

implementation of the Act and subsequent changes may further strengthen the legislation.

ENDNOTES

¹ Tim Slade et al., *The Mental Health of Australians 2: Report on the 2007 National Survey of Mental Health and Wellbeing* (Canberra: Department of Health and Ageing, 2009), 5.

² *Mental Health Act 2014* (Vic), s. 3, 4, Victorian Legislation and Parliamentary Documents, [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt9.nsf/DDE300B846EEDC7CA257616000A3571/21B8120F47E2942CCA257D810082DB4E/\\$FILE/14-26a004bookmarked.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt9.nsf/DDE300B846EEDC7CA257616000A3571/21B8120F47E2942CCA257D810082DB4E/$FILE/14-26a004bookmarked.pdf).

³ *Final Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Article 1.1, United Nations General Assembly, 6 December 2006, <http://www.un.org/esa/socdev/enable/rights/ahcfinalrepe.htm>. Article 1.1 reads, "The purpose of the present convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." See also Anne Wand and Timothy Wand, "Admit voluntary, schedule if tries to leave: Placing Mental Health Acts in the context of mental health law and human rights," *Australasian Psychiatry* 21 (2013): 137-140 at 138, <http://dx.doi.org/10.1177/1039856212466923>.

⁴ Stephen Smith, "Australia Ratifies UN Disabilities Convention," Media Release, 18 July 2008, <http://www.foreignminister.gov.au/releases/2008/fa-s080718.html>.

⁵ *Charter of Human Rights and Responsibilities Act 2006* (Vic), Victorian Legislation and Parliamentary Documents, [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt8.nsf/DDE300B846EED9C7CA257616000A3571/87318807B8E7A33ACA257D0700052646/\\$FILE/06-43aa013%20authorised.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/LTOobject_Store/LTObjSt8.nsf/DDE300B846EED9C7CA257616000A3571/87318807B8E7A33ACA257D0700052646/$FILE/06-43aa013%20authorised.pdf).

⁶ Owen Bradfield, "Chartering the limits of involuntary psychiatric treatment in Victoria: Interpreting the Mental Health Act 1986 (Vic) in the age of the Charter of Human Rights and Responsibilities Act 2006 (Vic)," *Journal of Law and Medicine* 18, no. 1 (2010): 130-142 at 141.

⁷ Australian Health Ministers Advisory Council, *A National framework for recovery-oriented mental health services: Guide for Practitioners and Providers* (Canberra: Commonwealth of Australia, 2013), 59.

⁸ Australian Health Ministers Advisory Council, *A National framework for recovery-oriented mental health services: Policy and theory* (Canberra: Commonwealth of Australia, 2013), 17.

⁹ *Ibid.*, 4.

¹⁰ Ruth Forrest, "The implications of adopting a human rights approach to recovery in practice," *Mental Health Practice* 17, no. 8 (2013): 29-33 at 30.

¹¹ *Mental Health Act 2014* (Vic), s. 68(2)(b).

¹² Advance statements are written when the person has capacity to consent and are signed, dated and witnessed by an external authorised person such as an authorised psychiatrist.

¹³ *A National framework for recovery-oriented mental health services: Guide for Practitioners and Providers*, 59.

¹⁴ *Mental Health Act 2014* (Vic), s. 73(1).

¹⁵ *Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Article 5.1. Article 5.1 reads, "State Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law."

¹⁶ *Ibid.*, Article 12.2. Article 12.2 reads, "State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

¹⁷ Penny Weller, "Psychiatric Advanced Directives and Human Rights," *Psychiatry, Psychology and Law* 17, no. 2 (2010): 218-229 at 220.

¹⁸ Victorian Government, *The Mental Health Bill 2014: An explanatory guide* (Melbourne: Department of Health, 2014), 4.

¹⁹ *Mental Health Act 2014* (Vic), s. 84-86, cf 87-88.

²⁰ *The Mental Health Bill 2014: An explanatory guide*, 6.

²¹ *Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Article 14.

²² Edwina Light et al., "Community treatment orders in Australia: rates and patterns of use," *Australasian Psychiatry* 20, no. 6 (2012): 478-482 at 478, <http://dx.doi.org/10.1177/1039856212466159>.

