Should the Euthanasia Act in Belgium Include Minors?

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In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

— *UN Convention on the Rights of the Child, Part I, Article 3.1*

Abstract

In 2014, Belgium became the first country in the world to legislate euthanasia for children. The decision evoked questions and criticisms in Belgium and in the world at large: Should children have the right to ask to die? Are children able to make reasoned and independent choices on such an important matter? Does maturity matter? Are children as autonomous as adults? Is it a logical move to grant terminally-ill children who are in intolerable pain this right? What happens if there is a conflict of wishes between the child and parents? It is argued that these questions should be addressed while legislators are fully aware of the relevant medical data regarding child development. Legislators should consider the

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likely consequences of this legislation. The article weighs arguments for and against euthanasia for children, discussing patient's autonomy, competence, age and maturity, pressure and abuse, and palliative care. It is suggested that the option of pediatric palliative care should be exhausted before proceeding to euthanasia, and that psychological counselling be made available to both children and guardians. It is further argued that the law should explicate the age of children and that it should insist on consensus between child and parents. Disregarding age makes a simplistic and questionable policy.

Key words: abuse, age, autonomy, Belgium, children, competence, euthanasia, maturity, palliative care

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Introduction

In 2014, Belgium became the first country in the world to allow euthanasia of minors, irrespective of their age. This paper explores whether this legislation enhances minors' rights or negates them.

Do minors have capacity for agency? Are they able to make decisions concerning life and death? Can minors understand death? Are minors capable to weigh various alternatives for treatment? Is there a difference between adult euthanasia and child euthanasia? Does life experience matter? Fundamentally, the questions relate not only to minors' capacity to make such life-and-death decision but also to safeguards against abuse. Are there sufficient mechanisms in place to ascertain that the best interests of minors remain intact?

These are genuinely difficult questions and they deserve close analysis. They necessitate research in child development and brain studies. These questions have troubled the legislature in Belgium for many years. In 2002, the legislature had limited the law to adults and "emancipated minors". But many liberals thought the law was discriminatory against minors and sought an opportunity to change it to include minors.

The following discussion relates to very sick and vulnerable minors who have to cope with much pain and suffering. The vulnerable condition may be regarded as a strong argument against euthanasia but it can also be viewed as a strong factor for euthanasia, arguing that those minors were forced to mature quickly, that they understand their dire

condition and are capable to make such grave decisions. They are the best judges about what is good for them.

One preliminary clarification is in order. One may ask whether there are ever cases in which a terminally ill child or teen is in such intractable pain and suffering, even after comprehensive palliative care, that euthanasia remains the only humane option. I explained my objection to euthanasia elsewhere (Cohen-Almagor 2001). The article is writing in the Belgian context where the practice of euthanasia is a given. I will analyse the extension of the Euthanasia Act to include minors and offer some constructive suggestions to help improve the policy.

The article opens with background information about the *Euthanasia Act*. Next it analyses pertinent considerations in the debate: patient's autonomy, patient's competence, patient's age and maturity, pressure and abuse, and palliative care. Upholding the "rule of sevens", it is argued that the legislature should have restricted the age of those who may ask for euthanasia to adolescents (14 +). Furthermore, it is suggested that consultation with psychological and medical research be made mandatory for the patient's guardians. It is further suggested that the law should insist on providing palliative care and on a consensus decision by the child and his/her guardian/s. The article ends by calling the Belgian public and legislature to monitor the situation closely, collect information and continue to scrutinize the policy and practice of euthanasia as more data about the differences between adult euthanasia and child euthanasia become available.

The Belgian Law

In 2002, Belgium legislated euthanasia for adults and emancipated minors (Deliens and van der Wal 2003; Griffiths, Weyers and Adams 2008; Vermeersch 2002).[2] The legislation explicate the terms for physicians to end the lives of "the adult or emancipated minor patient" who is in a medically hopeless condition of "constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident"."[3] "Emancipated minors" is a legal concept referring to minors of a comparable legal status, i.e., autonomous people capable of making decisions.[4] The provision on "emancipated minors" was a compromise between those who opposed opening euthanasia also to minors and those who supported euthanasia for all (Raus 2016).

Indeed, this legislation that restricted euthanasia to adults and emancipated minors was contested from the start. A survey among Flemish physicians showed that the majority of them (69.4%) accepted termination of life of minors under certain circumstances and favoured an amendment to the *Euthanasia Act* to include minors. 60.4% thought parental consent should be required before taking life-shortening decisions (Pousset, Mortier, Bilsen et al. 2011). Another survey highlighted that 88% of

[2] See also Patients Rights Council, http://www.patientsrightscouncil.org/site/belgium/ (accessed on November 26, 2017).

