

Minors and euthanasia

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Introduction: the issue

In Belgium, one of two countries in the world that legally allows euthanasia under specified conditions, a public debate is ensuing over whether or not the 2002 euthanasia law should be amended to include competent minors¹, who are currently excluded from the scope of the law. A proposal to that effect has been submitted to the Senate (Leduc Wille, Law Proposal 3-804/1 of July 7, 2004) and is being discussed in the media.

Legislating euthanasia

As we will use the term here, “euthanasia” denotes the deliberate ending, by a third party, of a patient’s life upon his or her explicit request, by the administering of lethal substances. The elements essential to euthanasia are thus: intentional ending of the patient’s life, explicit request by the patient to have done so, the use of lethal drugs and administration of these drugs by a third party, commonly a physician (or a nurse).

Euthanasia laws

In Belgium and the Netherlands, a law has been enacted (B. 2002, Neth. 2001)² which states that, in some cases, physicians who perform euthanasia will not be prosecuted, for when certain requirements are met and strictly followed, the act is not considered a crime.

The essence of the euthanasia laws, both in Belgium and the Netherlands, is that a request for life termination be well-informed, repeated (well-considered) and voluntary. Furthermore, it must be formulated by a patient suffering intolerably

from a medically irreversible condition, such as a disease or accident, as explicitly stated in Belgian law. If the request conforms to these requirements, the physician is permitted, though not obliged, to comply with the euthanasia request. In addition to these substantial requirements of prudent practice, procedural requirements should be met. For instance, the physician must obtain a written request, consult other physicians, keep a medical record of the case, and so on.

The euthanasia laws in both Belgium and the Netherlands are quite similar (Deliens & Van der Wal, 2003); however, a striking difference pertains to the qualifying age-population to which allowable euthanasia requests are applicable. In the Netherlands, minors from the age of 12 onwards can legally request euthanasia, but only when they are 16 and older can they do this without parental agreement. For minors aged 12 to 15, physicians are allowed to comply with the request for euthanasia, but only if the parents agree. Minors who are 16 and older can autonomously request euthanasia, which means that, although parents must be involved in the decision-making process, their permission is not required.³ Adults can choose whether or not they would like any involvement of family-members. In contrast, Belgian 'Law concerning euthanasia' (28th May 2002) explicitly excludes minors altogether: euthanasia for persons under 18 years of age, even when all legal requirements regarding the quality of the request for euthanasia are met, is prohibited and considered to be a crime.

The scope of the issue

While Flanders⁴ and the Netherlands combined account for several hundred end-of-life decisions regarding minors yearly, in only a very small number of these cases is euthanasia performed, for in the vast majority of instances, one or more of the elements essential to euthanasia is lacking (Van der Heide et al, 2003). The life ending may not be intentional, but merely accepted as a potential or even certain side effect of combating pain and symptoms, such as by using opioids (double-effect decisions). Occasionally, drugs are deliberately used to end the child's life without his or her explicit request, either because it is impossible to ask the child's opinion (e.g. in neonates), because the request would be

insufficiently informed (e.g. in young children) or because it is believed that the minor should not be burdened with considering and formulating a death request (no-request decisions). Drugs need not be involved at all; rather, the physician may decide to discontinue a current treatment or opt not to initiate a new one (non-treatment decisions).

Although double-effect, no-request and non-treatment decisions constitute the vast majority of end-of-life decisions, we will focus here only on the deliberate ending of a minor patient's life upon his or her explicit request, by the administering of lethal substances. For the Netherlands, data from Van der Wal et al (2003) cites approximately 5 cases of euthanasia in the category of 1 to 16 year-olds in 2001. For Belgium, the president of the Federal Commission for the Evaluation and Control of Euthanasia estimates the number of euthanasia cases involving minors at 5 to 10 cases yearly.⁵

Admittedly, the number of minor patients who would find themselves in a position to request euthanasia and would indeed do so is quite small, to the extent that one might question the need to statute clearly on the matter. The issue of unjustifiable age-discrimination must nevertheless be addressed, and furthermore, it is undesirable to condemn physicians to committing illegal acts, when a legal arrangement (in Belgium) extending the current euthanasia law is feasible. The National Disciplinary Board of Physicians has also contested this exception regime for euthanasia.⁶

We will argue, then, that where euthanasia is legally allowable for adults, should a minor competently and validly request euthanasia, it would be a discriminatory act to deem this request unacceptable on the basis of age alone. The acceptance of euthanasia for adults is taken for granted.⁷

The Netherlands vs. Belgium

So, in Belgium, minors are excluded from the scope of the law, thus, they are considered legally incompetent, even when functionally competent, to request euthanasia.⁸ Additionally, since only the patient can legally request euthanasia

and no third party can authorize this, it is absolutely prohibited for minors, even with all requirements met.

A comparison of the laws in the Netherlands and Belgium reveals that, from a legal perspective, the countries took markedly different paths regarding minors.

In the Netherlands, the existing rules regarding minors and medical decision-making apply equally for euthanasia requests; the law regulating euthanasia is in accord with general medical law and with legal doctrine regarding the position of minors. In Belgium, however, the age of legal majority for requesting euthanasia was put forward. Legal doctrine and medical law (e.g. the Belgian law on patient's rights and the mature minor-doctrine, see *infra*) do not apply here – euthanasia is considered to be an exception.

In previous parliamentary debate in Belgium, the position regarding euthanasia and minors was not thoroughly addressed, and ultimately the issue was set aside until further notice. In the following text, we will more closely examine the reasons for the sanctioning of this exception regime by exploring some of the issues commonly raised in the debate over minors and euthanasia: that they are not capable or mature enough to make such a decision, and that they should not be burdened with this (kind of) decision. Further, we will discuss the role of parents and other considerations relevant in this discussion.

