



Chisholm Health Ethics Bulletin

Drawing on thorough research, the best of human insight and the strengths of Catholic teaching, we offer an ethical vision to inform modern health care. We strive to guide our readers to greater knowledge and deeper understanding about issues in health care, and to assist all people in their search for insight and wisdom.

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Welcome to the Caroline Chisholm Centre for Health Ethics Winter 2016 edition of The Bulletin.

In Nov, 2014, **Pope Francis** was quoted as saying that **euthanasia** is a sin against God and creation. The Latin American pontiff said it was a “false sense of compassion” to consider **euthanasia** as an act of dignity... In this context, this edition of The Bulletin explores responses to the release of the Parliament of Victoria’s Legislative Council’s Legal and Social Issues Committee Final Report of the Inquiry into End of Life Choices published June, 2016.

In the introductory foreword, Hon. *Edward O’Donohue MLC Chair of the Inquiry Into End of Life Choices Committee* introduces the report with these first words:

“Death and taxes, the two certainties of life. Little has changed since this saying was coined several hundred years ago. What has changed, however, is our understanding of death. To past generations, death was familiar. Now it is often out of sight and shrouded in mystery.”

In May, 2015 the Inquiry Into End of Life Committee was requested to:

...inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;*
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and*

- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.*

Twelve months later the Report detailed 49 recommendations; Recommendations 1 to 29 inc. provided validation of a framework for moving “*toward a community based approach to palliative care*”; Recommendations 30 to 48 inc. focussed on “*improving advance care planning*”. Recommendation 49 made provision for a “*legal framework providing for assisted dying*”.

In this edition Frank O’Keeffe, in his article, **An Overview of the Proposed Victorian Recommendation for Assisted Dying and its Consequences**, explores the Inquiry Into End of Life Choices Final Report, in particular Recommendation 49. Frank received his Masters of Bioethics from the John Paul II Institute for Marriage and Family (Melbourne) in 2016. Previously, he obtained a Bachelor of Laws (LLB) from La Trobe University in 2013 and was admitted to the legal profession before the Victorian Supreme Court in 2015.

Dr Dilinie Herbert, in her article which draws upon research which includes her interviews with Associate Professor Natasha Michael and Associate Professor Mark Boughey, **Making Sense of a Wish to Hasten Death**, explores how a health professional might respond when a patient nearing end of life requests to die. Dr. Herbert is a writer for the Caroline Chisholm Centre of Health Ethics.

Thank you to Fr Kevin McGovern and Susannah Duncan for their contribution to this edition. Please feel welcome to discuss further by contacting the Acting Director of Caroline Chisholm Centre, Maureen Waddington, on 03 9320 6681 or on maureen.waddington@svha.org.au.

Maureen Waddington ✕

About the Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics is a Catholic bioethics centre:

- We research and publish about health care issues.
- We provide education and training about health ethics to health professionals and the general community.
- Over the phone or face to face, we assist without discrimination any person who seeks help in making decisions about health care.
- We contribute to community discussion and debate by making public comments about important matters related to health care.

We also assist health care institutions in the development of policies, protocols and procedures, particular in areas which might be ethically contentious.

Catholic bioethics is based upon both faith and reason. “Faith and reason,” Pope John Paul II once wrote, “are like two wings on which the human spirit rises to the contemplation of truth.” (John Paul II, *Fides et Ratio*) Thus, the long Catholic tradition contains much reasoned reflection on human experience – reflection which has discerned a natural ethic which is sometimes called the natural law. However, the Catholic tradition also contains much reflection on the wisdom which is found in what the Church recognises as divine

revelation. This includes the Bible and above all the example of Jesus Christ. Noting that Jesus healed the sick, for example, many Catholic health and aged care services proudly proclaim that they are continuing the healing mission of Jesus.

