Does the Belgian law legalising euthanasia for minors really address the needs of life-limited children?

Marie Friedel

The Belgian law on euthanasia for adults was approved in 2002, the same year as laws on patients' rights and on palliative care, which mostly address the needs of adults. On 13 February 2014, an extension of the euthanasia law that decriminalises euthanasia for children, without age restriction, was approved by the House of Representatives in Brussels (Belgian Ministry of Justice, 2014). In the opinion of the author, this extension reveals that paediatric palliative care is not sufficiently advocated for in Belgium. This is in line with the suggestion from the European Association for Palliative Care (2011) that the degree of medical specialisation in palliative care might be lower in countries where euthanasia is legalised. This article aims to analyse key aspects of the new law and whether it really addresses the needs of life-limited children.

Content and consultation

Requirements

Great strides toward clarification and collaboration to safeguard precise implementation of the law were achieved by the Royal Belgian Academy of Medicine (2014a; 2014b). As a result, the law requires strict conditions to be met: the request for euthanasia must be made in writing by the child themselves, who must be diagnosed with an incurable, terminal illness, and must be suffering from constant and untreatable physical pain. Furthermore, the child must be assessed by a psychologist or a child psychiatrist to gauge their judgement/competence and their comprehension of euthanasia. Parental consent is also obligatory.

However, constructive reflections from Clément de Cléty et al (2013) that would have helped to define whether self-requested euthanasia for children could be considered appropriate were not taken into account by the Senate. These reflections included that there is a need to promote and finance paediatric palliative care services; that a request for euthanasia should be submitted to and assessed not only by a physician or psychologist but also by paediatric palliative care teams; that all family members, including siblings, should be supported before, during, and after an act of euthanasia; that systematic debriefing of the team members involved would be needed; and that there is a need for a prospective study of the quantity of child requests for euthanasia that could be expected.

Consultation

Furthermore, as reported by Cousturié (2014), 160 paediatricians called on the government to postpone the vote in order to clarify the law, albeit they did so on the late date of 11 February. In addition, representatives of all of the main religions and philosophical committees asked to be heard by the commission but were refused an opportunity to present their points of view (Hovine, 2014). The ethics committee of a Belgian nurses' association (Association Belge des Praticiens de l'Art Infirmier, 2013) also alerted the Senate Commission to the lack of need for a law, arguing that the responsibility for end-of-life decisions should remain with paediatricians, who are best placed to make such decisions given their professional expertise and extensive knowledge of the families with whom they work (prior to the law, paediatricians could in effect take end-of-life decisions when faced with a child in unbearable pain, by administering medication to combat that pain and accepting that hastened death may result as a secondary effect). Finally, the bill was not submitted to the Belgian Council of State, which has an advisory role in establishing new laws. Taken together, these points demonstrate that there was insufficient consultation prior to the final vote.

Understanding and inclusion of end-of-life concepts

During times of public debate, conflicting and unclear terminologies give rise to confusion and misapprehensions. In Belgium, terms such as 'treatment withdrawal', 'sedation', and 'pain management' are still confused with euthanasia,

Marie Friedel is Paediatric Nurse and Lecturer in Paediatric Palliative Care, Haute Ecole Léonard De Vinci, Promenade de l'Alma 50, 1200 Woluwe-Saint-Lambert, Brussels, Belgium

Email: mariefriedelcastorini@gmail.com

while palliative care is sometimes misconstrued as compassionate care, care that prolongs life (sometimes in agony), and care that is only introduced when all treatments have failed. Understanding of paediatric palliative care as holistic, family centred care that is delivered by an interdisciplinary team, frequently in parallel with curative care, in order to improve the quality of the child's life (Oriot, 2006; Abu-Saad Huijer et al, 2007) is not yet widespread in Belgium. Nor are these characteristics mentioned in the new law.

'The law considers the presence of unrelieved pain to be sufficient to justify euthanasia. However, international studies show that physical suffering in children at the end of life is not sufficiently treated ...'

Meeting the needs of life-limited children

The law considers the presence of unrelieved pain to be sufficient to justify euthanasia. However, international studies show that physical suffering in children at the end of life is not sufficiently treated (Wolfe et al, 2000; von Lützau et al, 2012), so it is questionable whether euthanasia is an appropriate response to these children's suffering. Health professionals should be helped to offer optimum pain and symptom management, but this is not tackled by the new law, which merely states that information about palliative care must be offered to the family.