The argument from incompetence

The argument from incompetence will receive much attention in this paper, since, in our opinion, it is the most powerful argument utilized to exclude minors, and conversely, to *include* minors when the argument of incompetence is countered.

In current legislation regarding euthanasia in both Belgium and the Netherlands, the request of the (adult) patient is a necessary requirement. This request is considered meaningful only from a functionally competent person, i.e. a person who has the requisite *capacities* to make the decision at hand. The underlying moral rationale for allowing personal choice is the principle of respect for persons and their moral worth, acknowledging their capacity for self-determination

(Glass, 1997). The right to self-determination is only meaningful, however, if the person is appropriately informed (provided with sufficient information to enable the decision-making), is acting voluntarily (not under pressure or duress) and has the ‘capacity’ to make that particular decision.

Concerning euthanasia and minors, the question then arises whether they are *capable* of making such a difficult decision, that of which the consequences are final. It is often questioned whether or not they can make serious decisions pertaining to life and death, and with regards to euthanasia, the claim that this is ‘a special kind’ of decision, which requires us to be even more careful and necessitates additional protective measures, frequently arises. In the subsequent sections, we will delve into these issues. First we will point out the increased recognition of older minors’ competency to decide on health care matters, then we shall focus more specifically on end-of-life decisions, and finally we will discuss special problems related to euthanasia requests.

Minors and medical decision-making

By and large, the question of competency lies at the centre of the debate over self-determination rights for minors. Children and adolescents are often prevented from deciding on many issues affecting their lives. Minors are considered to be a vulnerable population and are generally presumed to be legally incompetent to exercise their rights autonomously. The major assumption underlying such exclusion is the notion that they are much less competent than adults in making decisions.⁹

Thus, parents and physicians traditionally have made all treatment decisions on behalf of children, although some exceptions, in which minors can provide informed consent themselves, are frequently granted: in specific medical conditions¹⁰, in certain emergency situations¹¹ or in dealing with an emancipated minor¹² (Zinner, 1995; Kuther, 2003). The rationale behind such exceptions is not necessarily based on an assumption or recognition of the minor’s competence to decide, but rather it is primarily intended to secure access to and the delivery of care. For instance, minors are permitted to seek emergency care and to obtain

certain services when requiring parental notification and/or consent would likely discourage many minors from seeking treatment important to their own and others' welfare.

Just as the concept of informed choice has developed over the last 30 years, consideration of children's roles in decision-making has also evolved (Harrison et al, 1997). Nowadays, it is commonly held that children and adolescents should be appropriately involved in decisions affecting them, and that once they have sufficient decision-making capacity, they should become the principal decision-maker for themselves. This is also reflected in article 12 § 2 of the Belgian Law on Patient's Rights (22nd August 2002), which states that the minor patient, befitting of age and level of development, should be involved in exercising his or her rights. If the minor patient is capable of exercising these rights, then he or she can do so without mediation or intervention by parents or guardians. Thus, a child may consent to or refuse treatment without parental consent if he or she is judged sufficiently competent to make the medical decision.

In determination of legal competence, two standards are commonly applied: the presumptive and the evidential (Elliston, 1996). The *presumptive* standard states that, provided that the child has reached a specified age, he or she is presumed competent. Age is the variable most often used as a reference point in making determinations about the 'appropriate' distribution of commodities such as rights and freedoms (Koocher & DeMaso, 1990). In effect, functional competence is *presumed* present upon reaching a certain age¹³, and on this presumption, one is granted legal competence, i.e. decisional authority within a particular domain. This presumption of competence can, as with adults, always be rebutted.

Nevertheless, even though a minor may not yet have arrived at the age of presumed competence, this minor may possess relevant capacities or abilities that constitute *functional competence*. Most experts distinguish between legal competence and functional competence in paediatric patients (Van der Feen & Jellinek, 1998). Thus, an *evidential* standard regarding medical decision-making and minors is often applied, commonly referred to as 'the mature minor rule'¹⁴ or

a ‘Gillick competent child’.¹⁵ This standard requires that children, those *under* the age to be presumed competent, demonstrate to the satisfaction of a medical practitioner (or judge) their attainment of the requisite degree of functional competence to decide on the issue in question. This standard acknowledges that, on account of the variability in decision-making capacity from one situation to another, one time to another, and one child to another, each child must be individually evaluated. What is in question, just as with adults, is their capacity, with the help of family, physicians and other members of the health care team, to understand the nature and consequences of alternative treatments sufficiently to be able to give or withhold informed consent to a recommended treatment alternative (Buchanan & Brock, 1990).

Let’s examine this evidential standard a bit more closely. Which capacities are required, what relevant variables are involved and what does empirical research tell us? The required functional criteria for decision-making include the abilities *to understand* (to comprehend essential medical information), *to appreciate the nature of the decision* (to recognize the gravity, immediacy, and permanence of the choice), *to reason* (to consider multiple factors in predicting future consequences) and *to choose voluntarily* (in relation to authority figures such as parents and physicians). Also mentioned is having or applying a set of values to aid in choosing from various options, or put otherwise, having a set of values as a stable conception of one’s good such that appropriate weight is assigned to future consequences of present decisions (King & Cross, 1989; Leikin, 1989; Buchanan & Brock, 1990; Glass, 1997). Additionally, possession of an *adequate conceptualisation of death* is essential for understanding, appreciating and reasoning about certain (especially end-of-life) decisions (Leikin, 1989).