Above all, faith and reason reveal the inherent dignity of each and every human being, no matter how sick, aged, frail or disabled we may be. In the Bible, the book of Genesis records that God created human beings “in the image of God.” (Gen 1:27) In the Catholic tradition, it is this *imago Dei* – the image of God which is present in every human being – which is the ultimate foundation of human dignity.

From this starting point, Catholic bioethics contributes to moral discourse in every stage of the life continuum from conception to natural death. This Catholic perspective strives to be holistic and to take into consideration all the needs of the individual – physical, emotional, psychological, social, and spiritual. The Catholic approach to care is marked by great emphasis on the importance of pastoral and spiritual care.

Catholic bioethics makes a significant contribution to the moral debates in our society that are critical in this age of advancing technology. It reminds us of our meaning and purpose in life, and guides us towards its fulfilment, not just as individuals but as people in community.

An Overview of the Proposed Victorian Recommendation for Assisted Dying and its Consequences

A recent report tabled in the Victorian Parliament has proposed that the Victorian Crimes Act 1958 be amended, allowing Victoria to become the only Australian state where euthanasia would be legal. Against this proposed legislation, this article contends the suggested amendments pose a threat to the fiduciary obligations that medical professionals owe to their patients. Moreover, that the parliamentary recommendation poses a considerable risk to the sick and dying, while creating tension within existing, currently overburdened, palliative care services. Any reforms that seek to treat dying patients in a more holistic manner, incorporating their emotional equilibrium, will instead make further provision for expanding the provision of palliative care services.

On 9 June 2016, a report entitled the Inquiry into End of Life Choices (IELC)¹ was tabled in the Victorian Parliament recommending the legalisation of assisted dying in Victoria. Recommendation 49 of this report requests, “That the Victorian Government introduce a legal framework providing for assisted dying...” (IELC 8.4) The state government has six months to respond to the report. The proposed recommendation will then be put to a conscience vote. While the report refers to “assisted dying”, this concept is generally referred to as “euthanasia and assisted suicide” (EAS), which is the terminology that will be used in this article.

The report recommends that EAS should only be made accessible to a person who is “at the end of life (final weeks or months of life), and suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.” (IELC 8.6.4) Moreover, the report states that:

- Assisted dying should be accessible only to adults, 18 years and over. (IELC 8.6.2)
- Only a person who is ordinarily resident in Victoria and either an Australian citizen or permanent resident may access assisted dying. (IELC 8.6.2)
- The Committee does not support access to assisted dying through any kind of advance care plan or directive. (IELC 8.6.2)
- A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. (IELC 8.7.1)
- Doctors would need to report all requests to die and assisted deaths through an Assisted Dying Review

Board, whose work would be overseen by a new entity, End of Life Care Victoria. (IELC 8.7.1)

- A patient must make three requests before a doctor can prescribe a lethal drug, or end a patient’s life by administering the drug. The patient must (1) make an initial verbal request; (2) complete a formal written request in a form outlined for that purpose; and (3) make a final verbal request. (IELC 8.6.3)
- The primary and secondary doctors must be independently satisfied that the patient’s request is enduring and that a reasonable amount of time has passed between the patient’s initial request and the provision of a lethal drug. (IELC 8.6.3)
- A substitute decision maker may not request assisted dying for a person, despite any power granted to them by virtue of their position as substitute decision maker. (IELC 8.6.3)
- The Committee recognises the right of doctors, other health practitioners and health services to conscientiously object to assisted dying. (IELC 8.4.2)

This submission made before the Victorian Parliament raises immediate questions regarding the potential ramifications that legalising euthanasia in Victoria could have for the terminally ill, their loved ones, and the medical profession. The primary arguments set forth by the parliamentary committee are analysed below.

Autonomy

The report contends that “each person has the right to determine the course of their life... within the limits imposed by the rights and freedoms of others.” (IELC 7.4.1) This argument is frequently asserted against all contentions that hold human life is inviolable and should be protected.

