Report from “Euthanasia and Assisted Suicide: Lessons from Belgium”

A conference hosted by the Anscombe Bioethics Centre, co-sponsored by the Scottish Council on Human Bioethics, the Centre for Bioethics and Emerging Technologies, St Mary’s University Twickenham and KU Leuven.

Saturday 1st November 2014
Euthanasia and Assisted Suicide: Lessons from Belgium

With Bills to legalise ‘assisted dying’ being considered in the Scottish Parliament and in Westminster, the Anscombe Bioethics Centre convened an international conference to consider the experience of euthanasia and assisted suicide in Belgium. The conference was co-sponsored by the Centre for Bioethics and Emerging Technologies, Twickenham, the Scottish Council on Human Bioethics, Edinburgh, and the Centre for Biomedical Ethics and Law, KU Leuven. It was held on Saturday 1 November 2014 at St Mary’s University, Twickenham in the historic setting of the Waldegrave Drawing Room.

In 2002 Belgium legalised euthanasia under three key conditions. Broadly: the patient is competent at the time of the request, the request is voluntary and consistent, and the patient is:

‘in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated resulting from a serious and incurable disorder caused by an illness or accident’.

Originally the law was subject to a lower age limit but in 2014 the scope was extended to include children of any age, subject to various further conditions, for example that it only covered physical suffering.

---

1 This account of the conference has been produced by Pauline Gately MA and Professor David Albert Jones. Though it draws on slides, abstracts, and notes taken at the time, it paraphrases contributions and should not be taken as a verbatim account. References have been added for further reading and the Centre has also produced separate video interviews with three of the speakers (Dr Beuselinck, Professor Van Gool and Professor Cohen-Almagor, the videos are available here: http://bioethics.org.uk/page/resources/multimedia). It is also hoped that the conference will provide the basis of a publication.

2 http://bioethics.org.uk/EuthansiaConferencePoster.pdf


In introducing the conference Professor David Albert Jones explained that the conference had been convened in order to learn from Belgium’s experience the impact that such a law could have on healthcare and on wider society. Its aim was to 'look at diverse aspects in order to begin to get a sense of the whole'. Professor Jones quoted Wittgenstein, who observed that certainty rarely comes from single arguments, rather it is that 'light dawns gradually over the whole'.

In the first talk Dr Benoit Beuselinck looked at developing practice in Belgium from his perspective as an oncologist. In 2013, in 73% of cases of euthanasia in Belgium, the underlying disease was cancer. As a consequence, medical oncologists are among the doctors that are the most exposed to euthanasia demands.

In outlining the law Dr Beuselinck noted that the suffering required for qualification for euthanasia may be either physical or mental in character. He observed that mental or existential suffering cannot be objectively assessed and that this offers scope for broad interpretation and abuse.

Between 2002 and 2013 deaths from euthanasia increased from 0.4% to 1.7% of all deaths in Belgium. Between 2007 and 2013 the proportion of non-terminally ill patients increased from 7% to 15% of all cases of euthanasia. Dr Beuselinck highlighted individual instances which suggest a widening of the scope of the law. Some patients had requested euthanasia at the first diagnosis of cancer, before even exploring therapeutic possibilities. Even where there was a physical diagnosis it often seemed that existential suffering was the main motivation for euthanasia rather than the actual physical symptoms which could be addressed medically.

---

For doctors, the availability of euthanasia causes additional pressures. Those who are willing to comply may feel they are asked too often. Dr Beuselinck cited a palliative care centre where the director became known for being very welcoming to euthanasia requests. The centre began to get referrals simply for euthanasia and this changed the pattern of practice and the character of the centre such that a number of staff subsequently left.

For those who are reluctant or unwilling to accede quickly to a euthanasia request the time required for counselling and exploring alternatives adds to their work pressures. Dr Beuselinck also noted moves to restrict conscientious objection rights by requiring both individuals and institutions to refer.

There are also implications for palliative care: Those seeking euthanasia may be referred first to a palliative care centre for assessment, with agreement contingent upon the outcome. This has led to confusion among some patients as to the nature of palliative care: Dr Beuselinck illustrated this by citing the case of a patient who declined to be referred to a centre for inpatient palliative care because, as a Catholic, he was conscientiously opposed to euthanasia.

