. 5th Research Forum of the European Association of Palliative Care, Trondheim, Norway, 29/05/2008.

Pousset G. Thuisoverlijden bij kinderen in zes Europese landen. 6e Vlaams-Nederlands onderzoeksforum palliatieve zorg, Rotterdam, 20/03/2009.

Pousset G. Medische beslissingen aan het levenseinde van minderjarigen in Vlaanderen. Voorstelling van onderzoeksresultaten voor medewerkers van het Vlaams Agentschap Zorg en Gezondheid, Brussel, 3/09/2009.

Pousset G. Home death for children dying in six European countries. 11th Congress of the European Association for Palliative Care, Vienna, 7/05/2009.

Pousset G. Attitudes van jongeren met en zonder ziekte-ervaring en artsen t.o.v. euthanasie bij minderjarigen. RWS-symposium "Waardig sterven en euthanasie bij minderjarigen in België - heden en toekomst", Geneeskundige Dagen Antwerpen, Wilrijk, 18/09/2009.

Pousset G. Autonomie en euthanasie bij kinderen. Gastcollege voor 3e Bachelor Pedagogie Universiteit Gent, Gent, 24/11/2009.

Pousset G. Minderjarigen en levenseinde: de sociologische aspecten. Studiedag Euthanasie, pijnbestrijding en levensmoeheid: juridische en sociologische aspecten, Wilrijk, 18/12/2009.

Pousset G. Thuisoverlijden bij kinderen in zes Europese landen. Open ZrL-seminarie, VUB-campus Jette, 17/03/2010.

Pousset G. Betrokkenheid van verpleegkundigen bij medische beslissingen aan het levenseinde. Lezingenreeks "Kinderen, Jongeren en Beslissingen rond het Levenseinde", VUB-campus Etterbeek, 22/03/2010.

Pousset G. Besluitvorming bij medische beslissingen aan het levenseinde bij minderjarigen. Symposium "Zorg en beslissingen aan het levenseinde van minderjarigen", Campus UZ Gent, Gent, 7/05/2010.

Pousset G. Twintig jaar thuiszorgteam kinderziekenhuis UZ Leuven: onderzoek naar de ervaringen van ouders, huisartsen en thuisverpleegkundigen. Leuvense Dagen Kindergeneeskunde, Campus UZ Leuven, Leuven, 27/05/2010.