However, a distinction can be made between respecting people who possess autonomy, and the value of their autonomous decisions. EAS advocates must concede that the report itself, by establishing criteria that specify who may apply to be euthanised, are thus denying certain suffering people who fall outside these parameters their desire to be euthanised. Autonomy thus conceived can become a ‘Trojan horse’ for justifying a plethora of moral assertions. Invoking patient autonomy as an argument for ethical decisions can also become extremely problematic when attempting to establish medical guidelines and laws to which medical professionals must adhere.

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It should be noted that the principle of the ‘inviolability of life’ is not a specifically religious principle, and has long been firmly entrenched within the ethos of the medical profession. The Hippocratic Oath (5th–3rd century BC) states that “I will not give a lethal drug to anyone even if I am asked, nor will I advise such a plan.”² International

human rights law states that “Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.”³

The moral intuition that it is wrong to kill is part of the common ethical standards of all humanity. I invite the reader to look into their own heart: Do you believe that it is wrong to kill another person? Do you believe that it is wrong to kill yourself?

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Patients and Loved Ones

The report holds that “Assisted dying enables people to ensure they are surrounded by loved ones at the time of death and have the chance to say goodbye to friends and family.” (IELC 7.4.2) Allied with this argument, the report touches upon “people who do not wish to be a burden to their loved ones.” It continues by adding that “if someone does not wish to be a burden on their loved ones, they should be allowed access to assisted dying. (IELC 7.4.2)

This is most disconcerting, and it raises concerns regarding whether a dying person, who would otherwise wish to remain alive, would opt to be euthanised so as to remove any “burden” their illness could potentially have for friends, family, and society at large. On this, an important counterpoint has been raised by the American Geriatric Society which argues that euthanasia would “open the door to abuse of the frail, disabled, and economically disadvantaged of society, by encouraging them to accept death prematurely rather than to burden society and family.”⁴

Requests to be euthanised cannot always be taken at face value, and psychiatric assessment is required to comprehend their covert meaning. The desire to be euthanised “incorporates hidden existential yearnings for connectedness, care and respect, understood within the context of the patient’s lived experience.”⁵

The report notes that “where either doctor is concerned that the patient’s decision making capacity may be impaired by mental illness, they must refer that patient to a psychiatrist to determine whether the patient is capable of making decisions about their own medical treatment. (IELC 8.7.1)

... Without mandatory psychiatric referrals, doctors may occasionally step outside the boundaries of their professional expertise ...

However, the report does not recommend mandatory psychiatric referrals for every suffering patient seeking to be euthanised. Without mandatory psychiatric referrals, doctors may occasionally step outside the boundaries of their professional expertise, and assuming the role of a psychiatrist, make unqualified judgments concerning their patient’s emotional equilibrium. In the US state of Oregon in 2009, no patients who were euthanised were referred to any formal psychiatric evaluation.⁶ Should the report recommendation regarding assisted death be accepted, it is questionable how often doctors will feel obliged to refer patients to appropriate psychiatric testing.

Effect on the Doctor-Patient Relationship

The report contends that through the proposed EAS legislation, “Doctor–patient relationships will be enhanced by the openness and honesty that legalising assisted dying will foster.” (IELC 7.5.6) However, if euthanasia legislation is to be accepted by the Victorian Parliament, it would weaken the fiduciary relationship between the healthcare professional and patient. If medical professionals are given the power to harm patients, then patients can never be certain that doctors will act in their best interests. The Dutch experience with euthanasia informs us that patients are increasingly insistent upon writing contracts that stipulate that they will not be killed without their explicit consent.⁷

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Furthermore, most national medical associations throughout the English-speaking world have spoken out against the practice of EAS. The World Medical Association (which represents 82 countries) states that, “Where the assistance of the physician is intentionally and deliberately directed at enabling an individual to end his or her own life, the physician acts unethically.”⁸ The Australian Medical Association affirms that, “medical practitioners should not be involved in interventions that have as their primary intention the ending of a person’s life.”⁹ Similar sentiments have been echoed by the British Medical Association,¹⁰ the New Zealand Medical Association¹¹ and the Canadian Medical Association.¹²

