

The Belgian case of euthanasia for children, solution or problem?

Filipa Martins Silva¹, Rui Nunes²

Abstract

By extending its euthanasia law to minors in 2014, Belgium has fuelled the international debate on this issue. In fact, Medicine does not always have something to offer when it comes to a child's serious disease. Nevertheless, should euthanasia be considered a viable solution? Keeping in mind the Belgian reality, this article analyses the relevance of the new law, considering, on one hand, children's growing self-determination capacity and, on the other hand, their lack of "life experience". Let's not forget, in addition, classical arguments against euthanasia, such as the disrespect for the value of human life and the eventual approaching of the slippery slope. An obvious solution for this problem is the implementation of a proper palliative care system. However, evidence about the quality of pediatric end-of-life care is scarce. Therefore, additional investigation is necessary in order to formulate and propose an appropriate public policy on the matter.

Keywords: Euthanasia. Child. Belgium. Palliative care.

Resumo

Caso belga de eutanásia em crianças: solução ou problema?

A aprovação da extensão da prática da eutanásia a menores de idade em 2014, pela Bélgica, reacendeu o debate internacional sobre as decisões médicas em fim de vida em crianças. De fato, a medicina nem sempre tem resposta para a doença grave de uma criança. No entanto, será a eutanásia uma solução equacionável? Partindo da realidade belga, este artigo analisa a premência da nova legislação, considerando, por um lado, a capacidade crescente de autodeterminação das crianças e, por outro, a sua falta de "experiência de vida", não esquecendo argumentos clássicos que contrariam a prática da eutanásia, como o desrespeito pelo valor da vida humana e a eventual concretização do argumento da ladeira escorregadia. Uma solução óbvia passa pela realização de cuidados paliativos apropriados. Todavia, sendo escassa a evidência sobre a qualidade dos cuidados pediátricos em fim de vida, é necessária investigação adicional para que se possam formular e propor políticas públicas adequadas a respeito da matéria.

Palavras-chave: Eutanásia. Criança. Bélgica. Cuidados paliativos.

Resumen

Caso belga de la eutanasia en niños, ¿solución o problema?

La aprobación de la práctica de la extensión de la eutanasia a menores en 2014 por Bélgica ha reavivado el debate internacional sobre las decisiones médicas en el fin de la vida de los niños. De hecho, la medicina no siempre ha de responder a la enfermedad grave de un hijo. Sin embargo, ¿debería considerarse la eutanasia como una solución viable? Partiendo de la realidad belga, este artículo analiza la emergencia de la nueva ley: considerando, por un lado, la creciente capacidad de autodeterminación de los niños y, en segundo lugar, su falta de "experiencia de vida", sin olvidar los clásicos argumentos que contradicen la práctica de la eutanasia, como el desprecio por el valor de la vida humana y la eventual realización de "rampa de deslizamiento". Una solución obvia es implementar los cuidados paliativos adecuados. Sin embargo, puesto que las pruebas sobre la calidad de la atención con el fin de la vida pediátrica son escasas, se requiere investigación adicional para poder formular y proponer políticas públicas adecuadas en esta área.

Palabras-clave: Eutanasia. Niño. Bélgica. Cuidados paliativos.

1. **Mestre** anafilpacmsilva@gmail.com 2. **Doutor** ruinunes@med.up.pt – Faculdade de Medicina da Universidade do Porto (FMUP/CFM), Porto, Portugal.

Correspondência

Filipa Martins Silva – Rua Mestre Guilherme Camarinha, 2º E, frente, nº 7.912B, Paranhos, CEP 4200-537. Porto, Portugal.

Declaram não haver conflito de interesse.

Authority and responsibility, once an exclusive domain of the physician in medicine, are now shared with the patient, who is given, as a mentally and emotionally capable individual, the freedom to choose from several options. The risks and benefits related to those options should be explained in advance¹. Add to that scenario technical advances and demographic changes which have given medicine a relevant role in determining the circumstances of death. Increasingly, death derives not only from the natural course of a deadly disease, but also from a number of medical decisions, such as the assignment of treatments that prolong the life of critical patients or the suspension of those treatments (life-saving technology can sometimes only delay the process of death) and the relief of severe symptoms by the use of drugs which can cause, as possible side effects, acceleration of death. This scenario can create difficult situations such as when patients feel hopeless, after realising that their suffering is unbearable, and ask the doctor to help them to end their lives²⁻⁵.