Practical considerations

How the criteria concerning the child's capacity to make judgements might actually be applied in practice raises additional concerns. In particular, it may be undesirable to bring into the team yet another person who the child does not know (the psychological assessor) while he or she is in a state of unrelieved suffering. Furthermore, uncertainty remains as to which psychological assessment tool(s) should be used to measure the child's capacity to make judgements. Moreover, there are questions around what should be done if the parents disagree about the end-of-life decision. One wonders too how giving children the autonomy to request euthanasia will affect the grief of their parents and siblings.

Ethical considerations

Beauchamp and Childress (1994) referred to four ethical principles that may have been partially misapplied in the new law: beneficence, non-maleficence, justice, and autonomy.

Beneficence

The aim of care for children with a life-limiting condition is to reduce suffering. It should be remembered that pain is a subjective experience with not just physical but also psychosocial and spiritual components (International Association for the Study of Pain, 1994). It is not sufficient to attempt to treat only physical pain before resorting to euthanasia: the child and their family's total pain must be holistically addressed. Attention to total pain may mitigate considerations of hastening death among parents of children with cancer (Dussel et al, 2010). There have been rare occasions when parents have requested euthanasia for their child; some of these parents changed their minds when their child's pain was treated and when they were supported by an interdisciplinary team that provided them with respite services (Champagne and Mongeau, 2012).

Non-maleficence

Involving a child in decision making is a well-accepted principle. However, giving children the ability to request euthanasia and then requiring parents to consent to it places a unique burden on the parents, and may have an impact on parental and sibling bereavement. The law says that two independent physicians have to agree with the request before it can be carried out, but it would be less harmful for the physician to take responsibility for the end-of-life decision after considering the child's suffering. Furthermore, Sullivan et al's (2014) study suggested that parents expect the physician to take responsibility for end-of-life decisions.

Justice

The law was intended to make the possibility of euthanasia equally available to all, regardless of age. However, it requires that children have the capacity to make the request. Therefore, children who are unable to express their views, e.g. very young or severely disabled children, are denied equality. To achieve genuine equality in the care of children and adults, the government ought to legislate to bring about effective palliative care for children, as there are no groups for whom palliative care cannot provide benefit.

Autonomy

It is misleading to suggest that children can ever be completely autonomous in requesting euthanasia, given that their development is embedded in a variety of relations that influence their perceptions and choices. Bluebond-Langner (1978) showed that children's perceptions about death are strongly influenced by their environment and the support they receive. Children are also instinctively loyal to their parents (Bluebond-Langner et al, 2012). Thus a young child may not be able to give a completely autonomous decision, however much the illness may have increased their maturity. Furthermore, individuals can only be autonomous in their decision making if they are presented with a genuine range of options, which they will not have while palliative care remains misunderstood, underfunded, and suboptimally delivered. To enable true autonomy, a society must first be able to offer an alternative to euthanasia.

> *‘Individuals can only be autonomous in their decision making if they are presented with a genuine range of options, which they will not have while palliative care remains misunderstood, underfunded, and suboptimally delivered.’*

Conclusion

The process leading to the law on euthanasia and minors prompted a much-needed debate about the dying of children. Death in general, but particularly the death of children, is profoundly challenging and forces us to consider our own mortality. However, uncertainty remains about the applicability of this law in practice. The law does not adequately take into account the complex relations between a life-limited child, their family, and their caregiver. There is good reason to be concerned about the reliability and validity of the tools available to assess a child's competence to request euthanasia. Above all, the law shifts the weight of responsibility about end-of-life decisions to children and their parents. In essence, this law does not address the complexity of paediatric end-of-life situations, which deserve much greater attention than a symbolic legal solution.

Caring for children with life-limiting illnesses involves making difficult choices while providing individualised care based on the clinical, psychological, and social needs of the child and his/her family. In these situations, decisions are never clear-cut. Provision of well-adjusted care that attempts to address the needs of life-limited children and their families requires a competent interdisciplinary team (Nancarrow et al, 2013) and systematically planned discussions about ethical considerations in the intentions, actions, and consequences of paediatric palliative care (Habermas, 1999; Hain, 2014).