²³ *Mental Health Act 2014* (Vic), s. 29, 31.

²⁴ *Ibid.*, s. 34, 35.

²⁵ *Ibid.*, s. 29, 36, 45-51.

²⁶ Guvant Patel, "Community treatment orders in Victoria: A Clinico-Ethical Perspective," *Australasian Psychiatry* 16, no. 5 (2008): 340-343 at 340,

<http://dx.doi.org/10.1080/10398560802233017>; Royal Australian College of Australian and New Zealand Psychiatrists, *Submission to Hon. Lisa Neville MP, Minister for Mental Health regarding the Mental Health Act 1986 Review*, February 2009, 1-33 at 14, <https://www.ranzcp.org/Files/Resources/Submissions/sub15-pdf.aspx>.

²⁷ *Mental Health Act 2014* (Vic), s. 54, 56.

²⁸ *A National framework for recovery-oriented mental health services: Guide for Practitioners and Providers*, 45.

²⁹ *Mental Health Act 2014* (Vic), s. 23.

³⁰ *Catechism of the Catholic Church*, English Translation, 2nd ed., n. 1700, Holy See, http://www.vatican.va/archive/ENG0015/_INDEX.HTM.

³¹ *Ibid.*, n. 1930.

³² The Mental Health Tribunal consists of a lawyer, a medical practitioner and a member of the community.

³³ *Mental Health Act 2014* (Vic), s. 57(2).

³⁴ Pat Mayers et al., "Mental Health Service Users' Perceptions and Experiences of Sedation, Seclusion and Restraint," *International Journal of Social Psychiatry* 56, no. 1 (2010): 60-73 at 61, <http://dx.doi.org/10.1177/00207640080898293>.

³⁵ *Ibid.*

³⁶ Hannah Cross, Ilan Rauchberger, and Jayashri Kulkarni, "Perspectives on the Mental Health Act 2014 (Vic)," *Australasian Psychiatry* (2014): 1-4 at 3, <http://dx.doi.org/10.1177/1039856214555342>.

³⁷ *The Mental Health Bill 2014: An explanatory guide*, 9.

³⁸ *Ibid.*, 10.

³⁹ *Mental Health Act 2014* (Vic), s. 120. For more on the role of the chief psychiatrist, see s. 119-148.

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Legalising Euthanasia for Children: Dying with 'Dignity' or Killing the Vulnerable?

In February 2014, the Belgian parliament passed an amendment to the Belgian Act on Euthanasia of May 28th, 2002 removing the age limit of those requesting euthanasia provided that they have discerning capabilities and their parents approve. After mentioning briefly the arguments against legalising euthanasia, this article questions the ethical validity of removing the age limit, as well as the presumption that ending lives prematurely allows people to die with dignity. Caring for people who are vulnerable in their suffering is the proper goal of the healing professions, not terminating lives.

Relieving unbearable suffering is one of medicine's greatest challenges, especially at the end of life when hope of cure fades away. Two management options have emerged in the course of medicine's rapid growth: palliative care, enabling the patient to die a more comfortable natural death, and the ending of the patient's life prematurely through acts of euthanasia or assisted suicide. Whilst palliative care continues to advance, lobbying to end life prematurely also continues.¹

In February 2014, the Belgian parliament passed an amendment to the *Belgian Act on Euthanasia of May 28th, 2002*² removing the age limit on those requesting

euthanasia. This article does not intend to fully re-present the arguments against legalising euthanasia but will briefly outline some aspects of these arguments. It will then explore some of what followed after the 2002 Belgian law was enacted and question the ethical validity of removing the age limit.