To provide appropriate care to a dying patient implies, therefore, to be able to handle complex situations and requires knowledge of ethical rules and controversies, pharmacological and non-pharmacological tools to manage symptoms as well as the risks and benefits of medical technology. Equally important, it is necessary to know how to discuss these issues with the patients and their families, while continuing to support them in what is probably one of the most difficult times of their lives⁵.

Over a third of all deaths are preceded, in several European countries, by end-of-life medical decisions⁶. The assignment or suspension of treatments and the relief of severe symptoms are generally considered common medical practice⁷. Still, in most countries, doctors are not allowed to accept a request for euthanasia (death resulting from the administration of drugs by a physician, with the explicit intention to hasten death)², although this is a topic which is being increasingly debated^{2-4,8}.

In 2002, The Netherlands and Belgium had adopted a law decriminalising euthanasia in certain conditions. A similar law was adopted in Luxembourg in 2009. This situation differs from the physician-assisted suicide, procedure decriminalised in the Netherlands, Luxembourg, Switzerland and four US states (Oregon, Washington, Montana and Vermont). In this case, the doctor prescribes a lethal drug but the patient will carry out a self-administration^{3,8-10}.

End-of-life medical decisions about minors are an even more complex matter and, although it

has received less attention, the subject is of growing interest in the scientific community⁸. In fact, the international debate on end-of-life medical decisions about children was reignited after Belgium approved, in February 2014, a law on euthanasia without reference to age limits⁹.

Despite the great scientific and technological advances, medicine doesn't always have the answer to children's serious illnesses. Therefore, minor patients and their families may have to face the reality of death in childhood⁶. The child, as a vulnerable individual, requires special care and, for this reason, end-of-life medical decisions concerning minors represent additional clinical and ethical challenges. The Convention on the Rights of the Child¹¹, adopted by the UNICEF, mentions four relevant rights about this subject: the inherent right to life (Article 6); the right to express their opinions freely (Article 12), the best interests of the child (Article 3) and the right to health care and education (Articles 24 and 28)¹².

The triangular interaction between health professionals, parents and patients makes the decision making particularly difficult. Parents - who in general are unprepared to deal with the devastating possibility of death of their child and act as the child's advocates - are usually the main intermediaries in communication with health professionals^{5,8}. When it comes to adults, there is often some prior information of the patient's wishes regarding decisions about end-of-life, decisions that family members might be aware of and use in order to make up their minds¹³.

In the case of minors it turns out that they don't always have the cognitive capacity to reflect and verbalise such desires and, therefore, parents and doctors have to make decisions in accordance with the best interests of the child¹⁴. In fact, the involvement of minors in the decision making process is not linear and depends on age, level of competence, nature of decisions and experience with chronic diseases. In ethical terms, this interaction between the role of parents as legal representatives and the child's decision making capacity raises important questions about the rights of minors to self-determination, the limits of parental control and the balance between the best interests of the patient and his or her wishes^{5,8}.

Studies show that^{5,6,14} most end-of-life care of children occurs in hospitals, especially in pediatric intensive care units (PICU). The decision to suspend the life support treatment is the most common - 30% to 60% of deaths in the PICU are preceded by a process of active suspension, usually starting with

the decision to not resuscitate, progressing then to the removal of assisted ventilation. Sedatives and analgesics are also regularly used, mainly after the decision to withdrawal treatment, emphasising the patient's comfort and palliation of symptoms^{5,6,14}. In about 3% of the cases, the death of the child is preceded by an euthanasia request (about a third of the cases are requested by the minor and the rest is requested by the family)⁶.

The causes of death in children depend on age: 50% of children with serious illnesses die during the first year of life; children older than one year die mainly due to external causes, such as traumatic injuries, followed by chronic diseases such as cancer, which is the most common cause of death by disease in children over 1 year. Situations such as frequent hospitalisation of chronic patients, gradual loss of vital functions and increased need for technical or medical support, considering the risk of death that they entail, must motivate the reflection on the goals of the treatment¹⁵.

In this context, this article aims to analyse the complexity of end-of-life medical decisions regarding children, in order to understand if euthanasia is a possible solution or, on the other hand, worsen the complexity of the decision making. Starting from the Belgian reality, the urgency of the new law will be evaluated, highlighting its advantages and disadvantages in the light of the doctrine of human dignity. It will be considered, for that purpose, the principles and the current practice of pediatric palliative care as well as how medical ethics should position itself in the face of social transformation resulting from the approval of this law.