The American Geriatric Society summarises the problem succinctly by stating that “To change the physician’s role to one in which comfort includes the intentional termination of life is to alter this alliance and could undermine the trust between physician and patient.”¹³

While the report notes that instances of euthanasia should involve as little doctor assistance as possible (IELC 8.11), prescribing a lethal drug immediately places medical professionals outside the present medical standards established by many national medical associations. Furthermore, the report does mention a “singular exception... where people are physically unable to take a

lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.” (IELC Annex 1)

Lastly, it should be noted that a suffering patient who seeks to be euthanised must be “at the end of life (final weeks or months of life),” and experiencing “unbearable suffering.” (IELC 8.6.4) How can medical professionals always infallibly diagnose that a patient is in the final weeks or months of life? Diagnoses of imminent death are not always accurate. The cases set out in the Parliamentary Report illustrate several instances where people demand to be euthanised, yet are not close to death, and they record a multiplicity of different kinds of suffering.

The report recommends that it is incumbent upon suffering and dying individuals to determine that their suffering cannot be relieved in a manner they deem tolerable (IELC 8.5.3). This opens the possibility that a patient may request to be euthanised in instances where medical professionals would generally regard the dying patient’s level of suffering to be manageable. Are medical professionals willing to accept euthanasia requests from patients whose pain may be alleviated?

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Suicide Prevention

The report asserts that “With assisted dying unavailable, people with illness or injury that are suffering, or anticipate suffering, suicide alone, often in violent or disturbing ways.” Thus, euthanasia would “allow these people to either end their lives in a more humane manner or let their illness run its course.” (IELC 7.4.3)

Firstly, it must be acknowledged that several cases of brutal suicides are highlighted throughout the report. However, what goes unnoticed is that several of these cases involve suffering people who do not satisfy the proposed criteria that the report outlines for patients who may make an application to be euthanised.

One case put forward in the report (Case 6.1) speaks of a man “suffering with depression and a variety of physical ailments. His mobility and eyesight were failing and he expressed resentment over his inability to pursue his hobbies.” The man subsequently committed suicide by ingesting medication that he had stockpiled from a previous prescription. (IELC 6.1)

Another case (Case 6.3) involved a woman who “suffered rheumatoid arthritis and experienced constant pain and discomfort despite pain relief medication.” In short, she was not dying. Her husband “was later diagnosed with lung cancer and depression.” The husband and wife elected to die together. The husband attempted to electrocute his wife, but the electric shock did not kill her, so he proceeded to smother her to death. He then unsuccessfully attempted suicide by taking an assortment of pills. (IELC 6.2.1)

In both these cases, the people who died would be unable to make an application for EAS under the proposed legislation. This raises concerns whether the legalisation of euthanasia could result in future attempts to extend EAS laws to vulnerable people who aren’t dying, but who encounter physical suffering. During the brief period when EAS was legal in the Northern Territory under the Rights of the Terminally Ill Act 1995, four people died who did not meet the criteria established by the Act.¹⁴

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Furthermore, EAS advocates ignore that attempted euthanasia doesn’t always guarantee that a patient will experience a painless death. Different people have varying reactions to lethal substances. Consider the above case (Case 6.3) in which a man who attempted suicide by taking an assortment of pills, was kept alive by a pacemaker. In certain instances, attempted euthanasia may result in increased pain as a direct result of an intervention made by a medical practitioner.

Impact on Palliative Care

The report asserts that “assisted dying is in itself palliative and gives many peace of mind.” (IELC Appendix 7.4.8) Notably the report recommends the provision of more extensive palliative care services through Victoria, particularly throughout rural Victoria, which is commendable. The report argues that “Government support and funding of palliative care has not declined when assisted dying frameworks have been introduced. (IELC Executive Summary)

But is this true? Some academics have already chronicled evidence that suggests that economic considerations inform the decision-making process that governs euthanasia in the Netherlands.¹⁵ What the report recommendation introduces is a tension between euthanasia laws and the provision of palliative care services.