Some patients are afraid to go to their doctor or hospital. Some carry cards requesting they not be euthanised. There are concerns that doctors will too quickly accede to a request for euthanasia and fail to facilitate the exploration of alternatives. Patient autonomy is perceived as paramount and the impact on others, including the family, doctors and society, is insufficiently considered. The incidence of euthanasia requests is higher among the lonely.

In response to these challenges, Dr Beuselinck offered four suggestions: The promotion of palliative care (properly understood), the avoidance of ‘therapeutic obstinacy’, palliative sedation where necessary, and legal protection for those individuals and institutions providing palliative care.

Professor Stefaan Van Gool, speaking as a paediatric neuro-oncologist, then considered the recent extension of legalised euthanasia in Belgium to children of any age. He questioned the necessity for this, given the palliative care now available and offered data from his own recent and informal enquiries among fellow professionals in seventeen countries. The responses suggest that, outside the Netherlands, there is little perceived need for such measures either among the general public or among paediatricians.

Professor Van Gool noted the many factors which may influence the child’s attitude to euthanasia including those related to age and illness and also the impact of carers, both family and professional. He noted with concern the absence of objective measures for assessing capacity, the need for extensive, specialist assessment, and the challenge of excluding external influences on the child in order to ensure the request is truly autonomous.
He argued that these challenges were not adequately addressed prior to the law being changed and concluded that this extension of the law was hastily considered and unjustified. ‘Freedom’, he observed, ‘induces pressure to use freedom’.

The first panel discussion was chaired by Professor Chris Gastmans. A participant from the audience pointed out that the Belgium law does not currently require a doctor to refer someone for euthanasia. In response Dr Beuselinck stated that, while this was the law at present, a proposed legal duty to refer had been debated in the Belgian parliament and, given other changes that had occurred, he had real concerns that the law would be extended in this way. Professor Van Gool also pointed out that, even within the current law, a refusal to refer on conscience grounds might be very difficult in practice as it could compromise a long established relationship between practitioner and patient.

Dr Trevor Stammers opened by declaring his support for organ donation post mortem as ‘the last act of grace’. However, he observed that donation should be made freely and not out of a sense of obligation. Otherwise it becomes ‘the last act of coercion’. He noted the tensions, generally, between the needs of the dying patient and the requirements for effective organ harvesting but also his view that in current best practice these can be reconciled.

It is against the background of a demand for donated organs which far exceeds supply that in Belgium, organ donation has been accepted from people after euthanasia. These cases, though relatively rare, are a new source of organs which offer good outcomes for the recipients. They already comprise a significant proportion of ‘donation after cardiac death’ in Belgium.

The possibility of donating organs following euthanasia raises ethical concerns with respect to the motivation of the potential donor: Could the potential for organ donation influence the patient considering euthanasia and perhaps reinforce that decision? If organ donation is raised with the patient, at what point and with what motivation?

---

7 For more details on the ethics of organ donation see the Anscombe Centre Report On the Ethics of Organ Transplantation: A Catholic Perspective available online http://bioethics.org.uk/Ontheethicsoforgantransplantationfinal.pdf
Dr Stammers then examined the utilitarian arguments presented by Wilkinson and Savulescu. They note the traditional ethical principles governing organ transplantation but also the current scarcity of organs. One possible suggestion to increase the supply of organs is to permit euthanasia by the removal of vital organs as the means by which the patient’s life is ended. If organ donation after euthanasia is acceptable, why not euthanasia by means of organ donation? The ethical arguments for and against this were examined. Dr Stammers pointed out a parallel between this reasoning and the case that might be made for using organs of someone executed for a capital offense, and thus for using organ donation as a means of judicial execution. While few might accept such a practice it seems to follow from the logic of the argument proposed by Wilkinson and Savulescu.

Professor Chris Gastmans opened by noting the new responsibilities arising from the increased incidence of dementia within the context of an ageing population worldwide and suggested a care approach aimed at enhancing dignity. He noted the influence on the elderly of concerns about dignity, dependence and being a burden alongside the perception of autonomy as a desirable social goal.