Euthanasia: the Belgian case

In 2002, a few weeks after the Netherlands new legislation, Belgium adopted a law decriminalising euthanasia under certain well defined conditions. These conditions include the voluntary request, thoughtful and repeated by a patient in unbearable and not mitigable suffering resulting from serious illness and incurable. The doctor must discuss other possible options with the patient, including palliative care⁹.

It is also necessary that the patient consult with another doctor before taking a decision on euthanasia. Under this law, euthanasia is a medical procedure, and the patient must be of legal age (*i.e.*, have completed 18 years of age) or an emancipated minor (usually as a result of marriage or, more rare-

ly, a court decision declaring the minor competent to deal with the situation)⁹.

A study in Belgian Flanders⁸ shows that, between June 2007 and November 2008, end-of-life medical decisions preceded 36.4% of deaths of children aged 1 to 17 years (which is consistent with findings in Holland). Excluding sudden deaths, these decisions were taken in 78% of cases. The decisions of no treatment (10.3%) are generally associated with the administration of drugs for relief of symptoms, the latter being the most frequent decision (18.2%).

There was involuntary euthanasia (poor prognosis and expectations of lower quality of life were the reasons used by doctors for this practice) in 7.9% of the cases studied in this region, against 7.2% in the Netherlands. It should be noted that, according to this study⁸, medically assisted death is not an isolated practice in Belgium, but rather part of a comprehensive process of care, usually resulting from the decision to increase the dose of morphine, with the consent of the parents, after a long disease period.

During the period of study, there had been no request for euthanasia in minors whilst four cases of people under 20 years were registered between 2002 and 2006. On the other hand, there are about 5 cases per year in the Netherlands. This disparity may be due to differences in how the cases are reported, and this information about the number of requests for euthanasia in minors in Belgium might not be reliable.^{6,8,9}

The analysis of doctor's attitudes in the monitoring of under-18s who died showed that most of them seem to accept medically assisted death in children in certain circumstances, revealing to be favourable to the extension of the law to minors, as long as the law takes into account the capacity of decision of the child¹⁶. With regard to other health professionals, the 2009 study shows that PICU's nurses are often involved in end-of-life medical practices (including administration of drugs that cause death), although they have limited participation in the decision making. The termination of life presents two controversies: on the one hand, euthanasia in children was illegal at the time and, on the other hand, the law stipulates that euthanasia must be performed by a doctor. Most nurses are also in favor of extending the euthanasia law to minors⁶.

In parliamentary debates in Belgium, age was considered less relevant when compared to the capacity to understand the situation and its impli-

cations. Thus, the bill which was approved by the Senate on December 12, 2013 and promulgated by the House of Representatives on February 13, 2014 (after two days of debate, with the majority in favor - 86 against 44 - and 12 abstentions) does not mention age limits^{9,12}. In this way, Belgium becomes the first country in the world to legally abolish all age restrictions for the performing of euthanasia¹⁷. This situation differs from the Dutch law, which allows terminally ill children who are older than 12 years to request euthanasia but with a mandatory parental consent if they are younger than 16 years old. From that age it is only necessary to inform the parents but their authorisation is not required^{9,12}. Euthanasia is only allowed if the patient is older than 18 years old in Luxembourg¹⁷.

The extension of the Belgian law to children rests on the same assumptions as that of adults and some specific criteria must be met:

- 1) "capacity for discernment" - carefully evaluated by a multidisciplinary pediatrics team, including a clinical psychologist or psychiatrist and the presentation of a written opinion;
- 2) the context of terminal or incurable disease that will lead to death within a short period of time (which should be agreed by the paediatrician and an independent doctor) with constant and unbearable suffering of the child;
- 3) written request from the child;
- 4) consent of the parents or legal representative;
- 5) The physician's responsibility and provision of psychological support to all involved^{9,12,17}.

Although extended to children, this new law restricts its application when it omits psychiatric disorders and, more importantly, when it specifies the need of a capacity of discernment, which unequivocally excludes children with consciousness changes, children with intellectual deficits, very young children and newborns⁹. Minors without cognitive or motor ability to express and write their request are also excluded¹². The law contrasts, therefore, with the Groningen Protocol¹⁸, a practice resorted to in the Netherlands and which results in active euthanasia, with parental consent, of a newborn with very severe prognosis or unbearable suffering^{9,18}. Although parents have to agree with the request, the Belgian law also excludes, undoubtedly, all requests by someone other than the patient, such as parents or professional health carers⁹. There is a committee that oversees the practice of euthanasia to ensure that the criteria are being properly fulfilled¹⁹.