The report itself notes that “increased demand has caused a strain on the system.” It further adds that “There are gaps that have emerged, particularly in rural and regional areas.” (IELC 1.4.2) If euthanasia were legalised and incorporated into palliative care services, many people seeking proper palliative care may be denied the possibility of receiving full and holistic treatment.

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Euthanasia and Refusing Treatment

The Parliamentary Report argues that “Assisted dying is no different to refusing treatment and receiving continuous palliative sedation.” (IELC Appendix 7.4.5) There is a clear moral distinction between refusing or stopping treatment when it is becoming overly burdensome and the direct killing of a human person (e.g. deliberate overdose).

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For instance, the report quotes the English case of *Airedale NHS Trust v Bland*, wherein “a hospital sought a declaration that doctors caring for a man in a persistent vegetative state, with no hope of improvement, could remove life support without facing civil or criminal liability.” (IELC 7.2) However, this would constitute refusing medical treatment that no longer corresponds to the real situation of the patient, because it is disproportionate to any expected positive results.¹⁶

The report raises concerns regarding whether euthanasia laws could potentially confuse the distinction between removing treatment once it has become overly burdensome, and directly taking the life of a patient. For instance, a survey taken from the Netherlands in 1990 revealed that of 10,558 patients whose lives had been deliberately shortened by doctors, 5,459 (52%) had not explicitly asked for their lives to be shortened.¹⁷ These cases involve people in a comatose state close to the moment of death, where the doctor assumes a direct and uninvited part in the taking of the patient’s life. EAS law would provide more protection to doctors from legal prosecution, but it leaves vulnerable patients exposed to die without consent. If this EAS legislation is passed, it is likely that increasing incidents of euthanasia will involve the direct intervention of a health professional.

Conclusion

... euthanasia laws could potentially confuse the distinction between removing treatment once it has become overly burdensome, and directly taking the life of a patient.

Euthanasia law can never be made safe. It grants doctors greater autonomy over the terminally ill by removing safeguards that prevent doctors from deliberately shortening the lives of their patients. This corrodes the confidence patients have with doctors, as the Dutch experience with euthanasia highlights. The proposed legislation doesn’t require mandatory psychiatric testing for every assisted death request, and fails to recognise that

cries to be euthanised sometimes hide covert longings for care, respect, and love. Euthanasia law runs counter to the ethos of palliative care services, which seeks to serve the dying with these values. Lastly, euthanasia law may require some terminally ill people to justify continuing their life, despite possibly being classified as a burden to others. In short, if euthanasia becomes a solution to one person’s illness, it could become a solution to many more people’s illnesses. The unintended consequences of legalizing EAS could be very serious indeed.

