

Child euthanasia: should we just not talk about it?

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Abstract

Belgium has recently extended its euthanasia legislation to minors, making it the first legislation in the world that does not specify any age limit. I consider two strands in the opposition to this legislation. First, I identify five arguments in the public debate to the effect that euthanasia for minors is somehow worse than euthanasia for adults—viz, arguments from weightiness, capability of discernment, pressure, sensitivity and sufficient palliative care—and show that these arguments are wanting. Second, there is another position in the public debate that wishes to keep the current age restriction on the books and have ethics boards exercise discretion in euthanasia decisions for minors. I interpret this position on the background of Velleman's 'Against the Right to Die' and show that, although costs remain substantial, it actually can provide some qualified support against extending euthanasia legislation to minors.

Since 2002 Belgium has had legislation permitting euthanasia for patients over the age of 18 years who are severely ill, experience constant and unbearable physical or mental suffering, and whose request for euthanasia is voluntary, well-considered and repeated. In December 2013 the Belgian Senate and in February 2014 the Belgian Chamber of Representatives voted in favour of extending the legislation to minors, making it the first euthanasia legislation in the world that does not specify any age limit. The conditions of the euthanasia law for minors are more restrictive: The young patient's ailment must be incurable and caused by accident or illness; the suffering must be physical (rather than mental) and impossible to alleviate; the expectation of death must be short-term; consent of the legal representatives (often the parents) is required; and the youth psychologist or psychiatrist must determine that the patient is capable of discernment.¹

There are three types of opponents of the extension of the euthanasia legislation to minors. *First*, some believe that euthanasia is morally impermissible in general and that lifting age restrictions just extends a morally reprehensible practice. I will not deal with arguments against euthanasia in general here. *Second*, some believe that euthanasia for minors is morally worse than for adults and hence legislation should not be extended to

minors. We find this position represented in the popular press and in an Open Letter signed by Belgian paediatricians.² I identify five arguments in support of this position and show that these arguments do not have much force. *Third*, some wish to retain the age restriction and keep the issue maximally out of the public debate, while hospital ethics boards should deal with requests from minors and exercise discretion. This position is represented in press interviews with Dr Marleen Renard, an oncologist in the University Hospital in Leuven (Belgium), and in an Opinion Text³ of a working group of the University Hospital of Leuven. David Velleman has defended a similar policy for euthanasia in general in his seminal article 'Against the Right to Die'.⁴ I show that Velleman's argument against legalising euthanasia has more traction for minors than for adults and can provide qualified support for retaining the age restriction in the legislation while letting ethics boards exercise discretion in rare cases, though the costs of this position remain substantial.

Five arguments for impermissibility

Here are five oft repeated arguments in support of the position that euthanasia for minors is morally worse than for adults^{2, 5}:

1. *Argument from Weightiness*. Minors should not be asked to make decisions in matters as weighty as euthanasia. We do not let minors vote or buy cigarettes and alcohol. Why should we let them make decisions about matters of life and death?⁵
2. *Argument from Capability of Discernment*. For a euthanasia request to be granted an assessment is required that the minor is capable of discernment. But minors are not capable of discernment.
3. *Argument from Pressure*. Parents and guardians will pressure minors in more or less subtle ways into making euthanasia decisions to find relief from their own emotional or financial needs.
4. *Argument from Sensitivity*. A minor will opt for euthanasia due to her sensitivity, that is, her desire to satisfy expectations from parents who can no longer bear the situation.
5. *Argument from Sufficient Palliative Care*. Euthanasia for minors is unnecessary: Physical suffering at the end of life can always be made bearable by means of palliative care; Requests for euthanasia come about due to poor palliative care.

Let us look at each of these arguments in turn.

1. *Argument from Weightiness.* This argument has rhetorical appeal, but it does not cut much ice. Consider the decision to withhold or withdraw treatment from a terminally ill minor when the benefit is minimal and the treatment is burdensome. This is also a weighty decision—maybe not as weighty as a euthanasia decision, but certainly much more weighty than voting or buying cigarettes and alcohol. Nonetheless, minors are very much involved in such decisions. This involvement is justified on grounds of a right to determine what happens in and to one's body, which underlies the 2002 Law on Patient Rights in Belgium and in other legislations.⁶ Hence, considering current legal practice, the sheer weightiness of a decision is not enough of a reason to take it out of the hands of minors.