The need for pediatric palliative care

One option to minimize the need for patients to request euthanasia is to improve palliative care and increase psychological support. These practices might make life tolerable although it doesn't necessarily prolong it^{12,20}. An appropriate palliation implies that the disease runs its natural course whilst the treatment seeks to promote the maximum quality of life for patients, as the time to death is in general uncertain (the outcome of this episode of disease, especially for patients without cancer, might not necessarily be fatal)⁵.

In fact, after controlling the symptoms, patients occasionally live longer than expected. Often a request for euthanasia is motivated by the desire to control the circumstances of death, but as we saw, both the patient and the family as well as the medical staff can benefit by admitting that there is not a total control over the timing of death⁵. Although the benefits of pediatric palliative care are indisputable, the recognition and dissemination of palliative care is still at an early stage, in which currently available services for children with incurable conditions and their families are precarious and fragmented. The precipitating causes of this situation are multiple and complex: the number of children who can benefit from palliative care is much lower when compared to the number of adult patients, plus there is inefficiency in organisational policies and management, shortage of qualified health professionals and emotional and cultural embarrassments related to child care in end-of-life, which conditions the social acceptance and understanding of the phenomenon of death in children.

There are inconsistencies about the time in the evolution of the disease when medical care should be restricted to palliative care for the own good of the patient. There are also inconsistencies about its meaning for the child and for the family, whereby the criteria must be standardised. This is an area that lacks research, focused either on the individual needs of the child or on the child's environment. Therefore, it is important to define clinical outcomes^{5,14,15,21-23}. Institutionally, the obstacles to the provision of appropriate palliative care can be overcome by the development and conduct of clinical protocols that adequately meet the needs of children and their families. It is also important to promote appropriate training to the providers of palliative care^{22,24}.

The Association for Children's Palliative Care (ACT) defines the paediatric palliative care as an active approach focusing on the longitudinal care:

from the diagnosis of the disease, along the child's life until death and even in the mourning stage¹⁵. It includes physical, emotional, social and spiritual elements, with a focus on improving the quality of life of the child or young person, including the management of symptoms of discomfort, the support to the family at the death and during the mourning^{15,22,25}. The prolonging of the life of children, unlike in the palliative care to adults, may be an important goal. The palliative care is, therefore, directed not only to a child suffering from an illness, but also to a child who lives with an illness¹⁵.

The prevailing model of palliative care in hospitals is the consultation service, although formal units of multidisciplinary palliative care are starting to emerge. By keeping the primary care team involved, this model ensures the continuity of the care in the hospital and saves financial and human resources. The goals are redefined according to the needs of the child and family, integrating palliative and interventionist care^{14,21}. The palliative care team should be multidisciplinary, with at least one doctor, one nurse, a psychologist and a social assistant^{15,22}.

The ACT advocates the discussion of such care in children with specific diagnoses, regardless of the stage of the disease and additional events, because of the advantage of starting the approach when the patient is still stable, making it easier for the family to discuss treatment objectives since the diagnosis of a life threatening condition¹⁵. Therefore, care is offered to patients at different times of the evolution of their diseases, so as not to deprive patients of the diagnostic and therapeutic resources that medical knowledge can afford. The early approach also allows the prevention of symptoms and complications related to the main disease, besides providing proper diagnosis and treatment of diseases that may develop in parallel with the main illness.

A good evaluation, based on the required exams in addition to the definition of the patient's behaviour, is essential for preparing a comprehensive plan of care, tailored to each case and adapted to each period of the disease progression²⁴. In practice, however, the most common reason for contact with the palliative care team is not the diagnosis, but rather events or additional needs. The palliative care in children with cancer, is commonly initiated when the disease stops responding to treatments¹⁵.

In general, children who die under 1 year spend much of their lives in the hospital but older children and adolescents live predominantly outside the hospital during their last year of life²⁶. It is, therefore, essential to adapt the care (with integra-

tion and coordination of hospital and home-based services) and individualise it, taking into account the particular needs of the child and the family, without nurturing any prejudices regarding the location of the provision of such care. If the location changes, a professional should be designated to ensure the continuity of the care (an universally known need which is not always guaranteed)^{15,26}.