Definitions

Complicating the euthanasia debate are different understandings of what euthanasia is. The Catholic Church defines euthanasia as “an act or omission which of itself and by intention causes death, with the purpose of eliminating all suffering.” The Church regards euthanasia as a grave moral wrong. By contrast, it accepts both the refusal of medical procedures which impose significant burden and offer limited benefits, and the use of painkillers and sedatives to relieve the patient’s pain even if this may shorten the patient’s life.³

What the Catholic Church terms ‘euthanasia,’ the European Association for Palliative Care Ethics Taskforce divides into ‘euthanasia’ and ‘physician-assisted suicide.’ It defines *euthanasia* as “a doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request.”⁴ It defines *physician-assisted suicide* as “a doctor intentionally helping a patient to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request.” The Association also determined, “Medicalized killing of a person without the person’s consent... is murder.”⁵

As the Association also notes, *palliative care* aims to prevent and relieve the physical, psychosocial and spiritual suffering that patients and families may undergo particularly when they face life-threatening illness.⁶ Palliative care “intends neither to hasten nor postpone death.” For this reason, euthanasia cannot be considered a treatment option in palliative care. Rapid advances in palliative care have now enabled its physicians to claim that almost all pain can be controlled through holistic means. What cannot, can be managed with proportional palliative sedation with the intention of relieving unbearable suffering, not causing death.⁷

Unfortunately misconceptions and varied definitions even amongst medical practitioners make it difficult to determine the true incidence of euthanasia.⁸ Past surveys are not without weaknesses, fraught by the phrasing of questions and the interpretations of euthanasia—a significant consideration in interpreting surveys, academic studies and public opinion polls.

Some Ethical Considerations

Euthanasia proponents argue that people have the autonomous right to determine how and when they die and to be assisted to do so. It is termed a positive right as it is incumbent on others⁹ to fulfil it, as opposed to a negative right which simply requires that others should not interfere to prevent the exercise of the right. John Stuart Mill in 1859 posited the concept of a right to self-determination, as long as this “does not affect the interests of others.”¹⁰ He specifically excluded children from this right. Through the Enlightenment period, this idea of self-determination evolved into a mindset of individualism and total independence, whereby personal rights are claimed with

little regard for the impact they may have on others. The corollary of this is the perception of being a burden on others when we are dependent on them for basic physical functions.

The pro-euthanasia movement rose at the time when palliative care was in its infancy and the knowledge of pain control limited. Watching loved ones die in severe pain is heart-wrenching. With significant advances in palliative care, pain control can be managed, and in 5-10% of patients where this is difficult, proportional palliative sedation is available.¹¹ Current reasons for requesting euthanasia are more existential and socio-psychospiritual: the loss of control of bodily function, and consequent dependence on others; feeling a burden; hopelessness; loneliness; loss of ability to do things that gave meaning and self-identity; and fear of pain.¹² These aspects of suffering are sometimes interpreted as a “loss of dignity.”¹³ Alleviation of these sufferings is aligned with the goals of palliative care. This raises the question as to whether receiving excellent and holistic palliative care would negate the need for legalising euthanasia. Pro-euthanasia groups may argue that until this service is guaranteed, euthanasia should be legalised. Legalising euthanasia however sanctions the killing of human beings, with consequences to society, not just the individual.

Euthanasia opponents argue that legalising euthanasia may result in a ‘slippery slope.’ Examples include: euthanasia in small numbers, gaining familiarity and acceptability and so unconsciously, over time becoming the norm¹⁴; prior strict boundaries become blurred, resulting in ‘mercy killing’ of people who are vulnerable and disabled, and/or judged by others to have lives that are not worth living. Whilst not overtly evident in other countries, the evidence is strong in Belgium.¹⁵ Euthanasia, some argue, should be made available to people with other unbearable suffering such as existential suffering, severe depression, isolation and loneliness. Caring for those with existential suffering would no longer be the norm, nor would it be the responsibility of society and government. The Lithuanian Health Minister has suggested euthanasia as an option for those who cannot afford health care.¹⁶

Belgium

The movement towards legalizing euthanasia in Belgium began in the 1980s with the establishment of two pro-euthanasia associations.¹⁷ The practice of ‘euthanasia’ was said to be tolerated at the time.¹⁸ The debate intensified ten years later with the introduction of bills to parliament. Euthanasia and palliative care movements developed side by side in Belgium. Two founding members of Belgium’s first palliative care organization were also advocates of the legalisation of euthanasia.¹⁹ In their minds, euthanasia was another option at the end of an ‘integral’ palliative care pathway.²⁰