ENDNOTES

- ¹ Legal and Social Issues Committee, Legislative Council, Parliament of Victoria, Inquiry into end of life choices: Final Report, Parliament of Victoria, http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf.
 - ² US National Library of Medicine, The Hippocratic Oath, https://www.nlm.nih.gov/hmd/greek/greek_oath.html.
 - ³ Office of the United Nations High Commissioner for Human Rights, International Covenant on Civil and Political Rights, Article 6, <http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>.
 - ⁴ Nicanor Pier Giorgio Austriaco, O.P., *Bioethics and Beatitude: An Introduction to Catholic Bioethics* (Washington: Catholic University of America Press, 2001), 149.
 - ⁵ Nicholas Tonti-Filippini, A dying man explains why euthanasia is so dangerous, 21 November 2010, http://blogs.news.com.au/heraldsun/andrewbolt/index.php/heraldsun/comments/a_dying_man_explains_why_ethanasia_is_so_dangerous/.
 - ⁶ Susan M. Wolf, “Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia,” in *Feminism and Bioethics*, ed. Susan M. Wolf (Oxford: Oxford University Press, 1996), 282–317.
 - ⁷ Neil M. Gorsuch, *The Future of Assisted Suicide and Euthanasia* (Princeton: Princeton University Press, 2006), 126.
 - ⁸ World Medical Association, WMA Resolution on Euthanasia, <http://www.wma.net/en/30publications/10policies/e13b/>.
 - ⁹ Australian Medical Association (AMA), Position Statement on the Role of the Medical Practitioner in End of Life Care 2007 (amended 2014), AMA, https://ama.com.au/system/tdf/documents/ps_on_the_role_of_the_medical_practitioner_in_end_of_life_care_2007_amended_2014_0.pdf?file=1&type=node&id=40572.
 - ¹⁰ Eamonn Mathieson et al., Submission 899, Inquiry into End of Life Choices 2015, Parliament of Victoria, http://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_899_-_Dr_Eamonn_Mathieson_signatories.pdf.
 - ¹¹ Scoop Health, NZMA Continues to Oppose Euthanasia, <http://www.scoop.co.nz/stories/GE0508/S00009.htm>.
 - ¹² Roland Chia, “Physician-Assisted Suicide,” *Ethos Institute for Public Christianity*, <http://ethosinstitute.sg/physician-assisted-suicide/>.
 - ¹³ As quoted in: Austriaco, 148.
 - ¹⁴ David W. Kissane, Annette Street, and Philip Nitschke, “Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,” *Lancet* 352, no. 9134 (3 October 1998): 1097–1102.
 - ¹⁵ Gorsuch, 128–129.
 - ¹⁶ John Paul II, *Evangelium Vitae*, 25 March 1995, Holy See, http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html.
 - ¹⁷ John Keown, “Euthanasia in the Netherlands: Sliding Down the Slippery Slope?” in *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*, ed. John Keown, (Cambridge: Cambridge University Press, 1995), 261–296 at 278.
- All online material accessed on 29 August 2016.

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Making Sense of a Wish to Hasten Death

How should health professionals respond if a patient nearing the end of life expresses a wish to hasten their death? To answer this question, this article draws upon peer-reviewed literature, the practices of palliative care, and the experiences of two palliative care physicians, Associate Professor Natasha Michael and Associate Professor Mark Boughey. The expression of a wish to hasten death does not necessarily imply a genuine desire to hasten death or to be helped to die. To the contrary, almost always this means that the patient has been overwhelmed by one or more serious concerns. While inadequate pain relief may be one such factor, more typically these concerns are social and spiritual, such as loneliness, social isolation, feeling oneself to be a burden on others, hopelessness, and fears about the process of dying. If a patient expresses a wish to hasten death, health professionals should therefore discuss with them the reasons for this request, and then devise and effectively communicate an individualised care plan which begins to address these concerns.

Healthcare is a balance of art and science. In order to diagnose and treat, the health professional needs to be compassionate and empathetic, and also must have an in-depth knowledge of medicine. Catholic health ethics teaches that life is precious, and that the illness narrative is part of life's journey.¹ When illness becomes terminal and the focus of care turns to patient and carer centred care, then the relationship between doctor and patient needs to follow suit. The transition is fraught, and, when negotiating various challenges at the end of life, patients and their carers can become overwhelmed. It is not uncommon for patients to express a wish to hasten death. This article will demonstrate that this wish to hasten death is not an expression founded on taking assertive action to die, but instead an opportunity to engage in conversations to address the underlying cause of a patient's distress. It begins with an exploration of peer-reviewed studies of the wish to hasten death. A second section describes the care which is provided at the end of life. This includes consideration of the negotiations which occur between patients, their families, and their health professionals – including discussions about any expressed wish to hasten death. Associate Professor Mark Boughey and Associate Professor Natasha Michael are eminent physicians who have helped to shape palliative care in Australia. These two doctors shared with me their experiences of working with patients approaching the end of their life and the challenges therein. Their observations are reported in the final sections of this article.