Pediatric palliative care can be divided into five phases: 1) first contact with the care team, be it due to recognition of treatment failure or due to impairment of the child's condition, having in mind that early palliative intervention should be considered for all patients whose condition presents risk of life, since the relationship between palliative care and curative care is not one of mutual exclusion and, in addition, the curative therapy and the one that maximises the comfort and quality of life should overlap as components of the care; 2) first contact between the palliative care team and the child and family, in order to develop a holistic support plan (having in mind that an advance planning is vital for the relief or a satisfactory control of the symptoms); 3) maintenance of the palliative care, providing stability to the child and the family, who should take advantage of their valuable time together; 4) terminal phase (end-of-life), in which the child can tolerate contact with only few people, being important to control the symptoms and to have a prior consideration about the mourning, by preparing for the fatal event (which may include the child's wish to say goodbye or leave messages to loved ones) and the planning of the death (including location and circumstances); 5) mourning phase, for which parents should have been prepared in advance. At the beginning of this phase the availability of caregivers is essential as witnesses of the loss. After all, what parents usually look for after their child's death is to share details of this common experience^{14,15,22,24,25}.

Mourning is an individual process of "relearning the world." The death of a child can never be overcome, but parents will learn to live with the loss despite of it. These phases are in general shorter in neonatology and there is little time to prepare for the mourning. Nevertheless, it is important to plan this phase before the parents leave the hospital. Despite its great importance, such sort of support during the mourning is still rare in many European countries^{14,15,25}.

The communication capability is particularly important in palliative care^{15,22,24}. Communication, beyond its immediate effects, could have a long-term consequence on families which should not be

underestimated. To be able to explain to the dear ones what one can and can not do, whilst it is ensured that the medication will be adjusted in the doses required to make the child comfortable, helps to build and preserve the family confidence in the palliative care team⁵. An important goal of communication is the redirection of the hope to realistic scenarios¹⁵.

Even so, the hope of a miracle (even with knowledge of the reality), which sometimes gives some stability to the parents, can be seen as “healthy denial.” However, some of the parents insist on aggressive treatment because they understand that other attitudes toward the disease would mean “do nothing” or, at least, don’t do all that is possible¹⁵. It may be easier to discontinue certain treatment if it is known that the discontinuation does not imply the immediate death of the child⁵. Besides, if palliative care professionals are able to share their emotions with the parents and reflect with them on what more could be done for the child who is dying - how to hold the child, stand by the side of the child, sing, pray - the idea of “do nothing” can be subtly changed to an image of love, closeness and peace¹⁵.

The involvement of children is recommended, as much as possible, in the decision making process in accordance with their maturity. The minor has the right to know the procedures that he or she will be submitted to, and if the parents refuse to share with the child this information, it is important to explore the reasons and underlying fears. It may be useful to mention cases of parents who involved the child in the decision making and felt well with it, while others who have not involved the child in the process repented. There are studies that show this fact²⁷. Besides, it may be emphasised that children should trust health professionals, hence it is essential to have an honest attitude towards the children¹⁵.

Studies conducted in Belgium and the Netherlands^{8,28} reveal that, in most cases, the decision making is shared with the parents, but patients are rarely involved in the process, as incompetence of the minor is given as a justification (most often because of comatose state or because the child is too young). According to these studies, the decisions about treatment and medically assisted death are always discussed with the parents, which may result from the effect of short course of life in both cases. A discussion with parents appears to be less common when it comes to the administration of drugs for relief of symptoms with possible hastening of death, which can be credited to the fact that doctors consider it their duty to relieve suffering. On the

other hand, this practice has been discussed with the patient more often, being usually requested by the patient, possibly because of a worsening of the symptoms⁸.

The alleviation of suffering is the priority in palliative care, even if it accelerates death, which can be justified by the principle of double effect. According to this principle, an unwanted effect (death) can be ethically acceptable if the desired effect (relief from pain) is intended, provided that the unwanted effect is not the medium to achieve the desired effect and there is proportionality between the benefits of the desired effect and risks of the undesired effect. Thus, it is acceptable that the pain relief results in the death of a patient who is about to die, but not of a patient who might otherwise live for a long time. However, it is proved that the proper medication to control symptoms does not significantly accelerate death. There is, in fact, a greater risk of under treatment of symptoms, causing needless suffering^{5,20}.

The understanding that to treat pain and reduce suffering is ethical and desirable helps the medical team to do their best without the worry of “crossing the line”. Indeed, the line between palliation and euthanasia can sometimes appear to be rather thin, since both aim to relieve the suffering. However, in palliation, the primary objective is to treat the symptoms, knowing that there is some probability of accelerating death whilst with euthanasia, death is the means to alleviate the suffering⁵.