Most palliative care proponents argued strongly and continuously for the need for well-executed palliative care negating the need for euthanasia. The *Federatie Palliatieve Zorg Vlaanderen (FPZV)*²¹ argued for the inclusion of a palliative care filter in the euthanasia bill whereby all patients requesting euthanasia would be referred to specialist palliative care to gain true informed consent.²² The FPZV contended that those who died inhumane deaths may not have received good palliative care, that it is “almost

always possible to permit incurably ill patients to die a humane, dignified death," that the majority of end-of-life physicians do not have palliative care expertise, and that true patient autonomy is not possible whilst unbearable suffering is present.²³

Belgium enacted its euthanasia law alongside the *Palliative Care Act* in May 2002. While on paper the Belgian law appeared to have safeguards in place, 1.8% of euthanasia deaths in 2007 were without the patient's explicit request.²⁴ Despite mandatory reporting of euthanasia deaths, half are not reported.²⁵ The practical slippery slope of the Belgium euthanasia law is well documented elsewhere.²⁶ It includes the criteria extension for requesting euthanasia to those without a terminal illness, those in a coma, or those who have dementia. Citing the so-called "law of necessity," some Belgian doctors believe that involuntary 'euthanasia' is necessary 'treatment' for those who cannot be cured.²⁷ Whilst Belgians were debating legalising euthanasia, palliative care was practised more. Post-legalisation, there has been an increase in euthanasia, raising questions as to whether this is evidence of a slippery slope.²⁸

Child Euthanasia

Children, deserving respect for their dignity as human beings, also need the protection of others, primarily parents, until they are mature enough psychologically and spiritually to decide for themselves. The proponents of removing the age criteria in the Belgian Euthanasia Act believe that chronological age does not determine the competency of people to make decisions about their own lives. Neuroanatomical studies however show that the brain does not fully mature until the 20s.²⁹ Adolescents may have developed amygdalae which mediate emotions, but their frontal lobes, mediating decision-making and abstract reasoning develop much later.³⁰ Adolescents "overvalue immediate events and discount long-term ones,"³¹ and lack the experience of adulthood which enables them to judge possible future realities against what is current. They lack the maturity to suppress their heightened emotions "to perform the dispassionate cognitive task required."³²

Some needs are strong in children including the need for acceptance and pleasing to gain affection and love. Minors may have the capacity to recall the consequences of choices, but it is difficult to determine if they truly integrate the implications of such decisions, or have the capacity to do so. Influences such as others' preferences, the benefit they believe others, including parents, would receive from their death, may have strong impact on their decision-making.³³ Questions arise as to whether their choices are free from external pressures, and whether their values, beliefs and perceptions of the meaning and purpose of life— that develop and evolve with each life experience—are sufficiently mature.

We all seek to ease suffering. One way of achieving this in children is ensuring their participation in end-of-life decision-making according to their capacity and desire to be involved.³⁴ This eases their fear of the unknown, and enables them to cope better with pain, discomfort, anxiety and even the loneliness of an unknown future.

The amended Belgian Act includes added safeguards, all of which are at least somewhat problematic. Thus, the child

must be an emancipated minor with capacity for discernment, but this is difficult to ascertain given the above considerations. The request must be voluntary without external pressure, which is again difficult to ascertain given their reliance on parents/caretakers for emotional support and identity. The child's condition must be medically futile and unbearable suffering must be experienced, but palliative care professionals claim unbearable suffering is inexcusable given current knowledge. A second independent physician and another psychiatrist/psychologist must be consulted to verify the child's capacity to discern, though this capacity still remains difficult to ascertain. Finally, the child and parents or legal representative must sign the request. This final precaution is counterintuitive. If the child has proven discerning capacity and the parents disagree, would the child's right for self-determination still stand? If not, why legislate?

It is conceivable that such safeguards may not be followed as happened with the 2002 Euthanasia Act. Not all euthanasia deaths are reported, even less so if 'euthanasia' is involuntary.³⁵ Those with depression, mental illnesses, other psycho-socio-spiritual suffering or fear of the unknown might be given the option of euthanasia as opposed to care, treatment, and respect for the dignity of who they are as human beings.