Advanced euthanasia directives would allow the competent to request euthanasia should they become incompetent and are now legally recognised in the Netherlands. In Belgium attempts have been made to extend euthanasia to those with dementia and advanced euthanasia directives are currently debated. Professor Gastmans contrasted two alternative approaches to this issue. The ‘principlist’ approach gives priority to autonomy with cognition: The expressed wishes of the ‘then self’ determine the outcome for the ‘now self’. In the other ‘ethics of care’ approach the aim is to establish and respect the wishes of the ‘now’ person.

Professor Gastmans argued that the principlist approach fails to recognise fundamental human dignity. Rather, it associates dignity with current cognition. Competent autonomy is over-emphasised and dialogue and shared understanding are under-emphasised. Thus the right normally accorded to those seeking euthanasia to change their mind up to the very end is denied to those who have compromised competence. He concluded that the lived experience of human vulnerability, not principlism, should determine dementia care ethics.

---

The second panel discussion, chaired by Professor Baroness Sheila Hollins, touched on the issue of healthcare attorneys and advance decisions in the context of dementia, the issue of voluntariness in the context of organ donation, euthanasia for prisoners and the role of theology and spirituality in this debate.

Professor Sigrid Sterckx then presented the results of a comparative study conducted jointly with others including Dr Kasper Raus (also present) on the approach to the use of continuous sedation in the UK and in Belgium.

Continuous, or palliative, sedation reduces or removes consciousness until death. It is used frequently in the UK (16.5%) and in Belgium (14.5%). Although it may be perceived as less ethically controversial than euthanasia there remain concerns. In this research medical practitioners and relatives in both countries were interviewed following and about specific cases of sedation at the end of life. From this Professor Sterckx identified three main differences between UK and Belgian practice.

The first concerned presentation and perception. In Belgium the terms ‘continuous’ and ‘palliative’ sedation were freely used between practitioners, patients and relatives. The process had an explicit identifiable start point, sometimes accompanied by an opportunity for loved ones to bid a final farewell. By contrast, the term ‘palliative sedation’ was avoided in the UK and some even avoided ‘sedation’, preferring ‘symptom control’ or ‘easing of suffering’. There was a perception of a continuum of care with no specific starting point.

Next, although the principle of proportionality (no more sedation than required to relieve symptoms) featured in relevant guidelines in both countries, in Belgium some doctors sedated deeply from the start. UK practitioners described a process whereby doses were increased only as necessary and with some reluctance where this might be perceived to hasten death: There was evidence that patients were sometimes left with insufficient pain control, suffering unduly as a consequence.

Finally, UK practitioners denied intending to shorten life and feared being perceived as doing so. Some even denied intending to sedate when providing sedatives. By contrast, although many Belgian practitioners also denied intending to shorten life it was not such an issue for them. A ‘handful’ even acknowledged that was their intention.

In conclusion Sterckx contrasted the approaches and attitudes in the two countries: Whereas the UK approach to continuous sedation apparently seeks to avoid any suggestion of finality or intent to hasten death, the approach in Belgium may, at times, ‘resemble’ euthanasia.

Professor Raphael Cohen-Almagor opened by outlining the existing law and providing some historical context, noting evidence that euthanasia was practised even before it was legalised but also that the incidence of legal euthanasia has increased steadily since 2002. He asked whether the terms of the current law encompass those who are ‘tired of life’. Does a person who finds no meaning in life ‘suffer unbearably’? Does this include the physically healthy?

He remarked that it would be almost impossible to judge whether the required criteria were satisfied if the symptoms could not be interpreted in the context of a physical condition.

He examined three cases which have tested the law. In his commentary on each he referred to Dr Wim Distelmans, who is a euthanasia advocate and practitioner but also co-chairs the Federal Committee on Euthanasia which is responsible for monitoring euthanasia cases to ensure compliance.

The first case was that of 93-year-old Amelie van Esbeen who requested euthanasia because she was tired of life. After initially being refused on the grounds that her case did not meet the required criteria, she was euthanised after 10 days on hunger strike. Dr Distelmans supported this decision, arguing that old people may endure unbearable suffering arising from a package of age-related conditions. So, it was implied, seniors who are tired of life qualify.