[3] The text of the law can be found in The Constitutional Court, Judgment no. 153/2015 (29 October 2015), http://www.const-court.be/public/e/2015/2015-153e.pdf (accessed on November 26, 2017).

[4] The Constitutional Court, Judgment no. 153/2015 (29 October 2015). See also De Bondt 2003: 301, http://www.austlii.edu.au/au/journals/IntTBLawRw/2003/12.html; Belgium: "Loi relatif à l'euthanasie," http://www.drze.de/in-focus/euthanasia/modules/belgium-loi-relatif-a-leuthanasie (both accessed on November 26, 2017).

physicians accepted quality-of-life ethic regarding minors, and 79% thought that prevention of unnecessary suffering was a professional task.[5]

Belgium decided to take this initiative due to political, cultural and religious considerations that came to play. The growing acceptance of euthanasia coincided with a decline in religiosity (Cohen, Marcoux, Bilsen *et al*. 2006). The *Euthanasia Act* was passed just before the elections of 2002 and the amendment to include minors was passed before the elections in May 2014. The free-thinking liberals ("libre pensée") pushed forward the right to self-disposal which for them was a significant ethical principle, more important than the right to self-determination. The Christian Democratic party did not support the amendment although it was part of the multi-party government coalition which included the pro-euthanasia liberal and social democratic parties. Due to the objection of the Christian Democrats, support for the legal amendment was sought from the opposition, namely the green parties and the NVA (New Flemish Alliance, a Flemish separatist party). Proponents of the euthanasia extension for minors reiterated the principles of inclusion and anti-discrimination (Belgian Senate 2010, 2013) which were appealing to the general public who was largely supportive of extending the law to minors (Saad 2017: 200). According to this view, patients should not be discriminated on the grounds of their age. The parliamentarians believed some children, especially after a long

[5] Those who endorse quality-of-life ethics argue that it is it possible to evaluate patients' quality of life and establish criteria to distinguish between a life of "quality" and a life that is "devoid of quality". This approach is in contrast to the sanctity-of-life approach. See Provoost, Cools, Mortier et al. 2005; Cohen-Almagor and Shmueli 2000.

disease history with an incurable disease, have the competency to make valid euthanasia requests.

In 2013, the Belgian Senate held a number of hearings with experts about the euthanasia law. During those hearings, many experts declared support for extending the law to include competent minors. Following those hearings, four senators submitted a legislative proposal which was debated and amended in the Senate. The law on euthanasia for competent minors was a compromise as some liberals wished the euthanasia law to include patients with severe dementia. The Christian-democrats and the extreme-right parties dissented. They wanted a cut-off at age 15 and emphasised the relational dimension of end-of-life decision-making, with more legally enforced involvement of the family and all caregivers (Bernheim, Distelmans and Mullie 2014). Subsequently a majority of senators voted in favour of the proposed amendment, which was then handed to the Chamber of Representatives (Belgian Chamber of Representatives 2014). In February 2014, after many legislative proposals to amend the *Act* and further extensive hearings, the Belgian parliament voted to extend the euthanasia law to include minors under the age of 18. The voting results were 86 in favour, 44 opposed, and 12 abstentions, an almost identical majority as the 2002 law for adults (Miller 2014; Raus 2016).[6]

The *Euthanasia Act*, Chapter II: Conditions and procedure, Section 3*,* §1holds:

[6] I thank Wim Lemmens, Kasper Raus and another leading Belgian bioethicist who wishes to remain anonymous for their comments and clarifications.

> The minor patient with the capacity for discernment is in a medically futile condition of constant and unbearable physical suffering that cannot be alleviated and will result in death within the foreseeable future, and is the result of a serious and incurable condition caused by illness or accident.[7]

The law is silent as to whether physicians can, should or should not initiate discussion about euthanasia. Physicians can and do initiate discussion on euthanasia. In her comments on a draft of this paper, Professor Jutte Van der Werff Ten Bosch wrote that “physicians can of course discuss euthanasia and initiate the discussion”. Testifying about her own experience, she said that “I always take it along in a discussion on end of life care decisions, explaining to parents if or if not their child could possibly ask for euthanasia”.[8]

When such a request is initiated by the medical team, this may affect the voluntariness of the decision. Even more so when children are concerned as they might be more susceptible to advice or authority. Proponents of the euthanasia law argue that patients can only request euthanasia if and when they are aware of the existence of euthanasia. But euthanasia is a well-known procedure in Belgium and the line between informing and suggesting is blurred. It might be the case that patients do not raise the issue because they do not wish to have euthanasia, and when the physician, who is

[7] The Constitutional Court, Judgment no. 153/2015 (29 October 2015).