Other Considerations

As with all creation we have a limited lifespan on earth. Our bodies deteriorate and we understand that suffering is part of being human. Unbearable suffering and the powerlessness associated with it calls for deep compassion especially from those in the healing professions. Medicine's primary role is to heal and minimize, if not relieve, suffering. Its success in fulfilling this role has led some physicians to view suffering and death as the enemy in their war to conquer it. What has eventuated is known as the medicalisation of health, whereby every aspect of human health has to be diagnosed and treated. For some, when that is not possible, life can be ended. The body is a commodity to be used and when no longer functional, discarded.

Yet the "duty of authorities to protect human life... is founded on the belief that human life is valuable from the perspective of human dignity alone..."³⁶ Christians believe in the sanctity of life, a gift from God who is Love. When suffering continues despite all attempts at alleviating it, the associated vulnerability can be seen as an opportunity for transformation into greater wholeness and final communion with God. Here, the dying process is viewed as an opportunity for healing, to make right what has gone askew in one's life, for acknowledging the essential truth of one's vulnerability, lack of total control, and reliance on others and God. Much can happen by just being with others as they await death.

Even if that is not one's personal belief, palliative care has determined that unbearable physical suffering can be eased or relieved. While palliative care practitioners cannot guarantee that everyone will have a peaceful death, they are able to facilitate a comfortable death for most of us.³⁷ The goal of palliative care is to minimize unbearable suffering and to care for patient and loved ones in a deeply compassionate, dignified and holistic way, enabling healing in the patient's final days. Inherent in this process is the

involvement of patients every step of the way, according to their desire and capacity. There is no reason to end a person's life prematurely, especially when doing so would go against every ethical and moral fibre, intuitive knowing, and the common morality of societies. Legalising euthanasia may encourage the subtle, unconscious but real change in societal values that leads to acceptance, then normalization of the killing of another, beginning with the vulnerable as seems to have happened in Belgium. To legalise euthanasia for children who are vulnerable and have not yet gained the wisdom and experience necessary to make truly free and informed decisions, is an indictment on society whose primary responsibility is to protect and care for them.

Conclusion

When faced with the possibility of unbearable suffering and/or death, the choice one makes between life (including dying) and death is dependent on the belief that one is loved in one's physical dependency and disability. The assurance of a comfortable death in light of physical suffering is the norm, but the perception as to whether it is peace-filled or not may be more determined by whether at this stage of life one can achieve a sense of being in right relationship with oneself, others, the world and for many, God. Dignity, "the quality of being worthy or honourable,"³⁸ involves the respect and love one has for one another and for oneself. Perhaps what is in question here is the worldview, that no matter who or what one is, one is still loved, respected and not scorned in one's distress. The growing openness to euthanasia and physician-assisted suicide may be a reflection of negative experiences where unbearable suffering was witnessed. The issue here is the accessibility of specialized palliative care to everyone. It would seem more appropriate to address this significant shortfall than to legalise euthanasia, especially with regard to children and other vulnerable people in society. It is prudent to take heed of the advice of our forebears to "first do no harm,"³⁹ and, "to cure sometimes, to relieve often and to comfort always."⁴⁰ The dignity of the human being, made in the image and likeness of God, must be upheld always. Every effort must be made to ease suffering, short of the intentional premature ending of life. The value of human life cannot be discarded even in its final stage where there is opportunity to transform one's suffering and so be at peace, in right and loving relationship with self, loved ones, creation and God. Dying in this way—not euthanasia—is truly dying with dignity.