By referring to these criteria for decision-making capacity, a decisional role may be assigned to the child commensurate with his or her level of functional competence (Freyer, 1992). In other words, there is no specific age at which a child becomes competent to make health care decisions; it depends both on the individual child and on the seriousness and complexity of the decision at hand.

It should be noted that competence is task-specific and depends heavily on the context in which the decision is to be made (Glass, 1997; De Lourdes et al, 2003). Competence is not a simple attribute that a child either does or does not possess, and consent itself does not occur in a vacuum. Much depends on the relationship and trust established between the child, family and health care professionals. Moreover, it relates to the child's capacity for utilizing information, the quality and quantity of the presented information, the form of presentation and the source of the information.

Evidencing an evidential standard

With regards to the general population of minors, recent research into the development of cognitive capacities indicates that adolescents beyond the age of 14 do not differ significantly from adults in their decision-making competence across a variety of domains, while young people under this age show more variable performance (Grisso & Vierling, 1978; Weithorn & Campbell, 1982; Lewis, 1983; Leikin, 1989; Buchanan & Brock, 1990; Ambuel & Rappaport, 1992; Scott et al, 1995). Buchanan & Brock stated in 1990 that, as a very broad generalisation, the developmental evidence supports the conclusion that children by age 14 or 15 usually have developed the various capacities necessary for competence in health care decision-making to a level roughly comparable to that attained by most adults.

More specifically, on the competency of young people aged 13 or older to decide on matters of life and death, a review article of research results concluded: "*An expanding body of literature indicates that adolescents, with some exceptions, are capable of making major health decisions and giving informed consent, whether in a clinical or in a research setting*" (Weir & Peters, 1997, p. 31).

According to Freyer, a broad consensus comprised of paediatric health professionals, developmental psychologists, ethicists and lawyers has emerged, which holds that adolescents of approximately 14 years of age should be presumed, unless demonstrated otherwise, to have the functional competence to make binding medical decisions for themselves, including decisions relating to

the discontinuance of life-sustaining therapy and other end-of-life issues (Freyer, 2004).

Furthermore, competence is not *dictated* by chronological age (Hill & Tisdall 1997, Alderson 2000). Children vary in their rate of development and are also influenced by their environment, which affects their cognitive, affective, social, moral, and physical growth. Competence is associated with cognitive capacity, rationality, and age, but it is now also held to be a function of a child's *experience* of the illness in question, unique experience on which to base decisions about future treatment (Crisp et al., 1996; Lowden, 2002). Minor patients who have gone through repeated treatment and hospitalisations and who have experienced years of physical and psychological suffering, are frequently mature beyond their years. However, experiencing a life-threatening illness may result in depression, anger, or pain, causing a child to regress *or* to become mature beyond his or her years: each child responds and copes in a different way (Van der Feen & Jellinek, 1998).

According to Freyer (in discussing paediatric cancer patients): “ ... *pediatric patients as young as age 7 or 8 years may possess important specific knowledge and general maturity not belonging to age-matched children lacking their medical experience*” (Freyer, 1992, p.139). Their understanding does not consist of abstract thought but instead of illness, disability and treatment experience: the suffering that characterizes their lives, the features of life that make it worth continuing, the benefits and burdens that accompany medical treatment and, for some, the prospect of death (Alderson & Montgomery, 1996a; Weir & Peters, 1997; Beidler & Dickey, 2001). Even the critical developmental step of acquiring a workable (and accurate) concept of death is influenced by children's encounters with it. It is the common experience of care providers that, due to their personal experiences with serious illness and medical treatment (and observations of hospitalised friends), even young children with life-threatening illnesses may acquire an accurate understanding of (their own impending) death long before

their healthy counterparts (Bluebond-Langner, 1978; Evans, 1995; Weir & Peters, 1997; Van der Feen & Jellinek, 1998; Freyer, 2004).

By the time they are faced with end-of-life decisions, many chronically ill children have acquired substantial context-specific experience through which they can understand the value of life and can weigh up alternatives and express consistent values based on a firm sense of identity, thereby demonstrating the moral and rational basis of wise decision-making (Alderson & Montgomery, 1996; Beidler & Dickey, 2001). Bearing in mind the disease-related experience, valid requests regarding end-of-life decisions, including euthanasia, are more probable in younger children than a valid consent to participate in a clinical trial (medical experiments) by an older child who lacks this context-related experience.

Considering the existing evidence, it seems reasonable to conclude that certain minors, in certain situations, can be considered capable of acquiring sufficient insight in their condition, situation and wishes and can be regarded as competent (i.e. as competent as adults) to decide on end-of-life issues. Thus, in end-of-life-decisions specifically, when the question arises on whether or not to respect a minor's wishes, an individual assessment of his or her decision-making capacities regarding the decision at hand is appropriate. Leikin proposes that if a child has dealt with an illness for some time, understands the benefits and burdens of treatment and can consider and make decisions related to the illness, and comprehends death and its implications for the family as well as for himself or herself, then that person, irrespective of age, is competent (Leikin, 1989).

Euthanasia a 'special decision?'

Does the same hold true for formulating a valid request for euthanasia; can a minor ever be considered competent to request euthanasia?

Minors are allowed to make weighty decisions regarding their health care when judged to be competent, and often when parents and/or health care professionals agree. For instance, in Belgium competent minors have the right to refuse life-

sustaining treatment, which means they will die. If they are allowed to refuse treatment and make decisions about life and death, then why are they not allowed to ask for their life to be ended intentionally, specifically by administering lethal substances?