[8] Email from 8 December 2017. Jutte Van der Werff Ten Bosch maintained: “However, the question to perform euthanasia should come from the patient. It's like being at the bakery. The one selling the bread can explain all the kinds of bread he has for sale, but he doesn't tell you which one you should pick”.

supposed to help them, in whom they put their trust, is offering euthanasia, then they are pushed to a place they rather not be. It is better that the patient initiates such a significant request (Cohen-Almagor 2002). Once the issue is raised and discussed, the law stipulates that the euthanasia request should be voiced by the minor patient. Patient's guardians cannot make such a request. One cannot ask euthanasia for somebody else. Then it would not be euthanasia. Thus the request needs to be made verbally by the minor patient, and it should be repeatedly made. Both parents need to agree. In her comments, Professor Jutte Van der Werff Ten Bosch wrote that "requests for euthanasia will only come from children who know their parents' minds are open enough to accept such a question".[9] In cases of parents' disagreement whether to agree to the request, no euthanasia request will be granted. The Euthanasia Act, Chapter II: Conditions and procedure, Section 3, §2 requires that minors consult a child psychiatrist or a psychologist, and inform him or her about the reasons for this consultation. The consulted specialist is required to take note of the medical record, examine the patient, and verify the minor's capacity of discernment. All the information, including the minor's request and the agreement of his or her legal representative, needs to be recorded in writing.

The treating physician is required to inform the patient and his or her legal representatives of the outcome of this consultation. At a meeting with the minor's legal representatives, the treating physician provides the patient with all the required information and verifies that the representatives agree with the request of the minor patient. The decision to request euthanasia must first be put in writing by the parents and

[9] Email sent on 27 November 2017.

the family are offered psychological support.[10] The healthcare team needs to ascertain that the child has decisional capacity and discuss with the patient whether the choice for euthanasia is the best option (Carter 2014). A commission oversees the practice of euthanasia to ensure compliance with the governance procedures (Editorial 2014).

Discussion

Autonomy

What do we know about minors cognitive and mental development, essential for the crystallization of one's autonomy?

Concerns about patient autonomy are the most important, but not the sole, factors driving current controversies and changes in end-of-life policies in Belgium and elsewhere (Beauchamp 2000). The notion of autonomy involves the ability to reflect upon beliefs and actions, and the ability to form an idea regarding them, so as to decide the way in which to lead a life. The central idea of autonomy is of self-rule, or self-direction. Minors' development is commonly described in terms of periods. The prenatal period is from conception to birth; infancy is between the time of birth to 18-24 months; early childhood extends from the end of infancy to 6 or 7-year-old of age. Then the frontal lobe of the brain develops rapidly, enabling children to plan and organise their activities and to pay attention to tasks (Santrock 2012; 118). Children learn to become more self-sufficient and to care for themselves. They develop school readiness skills such as following instructions and identifying letters. According to Piaget, children begin to go beyond

[10] In the Belgian discourse, the terms "family", "guardians" and "legal representatives" are used interchangeably.

simply connecting sensory information with physical action but they lack the ability to perform operations, internalized mental actions that allow children to preform mentally what they can do physically. They cannot perceive those operations in their mind without doing them (Inielder and Piaget 1958; Piaget 1975).

Middle and late childhood is the development period from the age of 6-7 to the age of 11. Children then can reason logically as long as reasoning is applied to specific examples. But their abstract perception is lacking. Thus children of that age lack sufficient autonomy to decide monumental end-of-life decisions.

Around the age of 11, children evolve into adolescence. The corpus callosum, where brain fibres connect the left and right hemispheres, thickens and thus enable adolescents to better process information. During this period, there are substantial changes in the density and distribution of dopamine receptors in pathways that connect the limbic system, where emotions are processed and rewards and punishments experienced, and the prefrontal cortex, which is the brain's chief executive officer (Steinberg 2013: 259). Piaget suggested that only between the ages of 12 and 16 minors reach a level of abstract thinking. This is a crucial stage in human development. Minors then are able to reason, develop systematic thinking, use information to extrapolate other information, use logic. It is thus problematic to ascribe autonomy to minors prior to this stage. Still minors in early adolescence, and obviously of younger age, find it hard to make predictions about things of which they have no experience (Inielder and Piaget 1958: 112; Tassoni 2007: 102). The result often is that rather than making a voluntary, autonomous decision, minors will likely opt to receive their parents' decision (Kaczor 2016: 57). While minors are capable of achieving a certain number of practical goals, until

rather late stage they still do not know how exactly these goals are accomplished (Piaget 1975: 147). Because dopamine plays a critical role in our experience of pleasure, these changes result in tendency for sensation seeking that is not always rational and calculated.