Nathan (Nancy) Verhelst was euthanised by Dr Distelmans following a botched sex-change operation prompted by his/her early parental rejection as a girl. Verhelst was deemed to qualify on grounds of unbearable psychological suffering.10

Finally twins Marc and Eddy Verbessem, who were born deaf and going blind, were also euthanised by Distelmans on the grounds of unbearable psychological suffering.

Professor Cohen-Almagor questioned whether the law is working as intended and expressed concerns about Dr Distelmans’ clear conflict of interest. He then offered some suggestions as to how the current situation might be improved. He argued for a trustworthy monitoring system, which would mean addressing possible conflicts of interest.11 The guidelines are there to protect, yet the Van Esbeen case was used to undermine these and enlarge the scope of euthanasia, opening the door wider to abuse.

10 This story was widely reported; see, for example, B. Waterfield, ‘Belgian killed by euthanasia after a botched sex change operation’ Telegraph 1 Oct 2013 http://www.telegraph.co.uk/news/worldnews/europe/belgium/10346616/Belgian-killed-by-euthanasia-after-a-botched-sex-change-operation.html

11 It should be noted that already in 2009 Professor Cohen-Almagor had raised concerns about the monitoring mechanism in the Belgian law arguing that it ‘lacks sufficient control and monitoring mechanisms in order to ascertain that no abuse is taking place’; see R. Cohen-Almagor ‘Euthanasia policy and practice in Belgium: critical observations and suggestions for improvement’ Issues in Law and Medicine. 2009 Spring;24(3):187-218, http://www.hull.ac.uk/rca/docs/articles/euthanasia-belgium.pdf
To sanction euthanasia for those who are ‘tired of life’ is dangerous and would, he implied, encompass the suicidal, regardless of their physical condition.

In conclusion Professor Cohen-Almagor noted that euthanasia is widely accepted in Belgium and has become part of the duties of the medical profession. Dissent is difficult. Yet the State has an obligation to protect the vulnerable. Although the law is still young and one could anticipate a process of learning from mistakes, so far the trend is for insufficient caution with scope iteratively widened both by precedent and law, rapid expansion of numbers and further pressures to extend the scope. ‘Haste’, he observed, ‘makes waste’.

Finally, Professor Calum MacKellar considered the ‘normalisation’ of euthanasia, what this means and whether there are indications that it has happened in Belgium. He defined normal as ‘usual, regular or common’ and observed that what is normal may vary by location or over time in the same location. It may be influenced by evidence of acceptance. For example, Parliamentary acceptance may suggest normality.

Professor MacKellar finished by ‘scanning the horizon’: He noted existing moves to extend the scope of legalisation in Belgium. He reported also a growing sense of euthanasia as a human right, with people increasingly insisting on it either for themselves or for others, and raised the possibility of consequences not originally envisaged or intended but rendered inevitable by virtue of the societal impact of normalisation. He concluded that such normalisation is occurring\(^\text{12}\) and that, this being the case, dissent is difficult.

This conclusion reinforced a point made by Professor Jones at the beginning of the conference. Such a momentous shift as the legalisation of euthanasia or assisted suicide, once accomplished, may be difficult to reverse. It is essential therefore that policy makers ‘look before they leap’, and there are only a few jurisdictions in the world to which one can look. One of those few is Belgium and we would do well to learn the lessons it offers.

\(^{12}\) For further evidence which seems to confirm the conclusions of Dr MacKellar see the report of the European Institute of Bioethics, Euthanasia in Belgium: 10 Years On, \url{http://www.ieb-eib.org/en/pdf/20121208-dossier-euthanasia-in-belgium-10-years.pdf} ; see also Graeme Hamilton “Suicide with the approval of society: Belgian activist warns of slippery slope as euthanasia becomes “normal”” \url{http://news.nationalpost.com/2013/11/24/suicide-with-the-approval-of-society-belgian-activist-warns-of-slippery-slope-as-euthanasia-becomes-normal/}