In the following paragraphs, we shall specifically address deciding on euthanasia to look for warrants that would justify an exception regime regarding euthanasia for minors.

Euthanasia as risky and extraordinary

Although no exception regime exists in the Netherlands, we notice that euthanasia is still considered an ‘especially risky’ option, this reflected in the requirement that parents should agree with the minor’s request, when under the age of 16. We presume that this view is also implicitly held by all those who agree that while terminally ill minors may refuse life-sustaining treatment, they cannot request euthanasia. Euthanasia is often characterized as a ‘special case’ and as somehow more risky than other end-of-life decisions, which would justify putting extra safeguards in place, such as imposing additional requirements on minors’ capacities to decide. This would, at least, be in order when a risk-related standard of competence is used, as seems to be the case. Standards of this type place the threshold for competence (the required decision-making capacities) higher when more serious risks or more severe consequences are involved.

But is a euthanasia decision really *more* risky than other end-of-life decisions?

Using the standard working definition, the “risk” carried by an event is the product of two components: the magnitude, if realised, of the harmful or negative impact of the event and the probability that it will occur. Arguably, euthanasia involves a highly harmful event, namely death, and moreover, the event is irreversible and thus irreparable. If properly performed, the probability of the event equals one, certainty.

It is difficult to see, however, how euthanasia might be more risky than, for instance, a non-treatment decision. Although the timeframe between the decision and death is usually, though not necessarily, longer in a non-treatment decision

than when lethal drugs are administered, the effects of both kinds of decision are just as certain to end with death of the patient. The magnitude of the risk for those requesting euthanasia exactly equals the risk of refusing treatment.

We would even argue that, for patients who desire it, euthanasia carries no risk at all. A risk is something one wishes to avoid, and those asking for euthanasia do not want to avoid death, but instead they choose it. What they do want to avoid is intolerable suffering, thus, in their opinion, needless suffering is the risk they take by not asking for their life to be ended.

Perhaps some might argue that a person asking for euthanasia would not want to err because his or her life is involved. The negative impact of allowing minors to ask for euthanasia, then, would not be that they expose themselves to death, but rather to the potential error of wanting death when they really do not wish it.

But accepting this, it remains difficult to see how euthanasia could be different from other end-of-life decisions, for one can just as well erroneously refuse treatment as ask for euthanasia.

Instead of focusing on the magnitude of the risk of requesting euthanasia, you could point out the extraordinary *character* of euthanasia.

In our view, it is unlikely that euthanasia could be characterized as a special kind of decision, one that requires additional or different capacities in comparison with other end-of-life decisions. Presumably, the same decision-making capacities are required for choosing euthanasia as for making other difficult decisions concerning life and death.

You could also argue, however, that euthanasia is extraordinary because it expresses a wish to have yourself killed rather than merely being allowed to die. Many, including philosophers and physicians, believe that euthanasia differs from the refusal of treatment in that the latter somehow allows nature to take its course, whereas the former requires the intentional causation of death.¹⁶

Now let's simply grant that *letting one die* is different from *killing*.

Killing requires an intentional ending of life, whereas letting one die does not necessarily involve that intention (Kuhse, 1987). For instance, a physician can decide to stop treatment in order to refrain from medically futile treatments,

foreseeing that the patient will die as a result, but not intending the resulting death. Arguably, accepting the patient's death as a consequence of a justified decision is different from deliberately killing the patient. Yet, we do not see how this distinction between merely foreseeing something and intending for it could help in pinning down the special character of requesting euthanasia, as opposed to asking for another kind of end-of-life decision, nor how this distinction could be relevant to the question whether or not allowing someone to ask for euthanasia.

We want to point out that the patient's request and the intention underlying his or her request is key here. When a patient asks to withhold or withdraw life-sustaining treatment, and when he or she asks for euthanasia, in our view, the same intention underlies the request: dying, as opposed to suffering intolerably, in a manner consistent with one's conception of dying with dignity. Or better stated: the chief aim is to relieve suffering and, to some, this implies dying, as in their view, the suffering is relieved in no other or better way. Therefore, even granted that the presence or absence of an intention to cause death constitutes an ethical difference, this does not help to define the presumed difference between asking to be allowed to die and asking to be killed. In both cases, the patient intends to die. What is different is that in euthanasia you require another individual to help you die. In this respect, we should stress the fact that no one is obliged to comply with this request, for as we shall see further, the physician can grant the patient's request according to his or her own judgment and unique position on euthanasia.

To conclude this section, *if* euthanasia could be characterised as a 'special decision' warranting an exception regime, then this does not apply only to minors but to adults as well. The proper question is why a request of a competent *minor* would be especially problematic?

As stated earlier, we will not address the issue of whether or not euthanasia can ever be morally acceptable. Building on the current euthanasia laws in Belgium and the Netherlands, it is simply accepted that in some cases (see requirements) euthanasia is permitted. If one accepts the legitimacy of a competent adult's request for euthanasia, then why not when a competent minor requests it? In our

opinion, if a problem with euthanasia as such exists, then this should hold true for both minors and adults. Consequently, if competent requests of minors are rejected on the basis of age alone, then this constitutes discrimination between minors and adults on the basis of an arbitrary and irrelevant criterion - especially in this context.

Euthanasia in specific: presumptive vs. evidential standards

Based on the quoted research results, we state that the current presumptive age-boundaries for legal competence regarding medical decision-making are often too high. For euthanasia in particular, we highlighted the fact that making end-of-life decisions pertains to a specific subgroup of minor patients, the ones that experience having a life-threatening, incurable and/or chronic illness. We feel that an approach which leaves room for specific characteristics of these situations and individual capacities of the involved child is always appropriate, but *a fortiori* in the case of a euthanasia request.