As minors lack adequate capacity to reason but they are emotionally more mature, they might be prone to act upon emotions rather than reason. This together with tendency for sensation seeking, makes empowering them with the capacity to end their lives a dangerous proposition. Nelson (2003; 2011) noted that adolescents develop strong emotions but their prefrontal cortex has not developed sufficiently the brakes to control or slow down emotions. Similarly, Dahl (2004: 18) argued that adolescents have charged feelings but they are equipped with un-skilled set of cognitive abilities to control their emotions, while Chan and Clayton (2006) argue that adolescents are emotionally unstable, intellectually immature, deficient in relevant experience, and impressionable and impulsive.[11] Let me expand on these matters by discussing minors' competence to make important decisions.

Competence

It is an open question whether adolescents fully understand the complexities of their condition, what options are opened for them, how successful they are likely to be, and what side-effects are likely to be manifested. Young children tend to understand illness in rather general, nonspecific terms, much like the way the example was phrased. They do

[11] Therefore Chan and Clayton (2006) oppose the suggestion to lower the voting age to sixteen. See also Cuman and Gastmans (2017).

not comprehend the differences between causes of illness and illness symptoms. Only from older childhood through adolescence they develop more advanced conceptions of illness (Kuther 2003: 346).[12]

By competence we refer to the ability to be independent and responsible. Most minors are dependent on others and thus have a very limited sense of responsibility. The relevant turning point is when minors have the capacity to assert what is important to them while bearing the consequences for the conduct designed to achieve that end. We do not think that minors are free to consume alcohol because we do not think that a 12-year-old has the self-rule to lose self-rule at will. We question whether the child has at all attained self-rule and we question the child's competency to deal with the effect of alcohol. Similarly we question the child's competency to deal with sexual matters. Societies decide on a certain threshold for some dangerous (to individuals as well as to others) activities: the right to have a driving licence, to drink alcohol, to have sex, to possess firearms. Article 1 of The UN *Convention on the Rights of the Child* (1990) defines childhood in terms of age: a child means every human being below the age of eighteen years.

Why eighteen years old?

The relevant Considerations relate to trust, responsibility and harm – to oneself and to others.

(a) We do not think that minors below that age have the mental competence to make very significant decisions;

[12] However, Murphy et al's (2012: 118) pilot study which included 7 teens indicates that teens with cancer have higher health literacy than teens without cancer, and that they desire all the information available about their options.

(b) With regard to alcohol we want people to first gain control over themselves to allow themselves to lose it;

(c) We do not wish to burden minors with responsibilities they might find very difficult to handle, i.e. parenthood.

Brain research found that teen brains are not fully developed compared to adult brains (Powell 2006: 865-867; Strauch 2003). Regions enabling primary functions, such as motor and sensory systems, mature earliest. Higher-order association areas, which integrate these primary functions, mature later (Casey, Getz and Galvan 2008). In particular, the frontal lobe, an important brain region for complex decision-making, is decidedly incomplete.

Between the ages of 10 and 12 years, the frontal lobes of the brain are evolving. Minors are developing the ability to think, to construe, to make logical assumptions and to plan (Tassoni 2007: 102). By the age of 12, a child's brain has the size, folding, weight and regional specialization of an adult's. But there is still a long way to go to reach adulthood (Powell 2006: 865). Our brains are said to continue maturing at least until we are in our mid-twenties. The prefrontal cortex that is important for impulse control and abstract thinking is in the process of development during the teenage years (Giedd, Blumenthal, Jeffries et al. 1999: 861-864).