ENDNOTES

- ¹ Euthanasia is legal in the Benelux countries: the Netherlands, Belgium and Luxembourg. Swiss law permits assisted suicide provided no "self-seeking motives" are involved. In the United States there are assisted suicide laws restricted to terminally ill and mentally competent adults in Oregon, Washington, and Vermont.
- ² Belgisch Staatsblad, "Belgian Euthanasia Act of May 28th 2002," trans. Dale Kidd and Herman Nys, *Ethical Perspectives* 9, no. 2-3 (2002): 182-188.
- ³ John Paul II, *Evangelium Vitae*, #65, Holy See, http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html. For an understanding of the Principle of Double Effect on which this is based, see also Susan Anderson Fohr, "The Double Effect of Pain Medication: Separating Myth from Reality," *Journal of Palliative Medicine* 1, no. 4 (1998): 315-328. Of note there is no evidence that appropriate use of medications used in pain management, including opioids, hastens death. This fear of hastening death unfortunately results in inadequate treatment of physical pain. See Lars Johan Materstvedt et al., "Euthanasia and Physician-Assisted Suicide: A View from an EAPC Ethics Task Force," *Palliative Medicine* 17, no. 2 (March 2003): 97-101 at 98.
- ⁴ Materstvedt et al., 98. The taskforce comprised individuals of various cultures and professions.

⁵ *Ibid.*, 98.

⁶ *Ibid.*, 98. The WHO definition quoted in the report is: "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

⁷ American Medical Association Council on Ethical and Judicial Affairs, CEJA Report 5-A-08, "Sedation to unconsciousness in End-of-Life Care" (American Medical Association, 2008): 1-8.

⁸ This is evident in a survey of doctors in Victoria, Australia. One doctor in this survey stated, "Giving adequate doses of analgesia for pain in terminal cancer often hastens death. This may be considered a form of euthanasia." To the contrary, this would not normally be considered a form of euthanasia. See David A. Neil et al., "End-of-Life Decisions in Medical Practice: A Survey of Doctors in Victoria (Australia)," *Journal of Medical Ethics* 33, no. 12 (2007): 721-725 at 725.

⁹ Most see this as the role of medical practitioners who have the training and expertise to assess the competency of patients and the knowledge of medications to end the life of another without causing distress. The argument is also put forward that others—non-physicians—could be trained specifically for this role.

¹⁰ Danuta Mendelson and Ian Heywood, "Minors' Decision-Making Capacity to Refuse Life-Saving and Life-Sustaining Treatment: Legal and Psychiatric Perspectives," *Journal of Law and Medicine* 21 (2014): 762-772 at 764.

¹¹ Alexander De Graeff and Mervyn Dean, "Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards," *Journal of Palliative Medicine* 10, no. 1 (February 2007): 67-85.

¹² Maggie Hendry et al., "Why Do We Want the Right to Die? A Systematic Review of the International Literature on the Views of Patients, Carers and the Public on Assisted Dying," *Palliative Medicine* 27, no. 1 (2013): 13-26.

¹³ *Ibid.*, 19.

¹⁴ In the words of euthanasia advocate David Benatar, "If, however, we cannot effect that legal change in one step, we recommend, in the first instance, a more limited liberalization of the law. Once that change has been made, people might realize that the next step and then the next are also acceptable, even if they cannot see it now." See David Benatar, "A Legal Right to Die: Responding to Slope and Abuse Arguments," *Current Oncology* 18, no. 5 (2011): 206-207 at 206.

¹⁵ European Institute of Bioethics, "Euthanasia in Belgium: 10 Years On," *Dossier of the European Institute of Bioethics* (2012). See also Raphael Cohen-Almagor, "Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement," *Issues in Law and Medicine* 24, no. 3 (2009): 187-218. In an interview, Professor Jean-Louis Vincent, the head of the Department of Intensive Care in Erasme Hospital, told Cohen-Almagor, "The law is not applicable to ICU...When no help is available, they put patients to sleep." 193.

¹⁶ Michael Cook, "Euthanasia Could Be Option for Poor, Says Lithuanian Health Minister," *BioEdge* (2014), http://www.bioedge.org/index.php/bioethics/bioethics_article/11071.

¹⁷ Association belge pour le droit de mourir dans la dignité (Belgian Association for the Right to Die with Dignity) in 1981 and the Flemish *Vereniging voor het recht op waardig sterven* (Association for the Right to Die with Dignity) in 1983. See Cohen-Almagor, 188.

¹⁸ Again, here the definition of "euthanasia" is varied and would include the withdrawal or withholding of futile treatment.