Some might say that the age-boundary to request euthanasia should be placed higher than with more ‘everyday’ health care choices, due to its final consequences. In contrast, we feel that in this subgroup of minor patients, some minors, even at a young age, possess the requisite capacities to make these end-of-life decisions, including a request for euthanasia. It might even seem more appropriate, then, to *lower* the current age-boundary for requesting euthanasia in Belgium. However, if set too low, a presumptive standard may include minors who are not functionally competent. While this presumption can always be rebutted in a specific case, it is nevertheless appropriate to set age-boundaries that reflect the capacities of the general population they pertain to. Is the current age-boundary that is used in the Netherlands regarding minors and euthanasia ‘accurate’? Instead of answering the question of which age-boundary to adopt, we contend that within the specific context of euthanasia age boundaries are superfluous.

There is no need for presumptive standards regarding the age at which minors can be considered competent to make this decision, since it is the validity of the

individual's request for euthanasia that should always be assessed. A request for euthanasia is, in itself, insufficient; a functionally competent person should formulate this request. Thus, under the provisions of the Belgian and Dutch laws pertaining to euthanasia, even adults are not competent by presumption, and in each case, decision-making capacities and competence to request euthanasia should be assessed. The use of age boundaries is a purely economic device, for simplicity's sake. It is important to keep this in mind when addressing the question whether competent minors should be legally allowed to formulate euthanasia requests. It is hard to see how it would be more convenient to put presumptive standards in place, as *each* request necessitates a thorough inquiry, regardless of the person's age.

As we have demonstrated, 'they can't make such a decision' is not a valid rebuttal because some, in fact, can, even at a quite young age. What is a valid rebuttal, however, is that competence is a blurry concept and assessing whether or not a minor patient can make this decision and is 'up for it' can prove a daunting task (Glass, 1997; Wong et al, 1999; Ganzini et al, 2003). The same can, of course, be said about assessing the request of an adult patient, but since we generally presume adults to be competent, until proven otherwise, and we assume that minors require more protection, confirming their decisional capacities is more important than with adults. While assessing the decision-making capacity of an individual (minor) is hard work and complexities surround the issue, it is pivotal in granting minor patients proper self-determination rights. We will not address the issue of assessing competence further, as this is beyond the scope of the paper. We merely state that each euthanasia-request requires the physician, possibly with the help of colleagues and/or other health care professionals, to assess each individual and his or her specific situation. The clarification of a wish to die also implies the consideration of several other factors beside competence, or only vaguely related to competence, that might be influencing the minor's decision: an underlying untreated depression, an unwarranted concern to protect her relatives against vicarious suffering, lacking quality of health

care, and so on (Jamison, 2000). A formalistic and legalistic approach is hereby not appropriate. Instead, thorough counselling with the minor patient and family is indicated. Considering that very few minors would request euthanasia, and that the majority of terminally ill adolescents and their parents have established, long-term relationships with their care providers (Freyer, 2004), individual assessments seem feasible. In this respect, we state that the crucial point for all health care professionals involved *"[...] is not to man the gate to assisted dying, but to nurture autonomous choice and diminish the anguish of the dying process"* (Sullivan & Ganzini, 1998, p.31). Our point of view will be further clarified below.

Self-determination, well-being and parental interests

Let's assume that certain minors, in certain situations, are capable of acquiring sufficient insight into their condition and situation so as to be regarded as competent (i.e. as competent as adults) to request euthanasia. Having the *capacity* to make these decisions does not immediately confer someone the right to *make* them. Restrictions on minors' medical decision-making are called into existence as means for protecting children; legislation is designed to protect minors from the consequences of immature and improvident decisions. Granting minors decisional authority on these matters is also based on whether or not any other values, besides self-determination, or considerations are at stake that would force us to limit their self-determination rights. We cannot delve into this extensively; however, in the following section, we will highlight some relevant considerations pertaining to minors and euthanasia.

Extreme ethic of self-determination?

By questioning the age boundaries that govern euthanasia requests, we have focused mainly on competence as a pivotal demarcation-criterion, and implicitly, we have found it imperative to respect the autonomous choice of the patient.

Opponents of euthanasia have stated that explicitly asking to end one's life, by administering lethal substances to hasten death, embodies an extreme ethic of self-determination. For us, self-determination is an essential reason for allowing people to request euthanasia. Some people are forced to think about the benefits and burdens of continued existence versus the prospect of death. In our view, only the person him or herself is entitled to weigh the one against the other. Does imparting this scope of deliberation to the patient boil down to some kind of extreme self-determination ethic? We believe not, for the following reasons.

Euthanasia is not an exactable right; it cannot be demanded or commanded. The current euthanasia laws (and preferably those of the future) merely authorize the physician to comply with the patient request when certain requirements are met. The physician can grant the request according to his or her own judgment and is only obliged to inform the patient of reasons for refusing to comply. The available data show that in the Netherlands, 61% of euthanasia requests for 2001 were not performed. In half of these cases (32% of all requests), the physician turned down the request for some reason (Van der Wal et al, 2003).

One of the reasons that can sway a physician into compliance with a euthanasia request is a desire to respect the wishes of a competent patient. Legally speaking, under the current euthanasia laws, this is a necessary and sufficient condition. It could very well be the case, however, that the physician interprets a valid request as a necessary, but by no means sufficient, motive. Beyond the condition that the request be a competently formulated choice, a physician may choose to comply with the request, not solely on the basis of respecting the patient's autonomy, but also out of compassion for an unbearably suffering, terminally ill patient.