2. *Argument from Capability of Discernment.* We restrict ourselves here to adolescent minors, since very young children clearly do not satisfy the condition of capability of discernment under any interpretation. The following response to the objection that minors are not capable of discernment is commonplace: Adolescent minors have often been dealing with their illness and confronting their mortality for a long time, and sometimes their whole lifetime, which enables them to approach their treatment and predicament in a measured way. In contrast, for adults, the dire prognosis and the concomitant end-of-life decisions often take them by surprise and they lack the inner resources to cope. Hence minors often are more rather than less capable of discernment than adults when it comes to making end-of-life decisions. This response to the objection requires empirical support which is beyond my remit here.

Let us ask instead: What is it for a person to be capable of discernment? We need to identify features of a decision that are indicative of capability of discernment in the context at hand. These features should be features in virtue of which the decision is authoritative, that is, is to be respected and not to be overruled. I propose that what makes a decision authoritative is (1) that the decision is responsive to reasons and (2) that the agent is the author of her decision, that is, she does not relinquish responsibility and defer the decision to others. I take these to be the features that are indicative of capability of discernment and that warrant the authoritativeness of the decision.

The Belgian Law builds in the safeguard that a youth psychologist or psychiatrist must determine that the minor is capable of discernment. Hence it is open to the possibility that minors have this capability. And indeed, I do not see why adolescent minors would lack conditions (1) and (2) in contexts of medical decision making. Arguments to the effect that minors typically are not capable of discernment confuse conditions (1) and (2) with other features in the neighbourhood that adolescent minors do indeed typically lack.

One line of argument is that minors are not capable of discernment because they have a different decision making style. They tend to be more impulsive, emotional and risk-prone which squares with what we know about human brain development.^{3, 7-9} But condition (1), that is, responsiveness to reasons, should not be confused with a particular decision making style.

Different ages may come with different typical decision making styles. The elderly, just like adolescent minors, have typical decision making styles that differ from the typical decision making style of middle-aged adults, but this does not make their decisions less responsive to reasons and hence less authoritative. The typical middle-aged adult's decision making style should not be held up as a standard for capability of discernment.

Nomy Arpaly^{10, 11} argues that the set of decisions that are responsive to reasons does not coincide with the set of decisions that are preceded by deliberation and are emotion-free. Reason-responsive decisions are compatible with various styles of decision making styles, and emotion-free deliberation does not guarantee that decisions are responsive to reasons. She gives the following illustration: the impulsive decision of a woman in emotional turmoil that she needs to leave her husband may be reason-responsive, whereas the conclusions on economic policy of a presidential aide whose deliberations in a cool hour are guided by conceit and self-deception may not be reason-responsive.

A second line of argument is that adolescent minors are not 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. Young adults typically come to form an identity with respect to world views in their late teens and early 20s. It is only at this later stage that they subject norms from parents and loved ones to critical scrutiny and come to act from a more deeply held conception of the good.^{3, 12}

However, condition (2) on capability of discernment, that is, authorship over one's decisions, should not be confused with identity formation and critical scrutiny. Critical scrutiny of norms is not required for authorship of one's decisions and is not what makes an end-of-life decision authoritative. If a minor who grows up in a socially conservative home adopts her parents' anti-euthanasia values, without subjecting them to much critical scrutiny, then we would be respectful of her rejection of euthanasia in favour of palliative care. So why should we not be equally respectful of a euthanasia request from a minor who grew up in a humanist home, even if she has not had the opportunity to subject her values to much critical scrutiny? Critical scrutiny is a Socratic ideal that, arguably, is constitutive of a life that is lived well, but it is not an aspect of capability of discernment by virtue of which decisions are to be considered authoritative.

The Open Letter² states that there is no objective test of capability of discernment for minors. Certainly such tests are less reliable than temperature readings. But my suspicion is that there would be much more agreement on particular cases when the assessment focuses on responsiveness to reasons and authorship over one's decisions and does not get side-tracked by decision making styles and identity formation, which are irrelevant to the authoritativeness of decisions.

3. *Argument from Pressure.* For this argument to work, the pressure towards euthanasia on a dying minor must somehow be greater than on a dying adult. Now, I would expect the pressure to be greater from an adult child on a dying parent than from a parent on a dying child. First, parents typically cling more to the lives of their children than adult children to the lives of their parents. Second, if medical care is socialised then a child's illness is typically less of a financial drain on a parent, whereas the cost of a parent's care facilities chip away from an inheritance. Third, a third party might reason that the elderly have had their fair innings, whereas a child has seen so preciously little of life. For all these reasons, I would expect pressure on the elderly towards euthanasia to be greater than on minors. Furthermore, with sufficient oversight one would also expect that the medical team would be able to recognise whether a minor is being pressured or not and block the euthanasia request on these grounds.