Despite this difference being clear in theory it can be difficult to discern between them in practice and to know if the doctor had intended to mitigate the suffering or to cause death. It is necessary to analyse the doses prescribed according to the clinical situation and verify if the medication had been properly prescribed based on signs and symptoms of the patient⁵. Other practices that may raise doubts in ethical terms are the suspension of artificial nutrition and hydration as well as the palliative sedation. The first may be reasonable in situations aimed to diminish the suffering, for example, when it is the feeding itself that is causing the pain or in a patient who is clearly in the last hours or days of life (it is unlikely that suspension of nutrition accelerates death)⁵.

Palliative sedation refers to the administration of sedatives in end-of-life to treat symptoms resistant to all other treatments. Commonly referred to as “terminal sedation”, the term “palliative”, however, is more suitable because it reflects the purpose of the medication. The treatment should be titled according to its effect. One should recur first to

safer alternatives, progressing later to riskier interventions in case the first ones had failed. Thus, the medication should be adjusted just enough to ease discomfort and it is unlikely that in this way, death will be accelerated^{5,20}.

According to that, it is important to improve the quality of pediatric palliative care, thus minimising the need to request euthanasia when children are in end-of-life situations. Howsoever, and even if they are properly developed, such palliative care can fail¹², making important the perception of the role that euthanasia in children should take in such cases.

The debate on pediatric euthanasia

One of the arguments put forward by pediatricians and politicians for the change in the Belgian law is the fact that, as long as the children's capacity of discernment is evaluated, they should enjoy the same rights as adults and, if they so wish, in a context of suffering from an incurable disease and likely death, put an end to their life¹². This way, the Belgian euthanasia law seeks to respect the moral status of children as agents of an increasingly self-determination capacity (which, as we have seen, has to be carefully assessed)²⁹. Some see this measure as the ultimate gesture of humanity: the relief of suffering, when the most advanced medicine has failed^{12,30}.

Although most of the public approve the change in the law, the medical, legal and political professionals are divided about it. So much so that a group of over 170 pediatricians signed an open letter before the vote of the law, asking members of the Belgian parliament to postpone the decision^{12,17}. Some of the authors who are opposed to this new legislation have doubts about the child's ability to make a lucid decision¹², since adults opt for euthanasia for reasons that go beyond pain, including the fear of loss of control, not wanting to be a burden to others, or the will to not spend their last days of life under sedation (wishes usually based on their life experience). According to those authors, children seem to have to choose between unbearable suffering on the one hand and death on the other, because they don't have the experience and sense of dignity and self-determination that adults commonly invoke (rightly or wrongly) at the end of their lives²⁹. However, it is shown that generally a child with terminal disease develops faster than other children of the same age¹².

Yet, this fact should never be taken as the norm, hence the need for careful assessment of

the child's sense of judgment by a multidisciplinary medical team and in accordance with the maturity of the child, not the child's chronological age. Although nowadays the Belgian law applies to all ages, in fact, euthanasia for children is likely to be limited to pre-teens, considering the requirement of "capacity for discernment"^{12,31}. As we have seen, the debate over medical decisions about children and young people focuses in general on this conflict between the competence to make decisions and the need that adults feel to protect children, even though, for some young people who are living with a serious illness for many years, this position may seem condescending¹⁹. In addition, the perspective of parents, manifested by their consent, can translate the notion that suffering is unbearable only for them, not for the child. Added to this the fact that the parents' decision requires the prior presentation of the options by the doctor, making their decision dependent on the information provided and the way it is given³⁰.

The historical connection between medicine and law led most societies to promote respect for life (though the answers to the "why" of the need to respect, maintain and protect life are usually given by religion, philosophy or politics). Opponents of euthanasia argue that the legalisation of this practice replaces the "treatment" for a mitigating "relief of suffering" or "avoidance of harm", restricting the scope of medicine as a treatment tool and the resulting disregard for the value of human life^{19,30}.

One of the most relevant arguments against the decriminalisation of euthanasia is the slippery slope argument, which trivialises the act of ending the life, implying the risk of misuse of the practice and the elimination of the most vulnerable patients^{9,32}. It is even suggested the possibility that a focus on the idea of "relief of suffering" could evolve into a "relief of abnormality," slipping to the danger of using perfection as a standard³⁰. From the example of the adoption of the euthanasia law in the Netherlands, it can be concluded that there wasn't an abusive increase in numbers nor, apparently, the extent of the practices to vulnerable patients. On the contrary, there was an intensification of symptom relief, that is, the improvement of palliative care³³.