It is even unlikely that people, who consider euthanasia for *minors* as (morally) permissible in some circumstances, would solely be motivated by an ethic of self-determination. Young children and adolescents experience pain and suffering, which sometimes cannot be alleviated, in largely the same way as adults. The wish to relieve a young person from suffering will probably serve as a strong

motive, which lies at the base or is compounded with the wish to respect patient choice.

Every day, minor patients cope with chronic conditions and struggle to survive with life-threatening illnesses; they contemplate the burdens of continued existence as compared with the prospect of death. Occasionally, a patient concludes that death is preferable to the suffering being experienced (Weir & Peters, 1997). The capacity of modern medicine to extend life is now so advanced that there is concern that the prolongation of life becomes the sole end, irrespective of the harm it may impose. When one accepts that a right to live does not entail a duty to live, and that some forms of living can be unbearable, then one can concede that it may be in the best (or a fundamental) interest of the child to allow the shortening or ending of his or her life.

Euthanasia allows patients to shorten intolerable, undesired and hopeless suffering in a manner consistent with their own conceptions of dying with dignity. Sometimes, there are other means available to shorten suffering, for instance terminal sedation¹⁷, but not all are consistent with a person's conception of dying with dignity. *If* one agrees that euthanasia can be considered as morally permissible when it is an explicit and well-considered choice by an individual, then age cannot be the determinative factor for excluding certain (categories of) persons. Age is not the right demarcation-criterion for children who suffer from a painful and incurable disease. Allowing minors to request euthanasia accords them the full right to participate in the process of assessing, clarifying and expressing their wishes at the end of their life. Their expressions of preference, when taken seriously by medical care providers and parents alike, are crucial "efforts of moral persuasion," as termed by Weir and Peters (1997, p.35).

Limiting self-determination?

Joint decision-making on medical decisions regarding minors is widely endorsed by health care professionals and relevant bodies of expertise. The child's parents are essential partners in the decision-making process, and their interest in making important choices about the welfare of their minor children is commonly

recognized as a substantial value in decisions about health care treatment for children (Buchanan & Brock, 1990).

Some hold that, regardless of a child's maturity, giving the child *autonomy* in treatment decisions leads to inevitable and unnecessary conflict. Parents should have primary authority over decisions affecting the welfare of their children, even when they are functionally competent, and in this line of thinking the notions of protection and parental rights are fundamental and override self-determination.

L.F. Ross believes that recognising the specialised claim of an adolescent's right to decide on a health care matter sets a troubling precedent for adolescent rights in wider society (Ross, 1997). However, as Freyer notes: "*It would seem difficult to predicate a compelling argument for expanding societal rights for minors on the extraordinary circumstances of terminal illness, where the notions of well being and autonomy take on rather different meanings*" (Freyer, 2004, p.383).

Limitation of children's autonomy is often motivated by the desire to prepare them for adulthood, to give them an education and to preserve their chances to an open future (Feinberg, 1980). Ross argues that present-day autonomy is precisely what must be sacrificed so that a minor may eventually gain the life and decision-making experience necessary for developing long-term autonomy (Ross, 1997). This is a relevant contention, and it is indeed appropriate to acknowledge cautionary views about granting decisional authority to minors, although these views must be evaluated in the context of terminal illness. In some medical contexts, especially when a child is dying, the long-term responsibilities appear in a somewhat different light. Unfortunately, the only form of autonomy relevant to the dying young person is present-day autonomy, since there is no prospect for long-term autonomy (Freyer, 2004). Consequently, limiting the child's decisional authority in order to protect long-term interests that the child no longer possesses would be deplorable and could, in fact, counter the child's present-day interests, for instance to shorten unbearable suffering.

The death of a child is universally seen as one of the most tragic experiences, but, equally, there is a clear awareness that futile and invasive overtreatment must be avoided. The side effects and other burdens of treatment may not be matched by a

genuine prospect of significant and sustained improvement (British Medical Association, 2001). Death sometimes is the *least bad* option.

The view that nowadays receives the most informed support is that the parental role as primary decision maker gradually fades as the child develops in maturity, although the importance of parents as a source of emotional support and advice should, ideally, remain (BMA, 2001). Health care professionals also have a fundamental obligation to focus on the interests of the patient and to provide benefit for that person. In this respect, we agree with the Canadian Paediatric Society (2004), who in their guidelines state that although the impact on the family –such as the burdens and harms they might experience – must be considered in end-of-life decision-making, these interests should not be allowed to override those of the child or adolescent. Although they usually coincide, the interests and/or views of the child and those of the parents are not automatically synonymous in every case (BMA, 2001). Fortunately, based on anecdotal information from paediatricians and also mentioned by Freyer, it seems that disagreement between the child and the parents on end-of-life decisions is highly exceptional and can usually be avoided (Freyer, 2004).

You can have it both ways

You might say that while some are *capable* of making these decisions, minors should not be burdened with them, nor should they be left alone in the decision-making process.

The reality of a child who is suffering from an incurable and life-threatening illness is extremely trying for all involved, parents, siblings, other family-members, friends and health care professionals, and decisions in this context are never taken light-heartedly. Parents have a central desire to be able to care for their child in accordance with their role as a nurturing and responsible guardian. Allowing the child to request euthanasia is never easy, and this can involve feelings of guilt: have we abandoned our child? Let's plainly face the fact that there is something horrific about the prospect of intentionally ending a child's life

at an appointed time. When defenceless children are involved, the idea that ‘the healthy’ abandon a broken patient at the moment he or she most needs them (Ricoeur, 1990) seems even more poignant. The idea of abandonment, in relation to euthanasia, is very forcefully expressed in the papal bull *Donum vitae*¹⁸. Allowing euthanasia is paralleled to the perfidy, as in the question of Cain: “Am I my brother’s keeper?” The answer: “You are!”