4. *Argument from Sensitivity.* Sensitivity from the side of the minors is the flip side of pressure from caretakers. The pressure may be kept fixed, but the sensitivity may differ from one person to the next. Minors are more sensitive to pressure than adults in their decision making. They are more prone to act on social expectations than on what they truly want. This is what is meant when opponents of child euthanasia say that minors are more 'vulnerable' than adults. A minor may recognise the fatigue in the eyes of her parents and read it as an invitation for her to request euthanasia. She may consciously or subconsciously reason, "I would personally opt for palliative care, but it is clear to me that it is too much for my parents. Since I do not want to disappoint them I will opt for euthanasia." It would indeed be problematic if we were to grant a minor a euthanasia request if this was her motivation.

To block an extension of euthanasia to minors, it must be more probable to find this motivation among minors than among adults. But is it more probable? I am not convinced. Granted, the fact that minors are more prone to act on pressure from loved ones (eg, peers) is a reason to think it is indeed more probable. But there are also reasons to think it less probable. First, I repeat my earlier point that the pressure from a parent on a child tends to be less than from a child on a parent. With less pressure, there is less to engage sensitivities. The pressure may even go the other way: A minor may request palliative care over euthanasia because she senses that parents find it very hard to let go. Second, an adult, and in particular a parent, typically feels more of a

sense of obligation that they need to make things well for their children—more so than a child feels an obligation to make things well for her parents.

5. *Argument from Sufficient Palliative Care.* If palliative care is sufficient for minors, then it is presumably also sufficient for adults. So this may be an argument against euthanasia in general, but not against the extension to minors. Furthermore, if palliative care can genuinely alleviate the suffering of all terminally ill minors, then legalisation of euthanasia will provide the proper incentive structure for its opponents. They will need to make the kind of palliative care that can alleviate the suffering accessible and affordable to minors, lobby the health sector, and educate palliative care providers in hospitals and hospice care. If the law is unnecessary then they should simply make it such by securing that its uptake will be minimal.

The discretion of ethics boards

Let us now turn to the third type of opponents of lifting age limits on euthanasia. We get a flavour of it in the following excerpt in the BBC news: Dr Marleen Renard, an oncologist responsible for paediatric palliative care at the University Hospital of Leuven, believes there is no need to legislate for child euthanasia, as there are already ways to end the suffering of a dying child. [She says:] “If we can't treat the pain, then we can sedate children. And if we see that the situation is really inhumane, we can go to our Ethics Committee and ask for permission to end life. But we have to have the consensus of a lot of people to do that.”¹³

Renard is even more explicit in the Belgian local press. When asked whether the University Hospital of Leuven would euthanise a child if the child asked for it she responds: If a 16 year old explicitly asks [for euthanasia] and satisfies all conditions, then we will grant the request. (...) But I have to say that I have never received such a request in 20 years of practice. (...) Do you really think that people care about is or is not stated in the law? The whole discussion about euthanasia for children is a non-issue that irritates us.¹⁴ [My translation]

The Opinion Text of the University Hospital of Leuven on euthanasia for minors, of which Renard is a coauthor, states: ... no legal framework can cover all real situations in all of their details. [New Paragraph] It may happen that a medical doctor will nonetheless find him or herself in a difficult situation and a conflict originates between two important principles, viz, ‘a doctor cannot and may not act in a life-ending manner outside of the legal framework’ versus ‘a doctor has to alleviate suffering’. In such difficult circumstances it can be justified to declare an emergency situation. This is

entirely defensible provided that the greatest care is taken: first with respect to the assessment of the suffering; second with respect to the expertise to alleviate this suffering; and third with respect to the question whether the active ending-of-life really is the only option.³ [My translation]

Let us try to lay out this position succinctly. There is no need for change in legislation or even to have any public debate—euthanasia for minors should remain illegal. Granted, there are circumstances in which euthanasia for minors would be justified, whatever the law says. At this point the ethics board should step in and exercise discretion.

This is a curious position. Why would we want to place a doctor into a conflict between what the law prescribes and what his or her professional code requires? Why would we not want to avoid such dilemmas through proper legislation?

Renard's position is reminiscent of Velleman.⁴ I quote from Velleman's concluding remarks: I feel most comfortable with permitting euthanasia (...) by a tacit failure to enforce the institutional rules that currently serve as barriers to justified euthanasia (...) [New Paragraph] I am (...) tempted to think that public policy regulating the relation between physician and patient should be weak and vague by design; and that insofar as the aim of medical ethics is to strengthen and sharpen such policy, medical ethics itself is a bad idea.⁴

Velleman is happy with barriers against euthanasia, in the same way as Renard is happy with barriers against euthanasia for minors, but there may be circumstances in which we should ignore these barriers. And furthermore we don't want strict conditions, designed by bioethicists and enshrined in law, under which a patient does have a right to euthanasia.