Some researchers emphasize the adolescents' tendency for engagement with risky conduct such as fast driving, unprotected sex that may result in unintended pregnancies and STDs, experimentation with drugs, acts of violence, intentional injury and automobile accidents. Furthermore, adolescent decision-making capacity is lacking especially in

emotionally salient situations. They need the support of adults who have a mature prefrontal cortex (Galvan, Hare, Voss et al 2007; Partridge 2013A; Steinberg 2013).[13]

Wilhelms and Reyna argue that adolescents tend to be emotional and impulsive, that they fail to take into account long-term and short-term consequences, and that they fail to understand the gist of what is at stake (Wilhelms and Reyna 2013). Even when adolescents can intellectually analyse and weigh short-term as well as long-term consequences, they still fail to apprehend what is at stake in the decisions they face (Partridge 2013: 251). Many adolescents are not competent, capable of discernment because they make decisions on ground of norms that are handed down from their parents and have not been subjected through a process of critical scrutiny (Arnett 2000). Steinberg and Cauffman (1996) argued that factors such as impulse control, susceptibility to social influence, and difficulties in making a rational appraisal of risk and reward sometimes lead adolescents to make incompetent decisions. Before adulthood, there is less cross-talk between the brain systems that regulate rational decision-making and those that regulate emotional arousal. During adolescence, impulse control is lacking and so also capabilities to plan ahead and compare costs and benefits of alternatives. Steinberg (2013: 261) explains that this is one reason that susceptibility to peer pressure

[13] While Partridge (2013A: 291) argues that adolescents under the age of 21 lack the capacity to envisage appropriately the long-term likely benefits and harms associated with their choices, Weithorn and Campbell (1982*:* 1589-1598) argue that adolescents are as able to conceptualize and reason about treatment options. However, they also caution against the idea that younger minors (below the age of 9) are able to evaluate risks and benefits of medical treatment options. See also Why are teenagers so susceptible to addiction?, https://inside-the-brain.com/2016/10/02/why-are-teenagers-so-susceptible-to-addiction/ (accessed on November 26, 2017).

declines as adolescents grow into adulthood. With maturity, individuals become better able to put the brakes on an impulse that is aroused by their friends.

Age and Maturity

The Belgian law does not provide age restriction but it does insist that a psychologist or psychiatrist verifies that the minors understand the consequences of their decision. Granted that the biological development of teenagers is not an exact science, and that their ability to make decision vary. This ability is influenced by their individual mental attributes, their environment, their sensitivity to context including physicians' and parental attitudes, and the way information is presented to them (Mårtenson and Fägerskiöld 2007; Coyne and Harder 2011; Ruhe, Tenzin Wangmo, Badarau et al 2015). Thus arguably a 17-year-old cancer patient might be perfectly mature and capable to make decisions about her life, but the law in Belgium did not specify any age at all. Age became irrelevant. The dismissal of the concept of adulthood is questionable.

Most young minors do not have particular life ends. Their sense of purpose and goal in life is limited and it might also be quite unstable, as they change their minds as they acquire new experiences (Partridge 2013A; Santrock 2012). These characteristics bring us to think that minors are not entitled to the same rights that adults have. We put limits on things that we believe require a certain amount of maturity and responsibility (e.g., driving, voting, fighting wars, buying a house even when the child is privileged and has the money). We establish age of consent and limit the voting age as we believe that some issues are better reserved to a later stage of life, when we develop our mental and physical faculties and could cope with partnership, sexuality, desires, the raising of

children and the duties of citizenship. The right to die is no less important than any of the above issues. Death brings to an end all other rights. Why should minors be allowed this right while other rights are denied? Indeed, if minors can consent to die, one may argue that they should enjoy the autonomy to drive, to vote, to bear arms, to marry, to have sex, to bring children to the world, and to do many other things that many of us believe minors should *not* have the right to.

A relevant distinction that might explain why people are willing to grant minors with the right to request euthanasia but not to drive, to vote, to bear arms, to marry etc. is between self-regarding and other-regarding conduct. Driving a car and having possession on weapons might have detrimental other-regarding consequences. Careless conduct with cars and guns might lead to loss of lives. But a 12-year-old child who requests euthanasia decides only for herself. The conduct does not harm others. Euthanasia might negatively affect the child's loved ones but surely the child should lead her own life and not forsake self-rule for the benefit of others. Most self-regarding actions do affect others (unless a person is completely lonely and does nothing of significance). But we do appreciate that driving, becoming a parent, and fighting wars have direct bearing on others whereas euthanasia is self-regarding.

The distinction between self-regarding and other-regarding conduct resolves part of the dilemma but not all of it. There are self-regarding actions that are restricted to minors. If minors are autonomous to request euthanasia, then this egalitarian logic suggests that they are also autonomous to consume alcohol and smoke. But somehow the autonomy reasoning is circumscribed when the latter issues are considered.