It is often feared that children will lose their right to protection when they participate in their own treatment decisions. When one ‘receives’ the right to make one’s own choices, the burdens and responsibilities which adult status entails are added and result in a loss of rights to protection: ‘you can’t have it both ways’. In fact, minors can have it both ways; they can enjoy self-determination rights while receiving support and assistance throughout their participation in the matters affecting them. In general, our contention is that participation in their care is essential to their welfare and does not preclude protection.

Let’s get one thing out of the way first: even competent minors do not *have* to make decisions regarding their care, and they certainly do not have to do so on their own. Children want to be allowed to make decisions *when they feel ready for it* (Cherney & Perry, 1994; Boylan, 2004). The minor patient is entitled to indicate in what way and to what degree he or she wants to be involved and may state wishes about further care. In this respect, no difference between adults and minors exists. Patients have a right to be informed about aspects of their own health, but they can also choose not to receive detailed information and can exempt themselves from decision-making (via waiver) that seems too difficult or emotionally taxing by asking someone else to decide for them (BMA, 2001). Some children and adolescents do possess the ability and desire to make their own decisions, thus physicians should carefully assess these factors, encourage joint decision-making by patients, families and the health care team, and support capable patients who wish to make their own choices. The more children are dependent on the protection and support of their parents and other adults, the

more the attention and empathy of health care professionals should be focused on the needs of children: this asks for support, advocacy and empowerment.

Again, for some minors only present-day autonomy is relevant and important. A sense of control of an, in essence, uncontrollable situation decreases anxiety and can enhance coping (McCabe, 1996; Van der Feen & Jellinek, 1998, Rushforth, 1999). Ideally, children should be given as much control and decision-making power as possible in their own treatment to help alleviate feelings of helplessness and to make them feel more empowered (Van der Feen & Jellinek, 1998; Melton, 1999).

Furthermore, self-determination should not be conflated with independence and being left alone in decision-making. There is no logical connection between affirming self-determination and negating vulnerability. Respecting the autonomy of a functionally competent minor does not necessarily equal deciding in lonely isolation without support (Alderson & Montgomery, 1996a,b).

You could say that *all* patients who are seriously ill find themselves in a dependent, vulnerable position. Euthanasia would certainly be an evil if it meant denying support to the dying and treating them as if they were as self-sufficient and vigorous as when healthy.

Complying with a patient's request for euthanasia is inseparable from the communicative framework wherein the request is embedded. In current euthanasia law, the consultation structure is fixed in legal standards for decision-making. In order to comply with the basic requirements of prudent practice, the physician should have several thorough consultations with the patient and relatives, as chosen by the patient. Furthermore, the physician must consult one or two colleagues, depending on the case at hand.

These are the basic requirements of *adult* decision-making regarding euthanasia. We would like to stress that for minors additional care should be taken to support the patient in decision-making, and additional prudential considerations may be introduced. This is done so in order to avoid errors in complying with a euthanasia request that should have been turned down. As stated earlier, protecting the minor and granting self-determination should be reconciled. In our

view, minors who are gravely or terminally ill should not be submitted to endless tests and expected to meet much more stringent requirements than adults simply based on their minority status. In contrast, additional support and counselling should be provided.

We would like to add that, ideally, these ‘good practice’ guidelines are already incorporated into the care of the minor patient from the early stages onwards. Being seriously ill is mostly very incapacitating. Steps must be taken to minimise the burdens, while ensuring that the benefits of involving the child are optimised. Not all the ‘work’ should be done at the final stages of their lives, for many will no longer be up to it. From the early stages on, the wishes of the child regarding care should be explored and evidence regarding capacities should be obtained. A kind of ‘value history’, with the strengths, vulnerabilities, values and preferences of the child and the family, should be mapped out, which is continually updated. The possibility of open communication should be conveyed to the child, and signs that the child desires to discuss these issues should be noticed. Specified moments and methods to address the issues pertaining to end-of-life care should be carefully chosen.

In yet another sense, the allowance of euthanasia rather than the simple forbidding of it would better protect minors. Incidence data on end-of-life decisions (in all countries where available) show that a considerable amount of these decisions are made *without* previous discussion or consent of the patient and/or relatives (Van der Heide et al, 2003). In contrast, euthanasia, by definition, necessitates a request made by the patient, as well as several other requirements pertaining to this request and other safeguards of prudent practice. Doctors complying with a minor’s request for euthanasia are legally obliged to respect these safeguards, which are well-specified, legally fixed and publicly controlled, this which is not the case with other end-of-life decisions.

The slippery slope argument is often heard when the issue of allowing (competent) minors to request euthanasia is raised. We do not propose to change

the requirements for a valid euthanasia request, but rather to eliminate unjustified age-discrimination. Therefore, the concept of euthanasia does not slide into a weaker version that implies an enfeeblement of the current requirements. While a category of persons is now included that previously was not (except in the Netherlands), we have argued that their categorical exclusion was unwarranted. And what about (younger) children that are incompetent to make such decisions?¹⁹ For us, end-of-life decision-making without a valid, competent request seems to be a far more difficult issue (beyond the scope of this paper) than the one addressed.