Velleman defends his position as follows. When euthanasia is not legally permitted then the dying patient has only one legally recognised option, viz, palliative care without exercising any choice. When euthanasia is permitted then the dying patient has two legally recognised options, viz, choosing for euthanasia or choosing for palliative care. Now if there is no choice, then a patient may prefer the available option, that is, palliative care, over the unavailable option, that is, euthanasia. However, if there is a choice, then she may prefer euthanasia over palliative care. Hence by making euthanasia available, the legislator reduces the welfare of a patient with such preferences—she can no longer have her favoured option, viz, palliative care without exercising any choice.

Why would a preference over palliative care drop below euthanasia once the option of euthanasia is offered—that is, once choice is offered? Start off with the option of euthanasia not being on the table and imagine that a patient is content with palliative care—she considers her last days in the palliative care unit worth living. Now introduce

the option of euthanasia. Once this option is offered then she can only get palliative care by making a choice for palliative care. But given that palliative care is a choice, there is now a social expectation that she should be able to give a justification for this choice. She may find herself at a loss to provide such a justification and consequently lose respect from loved ones and caregivers. Or, I may add, she may find palliative care with choice particularly hard because of the existential burden of decision making. Under these conditions, she considers her last days in palliative care no longer worth living. And hence she ranks euthanasia over palliative care with choice.

If everyone's preferences would be accurately described as palliative care without choice over euthanasia or palliative care with choice, then it is clear that we should not legalise euthanasia. However, there are people who genuinely prefer euthanasia to palliative care whether there is or is not a choice. And furthermore, there are also people who prefer palliative care with choice to either euthanasia or palliative care without choice: The knowledge that they have a choice gives them the strength to endure. Hence, by not legalising euthanasia the welfare of people with the latter two preference patterns is decreased.

To accommodate these people, we can do the following double act: Do not legalise euthanasia but let there be a tacit understanding that one can make a special request to the hospital ethics board. Boards will exercise discretion, looking at the particularities of each case. If you want euthanasia and you have a reasonable case, you can have it. If you want palliative care empowered by the knowledge that you could get euthanasia if you wanted it, then the knowledge that you can put in a request will give you the strength to endure—or maybe your request has already been granted and it is with this permission in hand that you are able to endure. But we don't talk about all this too much, since we don't want to put the euthanasia option on the table: Once it's on the table we can no longer satisfy the preference of those who want palliative care without choice.

This double act requires framing. A person with a preference for palliative care without choice frames the situation by focusing on euthanasia being illegal—the option is not on the table. Persons with a preference for euthanasia or palliative care with choice frame the situation by focusing on the option that they can file a request with the ethics board. By choosing the proper frame, we can guarantee preference satisfaction to a maximal number of people.

For such framing to succeed, we need to be mindful of all parties. For those who want palliative care without choice, we make sure that there is no clear and publicly available set of conditions under which such requests will be granted. For this we need minimal public discussion. Once there is such a set of conditions then for those people who satisfy these conditions palliative care without choice is no longer feasible. At the same

time, for those who want euthanasia or palliative care with choice, there should be a modicum of reasonable expectations. We can do so by sharing models of good practice between ethics boards.

Nonetheless, this is a precarious position. Once too many requests pass the boards of particular hospitals and the decision making of these boards becomes clear, then euthanasia moves de facto onto the table and palliative care without choice is no longer available. The strategy may be temporarily welfare enhancing though and the precarious situation may hold for a while.

It also comes at various costs. First, there is a cost in comparison to strict criminalisation of euthanasia. The policy described does not give patients who prefer palliative care without choice everything they want. Euthanasia is not on the table in plain view, but it is still on the table—viz, there is the common knowledge that patients could make a request to the ethics board. Second, there are various costs in comparison to legalisation: Ethics boards must work under conditions of relative legal vagueness and uncertainty requiring more moral courage than one might be willing to expect from such boards; The lack of transparency makes it more difficult to hold ethics boards accountable; Patients with a clear preference for euthanasia might not know that they can put in such a request—what they know in this respect will depend on the information that medical practitioners are willing to divulge, often based on their own moral views on euthanasia; And, even if they do know that they can put in such requests, they face the uncertainty and unreliability of a board decision which some patients will experience as unfair and as an indignity.