Brain studies suggest that adolescent's decision-making capacity fluctuates. Notwithstanding raging hormones, risky behaviour and rebellious tendencies, teenagers are unable to consistently make decisions as adults do. Other researchers suggest that adolescents lack experience and they are trying things for the first time. For some youth, this leads to problems. The desire to try new things, the urge to explore, might lead to impulsive behavior and unhealthy outcomes (Romer, Reyna and Satterthwaite 2017). This explains why adolescents are three or four times more likely to die than children past infancy (Powell 2006: 865). It is not obvious that minors have the ability to formulate their opinions clearly and independently. More so when they are unhealthy. Minors are impressionable, incapable of understanding complex medical conditions, lack maturity required to decide on life and death (Grisso and Vierling 1978; Kuther 2003: 347). Thus, so the argument goes, common sense dictates that we be extra careful when we discuss end-of-life issues with minors.

Research suggests that minors below the age of 11 generally do not have the intellectual ability and volition to give informed and rational consent (Grisso and Vierling 1978: 420-423; Weithorn and Campbell 1982; Kuther 2003: 350). For much less important issues, what film to watch, which diet to adapt, many young minors are dependent on adults, trusting their guardians to make the best decision for them. Minors believe the guardians' decision would be better than theirs. Leaving momentous decision of life and death to minors is worrisome.

One may argue that this is incorrect as the law requires parental consent and authorization of the medical team. It stipulates that at a meeting with the legal representatives of the minor, the treating physician provides them with all the information

and verifies that they agree with the request of the minor patient.[14] A question arises what happens in case of a child who wishes to die and parents who refuse to grant consent or when disagreement exists between parents. Future studies should inquire whether such cases exist and how they are resolved. Obviously the aspiration is for consensual decision but this might not always be the case. By insisting on parental consent, the legislators in effect recognized that the minor's euthanasia request might be premature or even wrong because the child is lacking the rational and mental capacities to make such a decision. Research suggests that adolescents become capable of providing voluntary consent that is not unduly influenced by others between the ages of 15 and 17 (Grisso and Vierling 1978**:** 412-427; Australian Government n/d). While any strict age criteria will only be an approximate match for maturity, age criteria are easy to test and enforce and offer more robust protection against immature decisions without a slippery slope. On the other hand they do not so easily allow exceptions. The Belgian should decide whether they wish to introduce strict age or a spectrum. As research speaks of the "rule of sevens" (Grisso and Vierling 1978: 423; Arnett 2000; Steinberg 2013: 265), I suggest that the law specifies a lower threshold of 14, i.e., minors younger than 14 should not be eligible to make euthanasia requests, while requests made by adolescents of 14-17 will be subject to a review of the medical team in consultation with parents, and adolescents over the age of 17 will be treated as adults. Many researchers have set the age limit on 14-15 (Steinberg 2013: 263; Grisso 1980; Grisso, Steinberg, Woolard et al.

[14] Belgian Euthanasia Law, http://www.const-court.be/public/e/2015/2015-153e.pdf (accessed on November 26, 2017).

2003; Kuther 2003; Grisso and Vierling 1978: 412-427; Melton, Koocher and Saks 1983; Van Gool and De Lepeleire 2017).

Pressure and Abuse

It is not obvious that minors have the ability to formulate their opinions clearly and independently. More so when they are unhealthy. The propensity of adolescents to risky behaviour as part of their identity explorations, the sensation and thrill seeking which is the desire for novel and intense experiences, the relative freedoms they enjoy as they are less constrained by adult responsibilities (Arnett 1994; Arnett 2000: 469-480; Galvan, Hare, Voss et al 2007) – all these tendencies undermine adolescents' capacity to take well-considered decisions for themselves. Common sense dictates that we be extra careful when we discuss end-of-life issues. Minors are more vulnerable than adults and it is our duty as a liberal society to protect them.

Peer pressure and social acceptance are very important for minors in the school age. Minors are keenly aware of physical and personality characteristics. They come to see themselves as their peers do. Weiner and Elkind write that peer group help each child to recognize, sometimes with pleasure and sometimes with pain the unadulterated truth about their physical and personality traits. The social status minors are assigned by their peer group has a large bearing on whether they are cheerful, friendly, relaxed, sad or touchy (Weiner and Elkind 1972: 132-133). Peer pressure might influence a minor to choose a treatment option prematurely and without due diligence.