¹⁹ The organisation was called Continuing Care Community and the two members were Karel Roelants and Jan L. Bernheim. See Jan L. Bernheim et al., "Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy?" *BMJ (Clinical Research Ed.)* 336, no. 7649 (2008): 864-867.

²⁰ *Ibid.*, 865. This is despite palliative care organisations insisting that euthanasia is not an option in palliative care and is not regarded as medical treatment.

²¹ Flemish Palliative Care Federation.

²² Bert Broeckaert and Rien Janssens, "Palliative Care and Euthanasia: Belgian and Dutch Perspectives," *Ethical Perspectives* 9, no. 2-3 (2002): 156-175 at 160.

²³ *Ibid.*, 161-164.

²⁴ Johan Bilsen et al., "Medical End-of-Life Practices under the Euthanasia Law in Belgium," *New England Journal of Medicine* 361, no. 11 (10 September 2009): 1119-1121 at 1119-1120. These were "mostly older, incompetent patients; patients with cardiovascular diseases or cancer; or patients dying in hospitals." This is despite the *Comité consultatif de Bioéthique*, commissioned to explore legalising euthanasia affirming that it does not apply to incompetent people. See Cohen-Almagor, 188.

²⁵ Tinne Smets et al., "Reporting of Euthanasia in Medical Practice in Flanders, Belgium: Cross Sectional Analysis of Reported and Unreported Cases," *BMJ* 341 (2010), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2950259/>.

²⁶ European Institute of Bioethics; Bruno Waterfield, "Mother of Sex Change Belgian: 'I Don't Care About His Euthanasia Death,'" *The Telegraph*, Oct 2, 2013. A Belgian transgender man, Nathan Verhelst, 44, whose failed gender re-assignment surgeries left him with "unbearable psychological suffering," after only six months of counselling was euthanised by Dr Wim Distelman, head of the Commission

authorised to ensure that the letter of the law was followed. The question arises as to whether this is an appropriate option for the severely depressed people. Dr Wim Distelman is an oncologist, a strong euthanasia advocate and the chair of the Federal Control and Assessment Commission charged with ensuring that the legal conditions for euthanasia are met. Questions have been raised as to whether there is a conflict of interest in his role as Chair of the Commission; Bruno Waterfield, "Euthanasia Twins 'Had Nothing to Live For,'" *The Telegraph*, Jan 14, 2013. 45 year old Belgian brothers Marc and Eddy Verbessem, born deaf and facing blindness from glaucoma, alongside many other medical problems, could not bear the thought of being dependent in an institution. Their brother was reported as saying "I sometimes think, if they had their own wives and children, perhaps they would have had something to live for."; Tom Mortier, "How My Mother Died," *MercatorNet* (2013),

http://www.mercatornet.com/articles/view/how_my_mother_died#.

Godelieva De Troyer suffering from allegedly treatable depression was euthanised by Distelman in 2012 without the family's knowledge.

²⁷ Jean-Louis Vincent, "End-of-Life Practice in Belgium and the New Euthanasia Law," *Intensive Care Medicine* 32, no. 11 (Nov 2006): 1908-11 p 1908. The law of necessity is applied "whereby otherwise criminal conduct may be excused if the defendant commits the act in order to avoid a greater evil or to achieve a greater good." Note that *involuntary* 'euthanasia' was defined earlier as murder, not euthanasia and that according to palliative care practice, euthanasia is not a 'treatment.'

²⁸ Johan Bilsen et al., "Changes in Medical End-of-Life Practices During the Legalization Process of Euthanasia in Belgium," *Social Science & Medicine* 65, no. 4 (2007): 803-808.

²⁹ Mendelson and Heywood, 770.

³⁰ Johannes Schiebener et al., "Developmental Changes in Decision Making under Risk: The Role of Executive Functions and Reasoning Abilities in 8- to 19-Year-Old Decision Makers," *Child Neuropsychology* (2014): 1-20. This results in higher risk-taking behaviours.

³¹ Mendelson and Heywood, 770.

³² Mendelson and Heywood, 771.

³³ Pamela S Hinds et al., "End-of-Life Care Preferences of Pediatric Patients with Cancer," *Journal of Clinical Oncology* 23, no. 36 (2005): 9146-9154.