The Belgian Law of 2002 was accompanied by an increase in all types of end-of-life medical practice (attributing the increase of euthanasia to a likely increase in the number of reported cases), with exception from involuntary euthanasia, and an extension of these practices to vulnerable groups³⁴ was not verified. On the other hand, some authors

mentioned the reduction of the legal scrutiny over time and the delegation of the practices to nursing professionals³⁰.

Although the frequency of medically assisted death without explicit request has declined in both countries over time, attention and thorough study of cases that still exist are necessary, in order to check for conceptual confusion or serious flaws in practice. The failure in the record of euthanasia in minors being around 20% of the cases in the Netherlands and about 50% in Belgium also raises an additional concern^{32,33}. Some authors suggest that what the legalisation of this practice for children really means is the implementation of a process that approaches a slippery slope¹².

It is anticipated that cases of euthanasia in children are very few in number⁹, which questions the urgency of the amendment of the Law¹². However, the practice advocates argue that, despite the small number of euthanasia requests, these will be of immense importance, since, with this option now available, open discussions on early death will be possible, allowing the appearance of solutions to a situation that may be intolerable¹². Ultimately, it is the rare situations that fail to be addressed, although euthanasia in such cases, even if it's not a positive solution, consists in a way to prevent that these children remain suffering¹⁷.

According to this perspective, the extent of the law to minors was a matter of principle, not necessarily of an immediate need³¹. Nevertheless, the lack of evidence as to the definition of "hopeless"

and "unbearable" suffering, without an objective quantification, is a major problem³⁰. In addition, to raise the issue of euthanasia in the context of end-of-life of a child in pain may further increase the emotional stress experienced by the parents. Indeed, it is known that in countries where euthanasia is permitted there is an emotional burden on doctors and family, with many professionals refusing these requests^{12,17}.

Final considerations

In short, in this ethical and social framework, the need for a law on euthanasia for children, as the example of the law passed in Belgium in February 2014, would be much more debatable if palliative care were available and developed enough to meet the needs of children, youths and families who face terminal life situations. However, with sparse evidence about the quality of pediatric care at end-of-life, the discussion of child euthanasia requires multidisciplinary research so appropriate public policies concerning this subject can be formulated and proposed¹⁹. Namely, it should be adequately clarified whether euthanasia of minors is or is not an, albeit covert, involuntary euthanasia³⁵.

In any case, by way of conclusion, it seems that the international debate on decisions about end-of-life in children, fostered by this recent political and social change in Belgium, could result in an investment in the improvement and accessibility of pediatric palliative care⁹.

References

1. Kapp MB. The practice of autonomy: patients, doctors, and medical decisions [book review]. *N Engl J Med*. 1999;340(10):821-2.
2. Van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ, Hanssen-de Wolf JE *et al*. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med*. 2007;356(19):1957-65.
3. Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, de Jong-Krul GJ, van Delden JJ, van der Heide A. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: A repeated cross-sectional survey. *Lancet*. 2012;380(9845):908-15.
4. Cohen J, Van Landeghem P, Carpentier N, Deliens L. Public acceptance of euthanasia in Europe: a survey study in 47 countries. *Int J Public Health*. 2014;59(1):143-56.
5. Morrison W, Kang T. Judging the quality of mercy: drawing a line between palliation and euthanasia. *Pediatrics*. 2014;133(Suppl 1):S31-6.
6. Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medical end-of-life decisions: experiences and attitudes of Belgian pediatric intensive care nurses. *Am J Crit Care*. 2009;18(2):160-8.
7. Nunes R. Proposta sobre suspensão e abstenção de tratamento em doentes terminais. *Rev. bioét. (Impr.)*. 2009;17(1):29-39.
8. Pousset G, Bilsen J, Cohen J, Chambaere K, Deliens L, Mortier F. Medical end-of-life decisions in children in Flanders, Belgium: a population-based postmortem survey. *Arch Pediatr Adolesc Med*. 2010;164(6):547-53.