Furthermore, coping with adolescent patients at the end of their life can be a draining, difficult experience. The burden on the patient's family might be for some too

much to bear. Guardian's conscience would not allow deserting their children. But coping with the constant strain and pressure might prove to be too difficult. If the minors ask for euthanasia then this would solve the problem. After all, this is the wish of the child. Thus families might manipulate their suffering minors to opt for that decision (Pivodic, Van den Block, Pardon et al. 2014).[15] Disturbingly, evidence showed that among the most important reasons for physicians to conduct adult euthanasia are "family request" and "situation unbearable for family" (Dierickx, Deliens, Cohen and Chambaere 2015).[16] Minors are more vulnerable than adults and it is our duty as a liberal society to protect them. The opposition to the 2014 extension of the law assert that there are not enough effective mechanisms installed to protect adult patients, thus it is our responsibility to find mends to existing problems before creating potentially greater problems.

The *Euthanasia Act* prescribes that the minor's legal representatives should consent to the child's euthanasia. It is unclear what should be done in case of disagreement between patient and legal representative/s. The implicit assumption is that euthanasia is warranted only in case of consensus. The silence of law also assumes that parents on such an important issue manifest agreement. But the law does not explicitly prohibit euthanasia when consensus is lacking. Thus in principle such a case can take place. The legislature should have explicitly insisted on consensus of the minor, the legal representatives and the medical team.

Presently, very few minors have asked to die: four cases in people younger than

[15] One may argue that this study pertains to adult euthanasia and may not be generalizable to child euthanasia.

[16] For further discussion, see Cohen-Almagor 2001, 2011.

20 years were recorded in Belgium between 2002 and 2006, and none between 2007 and 2011 (Dan, Fonteyne, Clément de Cléty 2014; Samanta no date). In September 2016, a 17-year-old terminally-ill patient has become the first to be helped to die in Belgium since the 2014 amendment to the law (BBC 2016). Since then, a young Walloon has also asked to be euthanized (Brussels Times 2017). Is it sensible to pass a law for so few minors? The legislature wished to cater for the needs of all patients, applying egalitarian principle. No child should be left behind. The legislators did not wish to exclude anyone on the basis of age, viewing euthanasia as a right that all patients should have. Indeed, the medical profession should not neglect patients at the time they need help.

Palliative care

People, all people notwithstanding their age, need compassion and care at the end of life. Medicine provides many avenues to ease patient's pain. Sedatives are available to help patients at the end of life. Palliative care is available to address the physical aspects of the disease, and also the mental aspects; addressing patients' fears, concerns, anxieties, offering aid at the end of life. With the growing attention to palliative care, physicians may recognize new vistas that are open to them and be hesitant to perform mercy killing.

Belgium is said to have one of the best paediatric palliative care systems in Europe (Centeno, Lynch, Donea et al 2013). The *Euthanasia Act* stipulates that physicians need to inform patients of the possible therapeutic and palliative courses of action and their feasible consequences.[17] Research is needed to establish whether strategies to optimize

[17] Belgian Act on Euthanasia, Chapter II, Section 3, no. 2(1).

medical care, to promote support services such as social, psychological and spiritual care, and to enhance effective methods of communication with minors are in place. Providing minors with solace and care, helping them cope with their misery may make euthanasia unnecessary. This is good doctoring. The euthanasia option should be narrowed as much as possible.

Healthcare professionals can assist adolescents to make informed decisions. They can provide the context that would circumscribe potential impulsive decisions (Steinberg 2013). Research has shown that prognostic disclosure about incurable cancer is improved when a psychosocial clinician is involved in the care of the child. Parents understand how to talk to their child about death and dying when appropriate. This suggests that an interdisciplinary approach improves communication outcomes (Kassam, Skiadaresis, Alexander and Wolfe 2015). The overall advanced care planning for minors with cancer improved after a specialized palliative care program was developed at their institution (Wolfe, Hammel, Edwards et al 2008). Kassam et al (2015: 1412) found that children with advanced cancer who receive standard oncology care in Toronto are at higher risk of *not* receiving essential end-of-life communication. Studies should inquire what the situation is in Belgium, whether medical care professionals discuss with young patients, as they discuss with old patients, diagnosis and treatment options, positives and risks. Advanced care planning discussions should take place with every child, assuring that he or she knows what to expect. Uncertainty does not benefit one's health. It unnecessarily adds anxiety and sometime unwarranted worries. Strategies to optimize end-of-life communication for minors are needed. As mentioned, the law requires that a child and adolescent psychiatrist or psychologist must be consulted to assess the minor's

'capacity for discernment'. The law does not require guardians to receive psychological counselling. Psychological treatment to minors *and* their guardians should be made mandatory. Support to enable coping with the tragic situation is invaluable.