³⁴ Katharina M Ruhe et al., "End-of-Life Decision Making in Pediatrics: Literature Review on Children's and Adolescents' Participation," *AJOB Empirical Bioethics* 5, no. 2 (2014): 44-54.

³⁵ Smets et al.

³⁶ Etienne Vermeersch, "The Belgian Law on Euthanasia. The Historical and Ethical Background," *Acta Chirurgica Belgica* (2002): 394-397 at 395.

³⁷ Peter Hudson et al., "Help the Many First," *The Age*, July 30, 2014.

³⁸ Oxford English Dictionary, "Dignity,"

<http://www.oxforddictionaries.com/definition/english/dignity>.

³⁹ Attributed to English physician Thomas Sydenham and is adopted as C. M.

Smith, "Origin and Uses of Primum Non Nocere--above All, Do No Harm!," *Journal of Clinical Pharmacology* 45, no. 4 (2005).

⁴⁰ This quote has been attributed to both Ambroise Pare (physician to King Francois I) and Edward Livingston Trudeau (a physician at the Adirondack Cottage Sanitarium at Saranac Lake in New York).

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Experimental Treatments for Ebola

The Ebola virus disease outbreak in West Africa is a tragedy of mass proportions. It has afflicted a region with poor public health infrastructure, communities fearful of medical intervention due to past atrocities, and in a situation where the people are protective of themselves and their families. As the death toll continues to rise, experimental treatments are being offered as a solution. The widespread use and management of these treatments is a challenge due to the social and cultural structures that exists in these communities. An approach that is sensitive to these experiences needs to be observed.

On 8 August 2014, the World Health Organisation (WHO) declared that the Ebola virus disease outbreak in West Africa – specifically in Guinea, Liberia and Sierra Leone – is a Public Health Emergency of International Concern. In answer to an unprecedented call to action, governments and private organisations around the world donated money and other resources to help manage the growing crisis.

The Ebola virus is not a new contagion; it was identified almost forty years ago. Yet, there is a lot about the virus that is still unknown. There is limited knowledge about the original reservoir that first transmitted the virus. After several outbreaks over the years in Africa and other countries, and resurgence of the virus as a significant bioterrorist threat, research is still ongoing into treatments and vaccine development. However, this is restricted, and clinical trials are delayed, pending the results from animal models. In an effort to manage the current outbreak, the WHO supported the use of experimental vaccines and treatments. It may be recognised as an instance where 'desperate times calls for desperate measures,' but is this decision ethically justified within a demographic plagued by social and economic disadvantage? This article will describe the current Ebola epidemic in West Africa. It will also explore some of the ethical considerations in determining the use of experimental treatments in this context.

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The Ebola virus is sometimes referred to as a prototype pathogen because it can cause several diseases with variable levels of severity and modes of transmission. To understand the nature of the virus that has led to widespread devastation in West Africa, it is important to begin by identifying the virus, its morphology and ecology. The genus *Ebolavirus* belongs in the family *Filoviridae* within the order *Mononegavirales*. Another member of the filovirus family is the Marburg virus, which causes a disease with symptoms similar to those of Ebola. The ebolavirus is an enveloped, non-segmented, negative-stranded RNA virus distinguishable by the obvious filamentous particles when examined under the microscope. There are five identified Ebola species. One of these, the Reston ebolavirus, does not cause disease in humans. The other four – the Zaire, Sudan, Tai Forest, and Bundibugyo ebolaviruses – do cause disease in humans. The most lethal of these is the Zaire ebolavirus (ZEV), which is the cause of the current outbreak.¹

The first outbreaks of Ebola virus disease were in 1976 in Zaire and Sudan. Since then, there have been perhaps as many as two dozen outbreaks of the disease in various parts of Africa.² The current outbreak is by far the most serious. It has caused more deaths than all the other Ebola outbreaks combined.³ Molecular biology can clearly demonstrate the pathogenesis of the Ebola virus; there is however a lack of knowledge about virulence factors and host responses which could be of benefit in the development of effective treatments and timely vaccines.⁴