Studies on the wish to hasten death

Good health and wellbeing are two of the hallmarks of what might be called a 'good life.' However, both body and mind are susceptible to disease. Disease can be genetic in origin or contracted through the environment and/or behaviours that negatively affect health. Because of disease, medicine and health care are important

contributors to the experience of a good life. The interaction between doctor and patient is set in a complex health system. Every aspect of a good life is not always possible, and disease can overwhelm the body. In people who are elderly and others experiencing chronic degenerative disease and cancer, symptoms of the disease or the side effects of treatment can sometimes lead to greater disability. End of life care is a matter of balancing social demographics, multicultural and institutional constraints, with the aim of facilitating what is commonly referred to as a good enough death.² It should also strive to ensure that patients can make informed choices, and that health professionals can support these decisions, as part of the hierarchy of care "ensuring some kind of certainty and control in an otherwise uncertain process."³

End of life care is a matter of balancing social demographics, multicultural and institutional constraints, with the aim of facilitating what is commonly referred to as a good enough death.

Patients who express a wish to hasten death, often at the end stages of a disease, may anticipate or feel that they are experiencing incurable and even unbearable pain. As we reflect on this, it is helpful to keep in mind the concept of 'total pain.' This is an insight from Cicely Saunders, the founder of the modern hospice movement. She taught us that pain is not simply physical. To the contrary, pain is at once physical, psychological, social and spiritual. What may appear as physical pain "might be a consequence of loneliness, spiritual distress, inappropriate diet, or tumour growth."⁴ Total pain may also be related to social aspects such as concerns about being a burden to one's family, quality of life after medical intervention, and disease chronicity perhaps over a very long time. In the illness narrative, periods of good health and poor health unfold in a dynamic state of flux, often causing the pendulum to move between a wish to die and the willingness to live. Having an insight into this illness narrative enables clinicians to explore with patients the underlying factors that influence a wish to hasten death. Better management plans which address these factors can then be devised.

A meta-ethnographic study is a systematic review of the existing literature to identify prominent and key themes. One such study of the wish to hasten death was conducted in 2012 by Cristina Monforte-Royo and her colleagues. It found six themes which may motivate this wish to hasten one's death. The first is in response to physical, psychological and/or spiritual suffering. The second is loss of self, which can include "loss of function, loss of control and loss of meaning." A third motivation is fear – both fear of the dying process and fear of imminent death. The fourth theme is rather paradoxical. Rather than a "genuine wish to die," this motivation is "a desire to live but not in this way." The authors also describe this as "a cry for help in the face of suffering." A fifth motivation is simply the desire to end suffering. The final motivation identified in this meta-ethnographic study is as a kind of control over one's life in situations where people felt that they had lost

control over many other aspects of their life. The authors also describe this as having “an ace up one’s sleeve just in case.” The authors conclude therefore that a wish to hasten death is a “multifactorial construct with multiple meanings that do not necessarily imply a genuine desire to hasten death or actually taking steps towards this.” Thus, they counsel that “any manifestation of the wish to hasten death should be carefully assessed, with the possible reasons for it being considered.” This in turn can lead to the development of individualised care plans for these patients. If lack of control is an issue, for example, a care plan should be devised which offers the individual “some control over the central aspects of his or her care.”⁵

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Another systematic review sought to synthesise the international evidence of people’s views and attitudes towards euthanasia. This study was conducted in 2011 by Maggie Hendry and her colleagues. They identified four themes for or against euthanasia: concerns about poor quality of life, the desire for a good quality of death, concerns about abuse if euthanasia were legalised, and the importance of individual stance related to euthanasia. They found that “unbearable suffering relating to psycho-emotional factors such as hopelessness, feeling a burden, loss of interest or pleasure and loneliness were at least as significant as pain and other physical symptoms in motivating people to consider assisted dying.” They added that “the effect of adequate pain relief was particularly clear in studies where participants had personally expressed a wish to die and subsequently changed their mind when their pain was controlled.”⁶ When a wish to hasten death is expressed, these findings again remind us of the need both for thorough discussion about the reasons for this request, and for the subsequent development of appropriate, individualised care plans.