Conclusion

In this paper, we addressed some justifications that are frequently raised to exclude minors from making serious and difficult decisions pertaining to their medical care, and, in particular, for requesting euthanasia. The argument from incompetence was countered as being both irrelevant and invalid in the ensuing debate over minors and euthanasia requests. No warrants were found to justify the exception regime barring minors from opting for euthanasia, while allowing adults to freely choose it. If euthanasia remains legally allowable for adults, should a minor competently and validly request euthanasia, it would be a discriminatory act to deem this wish unacceptable on the basis of age alone.

We argued in favour of including competent minors in the population to which the euthanasia law applies. We noted that by doing this, the protection of minors increases, as the safeguards of prudent practice for euthanasia are well-specified, legally fixed and publicly controlled.

We recognised that the seriously ill child or young person particularly needs assistance and support, as both illness and young age tend to relate to an increased dependency and vulnerability. In this respect, we have left opportunity for additional prudential considerations regarding minors, and we have advocated for an approach that reconciles self-determination and protection. In each case, an assessment of the individual's decision-making capacities and the validity of his

or her request should be made. A formalistic and legalistic approach is hereby not appropriate. Instead, thorough counselling with all involved parties is essential, whereby the interests of the minor patient are paramount, and, ideally (and usually), agreement on which course to follow is achieved.

Pretending to have all the answers is certainly not our intention, instead, we aim to deepen the discussion on these delicate issues.

Notes

¹ Minors are under 18-year-olds, with 18 as the age of legal majority in Belgium.

² Belgium: Law concerning Euthanasia, 28th May 2002. The Netherlands: Law concerning control of life ending upon request and assisted suicide, 12th April 2001.

³ In the Netherlands, the position of minors was debated in the Second Chamber on November 21, 2000. Intervention of MP Rouvoet. Second Chamber Piece 25-2043-44.

⁴ Flanders is the Dutch-speaking part of Belgium; research data apply to this region (no data exists for the French-speaking part of Belgium).

⁵ Rough estimation based on the database used in Deliens, L.; Mortier, F.; Bilsen, J.; Cosyns, M.; Vander Stichele, R.; Vanoverloop, J.; Ingels, K., "End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey", *The Lancet* 2000 (356), 1806-11; Prof. W. Distelmans (2002) personal communication.

⁶ National Disciplinary Board of Physicians (Nationale Raad van de Orde der Geneesheren), Advise on Euthanasia January 15, 2000; March 22, 2003.

⁷ This is not to say that allowing euthanasia or seeing it as morally acceptable is self-evident, but that we shall not go into this discussion in this paper. Here we address the question why minors are treated differently from adults with respect to (the legislation of) euthanasia.

⁸ See further for a clarification of this distinction.

⁹ See for instance: Ambuel, B. and Rappaport, J., "Developmental trends in adolescents' psychological and legal competence to consent to abortion", *Law and Human Behavior* 1992 (16), 129-54.

¹⁰ This might be the case for certain problem-related treatments, such as sexually transmitted diseases, contraception, drug abuse and psychiatric problems. See for instance: Brody, J.L. and Waldron, H.B., "Ethical issues in research on the treatment of adolescent substance abuse disorders", *Addictive Behaviors* 2000 (25), 217-28; Committee on Adolescence, American Academy of Pediatrics, "The adolescent's right to confidential care when considering abortion", *Pediatrics* 1996 (97), 746-51;

¹¹ A minor may consent if he will be in serious danger unless health care services are provided (emergency care) –in this case he or she is a 'conditional minor'. This is not

based on the minor's capacity to consent, but on a theory of *implied consent* by the parents.

¹² Emancipated minors are those who live independently of their parents. They may consent to medical care, and refuse it, as if they were adults. The criteria for emancipation vary, e.g. marriage, parenthood, financial independence. In: Kunin, H., "Ethical issues in pediatric life-threatening illness: dilemmas of consent, assent, and communication", *Ethics & Behavior* 1997 (7(1)) 43-57.

¹³ For example, in the UK consent to treatment of a 16-year-old should be sought and this consent shall be as valid in law as if he or she were an adult.

¹⁴ The 'mature minor doctrine' is the common-law rule (originated in the USA) that allows an adolescent who is mature to give consent for medical care. See Sigman, G.S. and O'Connor, C., "Exploration for physicians of the Mature Minor Doctrine", *Journal of Pediatrics* 1991 (119 (4)), 520-25; for the Belgian equivalent of the Mature Minor Doctrine: see Van Slycken, L., "Beschikkingsrecht van de minderjarige over eigen leven en lichaam", in: *Over zichzelf beschikken? Juridische en ethische bijdragen over het leven, het lichaam en de dood* (Antwerpen/Apeldoorn: MAKLU, 1996).

¹⁵ In *Gillick v West Norfolk Area Health Authority* [1985] 3 All ER 492, the House of Lords gave guidance on what consent can be given by children. The case concerned a challenge by Mrs Gillick of the legality of advice provided to doctors by the Department of Health that in certain exceptional circumstances a doctor could give girls under 16 contraceptive advice and treatment without the consent, involvement or knowledge of their parents. The parental right to determine whether or not a child below the age of 16 will or will not have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to enable him to understand fully what is proposed. It is for the doctor to decide whether or not an individual child is Gillick competent or not.

¹⁶ See for instance: Quinn, W.S., "Actions, intentions, and consequences: The Doctrine of Doing and Allowing", *Philosophical Review* 1989 (98), 287-312.

¹⁷ Terminal sedation means bringing the patient into a deep sedation or coma until death. This may take some hours to several weeks. Terminal sedation is often practiced while simultaneously withdrawing artificial hydration and feeding, but not necessarily so.

¹⁸ John Paul II, *Evangelium Vitae*, 1995, § 8.

¹⁹ The same applies to the severely demented elderly and other incompetent persons.

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