9. Dan B, Fonteyne C, de Cleyt SC. Self-requested euthanasia for children in Belgium. *Lancet*. 2014;383(9918):671-2.
10. Chambaere K, Bilsen J, Cohen J, Onwuteaka-Philipsen BD, Mortier F, Deliens L. Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *CMAJ*. 2010;182(9):895-901.
11. United Nations Children's Fund – UNICEF. Rights under the Convention on the Rights of the Child. [Internet]. 2005 [acesso 24 jul 2015]. Disponível: http://www.unicef.org/crc/index_30177.html
12. Gormley-Fleming L, Campbell A. Rights of the child: to die? *Br J Nurs*. 2014;23(6):302.
13. Burla C, Rego G, Nunes R. Alzheimer, dementia and the living will: a proposal. *Med Health Care Philos*. 2014;17(3):389-95.
14. Longden JV. Parental perceptions of end-of-life care on paediatric intensive care units: a literature review. *Nurs Crit Care*. 2011;16(3):131-9.
15. Bergstraesser E. Pediatric palliative care-when quality of life becomes the main focus of treatment. *Eur J Pediatr*. 2013;172(2):139-50. p. 141.
16. Pousset G, Mortier F, Bilsen J, Cohen J, Deliens L. Attitudes and practices of physicians regarding physician-assisted dying in minors. *Arch Dis Child*. 2011;96(10):948-53.
17. Watson R. Belgium extends euthanasia law to children. *BMJ*. 2014;348:g1633.
18. Verhagen E, Sauer PJ. The Groningen protocol – euthanasia in severely ill newborns. *New Engl J Med*. 2005;352(10):959-62.
19. Kelly D. Euthanasia for children and young people? *Int J Palliat Nurs*. 2014;20(5):211.
20. Taboada P. El derecho a morir con dignidad. *Acta Bioethica*. 2000;6(1):91-101.
21. Solomon MZ, Sellers DE, Heller KS, Dokken DL, Levetown M, Rushton C *et al*. New and lingering controversies in pediatric end-of-life care. *Pediatrics*. 2005;116(4):872-83.
22. Capelas ML. Cuidados paliativos para recém-nascidos, crianças e jovens. Roma: Fondazione Maruzza Lefebvre D'Ovidio Onlus; 2009.
23. Diniz D. Obstinação terapêutica em crianças: quando a morte é um ato de cuidado. *Cad Saúde Pública*. 2006;22(8):1741-8.
24. Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos. Rio de Janeiro: Diagraphic; 2009.
25. Salinas MM. La relación entre el equipo de salud y la familia del niño muriente. *Acta Bioethica*. 2011;17(2):247-56.
26. Feudtner C, DiGiuseppe DL, Neff JM. Hospital care for children and young adults in the last year of life: a population-based study. *BMC Med*. 2003;1:3.
27. Kreicbergs U, Valdimarsdottir U, Onelov E, Henter JI, Steineck G. Talking about death with children who have severe malignant disease. *N Engl J Med*. 2004;351(12):1175-86.
28. Vrakking AM, van der Heide A, Arts WF, Pieters R, van der Voort E, Rietjens JA *et al*. Medical end-of-life decisions for children in the Netherlands. *Arch Pediatr Adolesc Med*. 2005;159(9):802-9.
29. Siegel AM, Sisti DA, Caplan AL. Pediatric euthanasia in Belgium: disturbing developments. *Jama*. 2014;311(19):1963-4.
30. Carter BS. Why palliative care for children is preferable to euthanasia. *Am J Hosp Palliat Care*. 9 jul 2014 [publicado online antes de impresso]. DOI: 10.1177/1049909114542648
31. Chambaere K, Roelands M, Deliens L. Euthanasia for minors in Belgium. *Jama*. 2014;312(12):1258.
32. Pereira J. Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls. *Curr Oncol*. 2011;18(2):e38-45.
33. Lo B. Euthanasia in the Netherlands: what lessons for elsewhere? *Lancet*. 2012;380(9845):869-70.
34. Bilsen J, Cohen J, Chambaere K, Pousset G, Onwuteaka-Philipsen BD, Mortier F *et al*. Medical end-of-life practices under the euthanasia law in Belgium. *N Engl J Med*. 2009;361(11):1119-21.
35. Nunes R. Eutanásia infantil. *Boletim da Ordem dos Advogados (Portugal)*. 2014;112-113:14-5.

Participation of the authors

Filipa Martins Silva was responsible for the conception and design of the study, the research and literature review, as well as the wording of the original text; Rui Nunes proceeded to critical analysis of the intellectual content of the work. Both changed the final version submitted for publication.