Surplus plausibility of Velleman's argument for minors

Velleman's argument is a utilitarian argument against the legalisation of euthanasia, while giving ethics boards some leeway and discretion in the matter. Does it succeed? As utilitarian arguments go, much will depend on empirical details concerning the society in question which will feed into the cost–benefit analysis. Might it succeed against the extension of euthanasia legislation to minors? For the argument to be successful against lifting age restrictions there must be certain features about euthanasia for minors, as opposed to euthanasia for adults, which make a difference to the cost–benefit analysis. There are indeed two respects in which the cost–benefit analysis comes out more favourably when we consider euthanasia for minors.

First, for Velleman's position to be feasible, it must be the case that the preference for euthanasia over palliative care without choice is a minority preference. The more

patients the ethics board has to accommodate with this preference structure, the harder it is to keep the cat in the bag and the more visible the euthanasia option will be. Renard says that she has never had a minor ask for euthanasia over her 20 years of practice.¹⁴ The Opinion Text³ states that there have been no requests for euthanasia in the Netherlands among 12–29-year-olds from 2006 to 2011, though it should be added that the database¹⁵ the authors rely on does not pretend to be complete. (In the Netherlands, euthanasia has been legal since 2002 for 12–17-year-olds as well as for adults.) Requests for euthanasia only enter for age groups over 29 years. Given the strong preference for palliative care (even palliative care with choice) among younger patients, we may expect very few minors to rank euthanasia above palliative care without choice. Such rare cases can then be dealt with in ethics boards. Given the low numbers of requests, conditions can remain opaque and the euthanasia option won't be out in the open.

Second, it must be the case that patients do not consider it an indignity that the final decision is taken out of their hands. Some adults would object to this and consider it a violation of their autonomy—they do not want their fate decided by an ethics board. But minors typically accept that they are being aided in their decision making. They are more willing to accept some fiduciary model of decision making in which they have some input, but in which trustees make the final decision for them. So it is more acceptable for minors to let ethics boards be involved in the decision than it is for adults.

There is also another advantage. Note that the Belgian legislation requires parental consent. It is an open question whether parental consent is a reasonable requirement. What could be the purpose? The euthanasia requests are restricted to end-of-life cases, so withholding parental consent does not introduce a waiting time for reconsideration. If minors could ask for euthanasia on grounds of mental health then the clause would make sense on these grounds—but the legislation does not permit this. Furthermore, a determination is required that the minor is capable of discernment, so parental consent does not complement for a lack of capability of discernment.

I can see three responses. First, adding this clause may just be an issue of political expediency—it may draw in a few more votes on the cusp. Second, parental consent may be considered a safeguard if one would expect that medical practitioners will start slacking on the conditions of end of life and capability of discernment. Third, we may think that a parent is so deeply affected by the minor's decision that this overrules the minor's right to be solely decisive. These may all be good reasons, but parental consent remains worrisome when we envision a minor who elects euthanasia, but consent is not granted due to dysfunctional family relations or a religious ideology from which the minor has distanced herself. There will clearly be cases in which parental consent operates as an unreasonable impediment.

We do not want to stake out a position on whether it is advisable to include parental consent in legislation on euthanasia for minors—this will be a contested issue, as it is in legislation on abortion for minors. What is interesting for our purposes is that, on Renard's position, the ethics board can take into account the parental position in its decision making without making parental consent a necessary condition. The threat of lawsuits is not unreal but the court may not side with the parent(s) and there is room for developing models of good practice in this contested area.

Conclusion

Opponents of the extension of the euthanasia legislation in Belgium argue that euthanasia for minors is worse than euthanasia for adults because such end-of-life decisions are too weighty for minors, because they are not capable of discernment, because they will be subject to pressure, because they are particularly sensitive or because there is sufficient palliative care for them. None of these arguments provide sufficient reason to refrain from extending euthanasia legislation to minors.

There is another line of argumentation in the Belgian debate: We should not extend legislation to minors but we should deal with individual requests in ethics boards who may grant requests in particular cases even if this contravenes the age restriction. Velleman provides a utilitarian argument to the same effect for euthanasia in general based on the fact that less choice may be better than more given particular preference structures.

As utilitarian arguments go, it is not easy to balance the costs and benefits of this position. The position has more traction for minors than for adults due to the low number of requests and the greater acceptance of fiduciary decision making for minors and hence it can provide some qualified support for not extending the legislation to minors. The costs remain substantial though, viz, the legal uncertainty, the accountability of ethics boards, the variability in their decisions and the lack of transparency of procedures when there is no public discussion.

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