However, literature has shown that there are strong-minded people who wish to determine the time of their death notwithstanding palliative care (Emanuel, Onwuteaka-Philipsen, Urwin, and Cohen 2016; Cohen-Almagor 2001; 2004). It can be assumed that similarly palliative care will be of help to many sick minors, but not for all of them. Coping with pain and suffering can drain all of the patient's emotional strength, exhausting the ability to deal with other issues. A persistent euthanasia request could be attributed to intractable pain and to fundamental spiritual or existential suffering (Dierckx de Casterlé, Verpoort, De Bal et al. 2006). Palliative care may not resolve all cases. Physical suffering at the end of life cannot always be made bearable by means of palliative care. Thus unfortunately, although palliative care is important and should always be tried, it might not always be a solution for all adolescents.

Conclusion

The first medical duty is Do No Harm. Granting minors the ability to end their lives is problematic because we mature intellectually before we mature socially or emotionally. Issues of such momentous significance, of life and death, are ethically challenging.

We need to distinguish between Infants, children and adolescents. Infants are under 7 year-old; children are 7-14 year-old, while adolescents are over 14. The "rule of sevens" has reasonable grounding in science (Steinberg 2013: 265). It was suggested

that only adolescents have the capacity to make competent decisions (Grisso and Vierling 1978: 424).

Others

In the UK, the General Medical Council (GMC), the statutory regulator for the medical profession, published in 2010 guidance on treatment and care towards the end of life. The guidance states the important role that parents play in assessing their child's best interests and that physicians should work in partnership with them when considering medical options for their children. The GMC (2010) instructs physicians to provide emergency treatment without consent in order to save the life of a child or to prevent serious deterioration in child's health. 16 is deemed as an important age. The guidelines hold that when assessing a young person's capacity to consent, physicians should bear in mind that at 16 a young person can be presumed to have capacity to consent, and that a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand.

Given the physical, emotional, social and financial dependence of minors on others, given their young age and lack of experience in dealing with illness and pain, given their difficulties in making grave decisions, it is doubtful that young minors are able to make autonomous and voluntary decisions. This article raises a voice of caution. It objects to sweeping generalizations such as the use of the general term "minors" without age specification. There is a scale of development and we need to recognize the importance of this scale. While minors' participation in shared decision-making processes regarding treatment options with parents and care givers is to be encouraged, the extent

to which minors are able to take equal share in the process is gradual. Caring for the minors' best interests demands caution.

Let me conclude with the following guidelines that incorporate to the present law the main insights of this study:

The euthanasia request should be initiated by the minor patient.

Euthanasia for minors may be considered if the patient experiences continuous and unbearable physical suffering that cannot be alleviated and that will result in death within the foreseeable future.

Physical suffering that is not expected to result in death in the foreseeable future and psychological suffering are not legitimate grounds for euthanasia.

The physician must ascertain that the minor's legal representatives agree in writing with the minor's euthanasia request. Euthanasia will not be performed when there is disagreement among guardians.

The attending physician must consult a second independent physician and a child and adolescent psychiatrist or psychologist.

The psychologist or psychiatrist needs to check the medical file of the minor, examine her, ascertain her capacity for discernment, and testify to the latter in writing.

Minors might not be the best judges of their own interests. Generally speaking, maturity comes with age. It is suggested to restrict the age of minors eligible for euthanasia to 14.

The patient must be informed of the situation and the prognosis for recovery or escalation of the disease, with the suffering that it may involve. There must be an exchange of information between physicians and patients. Physicians should resort to clear and understandable terminology.

It must be ensured that the patient's decision is not a result of familial and environmental pressures. At times, patients may feel that they constitute a burden on their loved ones. It is the task of the medical team to examine patients' motives and to see to what extent they are affected by external pressures as opposed to a truly free will to die.

The physician must inform the minor patient and her legal representatives of the findings of the psychiatrist or psychologist.

The minor patient who requests euthanasia should receive comprehensive palliative care that addresses the physical, mental and spiritual concerns of the patient. The importance of comprehensive palliative care should not be underestimated.

Psychological counselling should be provided to both minor patients and their guardians.

Euthanasia is an act of last resort after exhausting all possible avenues for treatment.

There must be extensive documentation in the patient's medical file, including the disease diagnosis and prognosis by the attending and the consulting physicians; attempted treatments; the patient's reasons for seeking euthanasia; the patient's request in writing or documented on a video recording; documentation of conversations with the patient and her guardians; guardians' consent in writing and an explanation if for some reasons both parents do not sign the consent form; a psychological report confirming the patient's decision; a report of the palliative care specialist about course of treatments and their effects.

An annual report should be published documenting all cases of euthanasia for minors. The reports should be made available to the public. Discussions and debates about their findings should be promoted and encouraged.

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