A more constructive approach than upholding this new law would be to use all the means at our disposal to find ways of relieving the psychological, physical, social, and spiritual suffering of life-limited children and their families. This would require education about paediatric palliative care and steps to improve the quality and availability of such care. For that, it would be necessary to extend the existing Belgian law about palliative care (Belgian Ministry of Justice, 2002) to enshrine the right of children to benefit from high-quality palliative care. This would be a coherent policy in accordance with the recent resolution of the 67th World Health Assembly (2014) to integrate palliative care into national health policies. IJPN

Acknowledgments
My warmest thanks go to Jenny Hunt and Shelagh McConnell for their support with the English translation. I am also very grateful to Professor Stéphan Clément de Cléty for his proofreading and his long-lasting support of paediatric palliative care in Belgium.

Abu-Saad Huijer H, Benini F, Cornaglia Ferraris P et al (2007) Standards for paediatric palliative care in Europe. *Eur J Palliat Care* **14**: 2–7

Association Belge des Praticiens de l'Art Infirmier (2013) A propos de l'euthanasie sur les mineurs. http://bit.ly/1kFK8cI (accessed 5 May 2014)

Beauchamp T, Childress J (1994) *Principles of Biomedical Ethics*. 4th edn. Oxford University Press, Oxford

Belgian Ministry of Justice (2002) Belgian Law on Palliative Care. http://bit.ly/1jtDEOv (accessed 5 May 2014)

Belgian Ministry of Justice (2014) Law that modifies the law of 28 May 2002 that relates to euthanasia, with the aim to extend euthanasia for minors. [In French] http://bit.ly/1l4xKJ7 (accessed 12 June 2014)

Bluebond-Langner M (1978) *The Private World of Dying Children*. Princeton University Press, Princeton NJ

Bluebond-Langner M, DeCicco A, Nordquest Schwallie M (2012) Children's views of death. In: Goldman A, Hain R, Liben S, eds. *Oxford Textbook of Palliative care in Children*. 2nd edn. Oxford University Press, Oxford: 68–77

Champagne M, Mongeau S (2012) Effects of respite care services in a children's hospice: the parents' point of view. *J Palliat Care* **28**(4): 245–51

Clément de Cléty S, Dan B, Fonteyne C (2013) Ethical reflections about end of life and euthanasia for children. Royal Belgian Academy of Medicine, Committee on Ethic and End of life, Subcommittee on End of Life for Children

Cousturié I (2014) Euthanasie des mineurs en Belgique: 160 pédiatres s'opposent au projet de loi. [In French] http://bit.ly/1oh9HJl (accessed 5 March 2014)

Dussel V, Joffe S, Hilden JM et al (2010) Considerations about hastening death among parents of children who die of cancer. *Arch Pediatr Adolesc Med* **164**(3): 231–7

European Association for Palliative Care (2011) Palliative Care Development in Countries with a Euthanasia Law. http://bit.ly/1lcAYV8 (accessed 12 June 2014)

Habermas J (1999) *De l'éthique de la Discussion*. Flammarion

Hain R (2014) Oral presentation. 1st ICPCN Conference, Mumbai, 10–12 February 2014

Hovine A (2014) Je voterai contre la loi sur l'euthanasie des enfants. En âme et conscience. [In French] http://bit.ly/1nyqSCx (accessed 12 June 2014)

International Association for the Study of Pain (1994) IASP taxonomy. http://bit.ly/1i3xYjw (accessed 16 June 2014)

Nancarrow SA, Booth A, Ariss S, Smith T, Enderby P, Roots A (2013) Ten principles of good interdisciplinary team work. *Hum Resour Health* **11**(1): 19

Oriot D (2006) Définition des soins palliatifs pédiatriques. [In French] http://bit.ly/1qUhKcf (accessed 16 June 2014)

Royal Belgian Academy of Medicine (2014a) Avis du 21 janvier 2014 des Académies de Médecine de Belgique concernant l'extension aux mineurs d'age de la loi relative à l'euthanasie du 28 mai 2002. [In French] ARMB

Royal Belgian Academy of Medicine (2014b) Advice about the law on euthanasia extended to children. ARMB

Sullivan J, Monagle P, Gillam L (2014) What parents want from doctors in end-of-life decision-making for children. *Arch Dis Child* **99**(3): 216–20

von Lützau P, Otto M, Hechler T et al (2012) Children dying from cancer: parents' perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions. *J Palliat Care* **28**(4): 274–81

Wolfe J, Grier HE, Klar N et al (2000) Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* **342**(5): 326–33

World Health Assembly (2014) Strengthening of palliative care as a component of integrated treatment within the continuum of care. http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf (accessed 12 June 2014)