A series of case studies by Kathrin Ohnsorge and her colleagues offers further evidence of the complexity of a wish to hasten death. After many interviews and an interpretive phenomenological analysis, they identified intentions, motivations and social interactions as the three dimensions crucial for understanding a wish to die. They further divided motivations into reasons, meanings and functions. Reasons are the factors that patients identify as the causes of their wish to die. Meanings are the larger narratives in which these reasons are embedded. And functions are the effects which a wish to die has either on the patient themselves or on significant others. Like many other studies, this study reported that the reasons for a wish to die are “predominately social and spiritual.” These include loneliness, social isolation, hopelessness, an awareness of the incurable and terminal condition of their disease, and the uncertainty of the dying process. This study insisted however that much more attention must be given to the meanings of a wish to die and the narrative framework in which this wish makes sense.⁷ Obviously, all

this is infinitely more complex than simply taking a wish to die literally.

An Australian study by Brian Kelly and his colleagues investigated 256 terminally ill cancer patients. It found that a small proportion (3.1%) had requested interventions to end their life, while 18% had discussed a wish to die with a family member, and almost 14% had discussed a wish to die with a doctor or nurse. The study sought to investigate the association between an expressed wish to die and psychological factors such as depression and anxiety, social factors such as family relationship, social support and the perception of being a burden on others, and the impact of physical symptoms. In order, the factors found to be most associated with a wish to die were depressive symptoms, being admitted to an in-patient hospice unit, perceiving oneself to be a burden on others, lower family cohesion, lower levels of social support, higher levels of anxiety, and (to a lesser extent) the presence and severity of physical symptoms. The authors commented that their study “confirms the more important independent effect of psychological symptoms, particularly depression, and the social factors outlined” in the development of a wish to hasten death. They therefore also concluded that “greater attention needs to be paid to the assessment of psychological and social issues in order to provide appropriate therapeutic interventions for terminally ill patients.”⁸

Care at the end of life

Interviews with health professionals reveal a mixed reaction towards acting on patients’ wishes to hasten death. One study found that professional role (whether doctor or nurse), seniority in that role, and religious affiliation sometimes influence the health professionals’ attitudes towards patients’ expressed wishes to hasten death.⁹ In another study, Charles Waddell and colleagues invited medical practitioners to respond to a series of vignettes using a self-administered questionnaire. Interestingly, participants generally did not act on patients’ requests to hasten death, citing medical training and the wishes of the family as influencing their decisions, and, rarely, the nature of the medical condition itself. These results suggest that training in certain medical specialities and religious persuasion can influence health professionals’ decisions about a patient’s wish to hasten death.¹⁰

As we have already noted, research in this area also reveals that personal values and belief systems have significant roles in patients’ wishes to hasten death. If a desire to hasten death is expressed, this desire should not, in most cases, be interpreted as an intention to die or to be helped to die. On the contrary, it should be better understood as an expression about loss of self, control and identity. The health professional is part of this conversation, and assumes the role of moderator and gatekeeper of medical resources. Generally, the physician’s responsibility (along with other health professionals working with patients at

... a desire to hasten death ... should be better understood as an expression about loss of self, control and identity.

the end of life) is to act in the best interests of their patient. Ethical decision-making in clinical practice is for the most part a fine balance between the physician's responsibility and the patient's wishes. Caroline Ong RSM proposes that factors underpinning the euthanasia debate and understanding the wish to hasten death are often confused by communities' and health professionals' lack of knowledge of the definitions of euthanasia and palliative care, and the acceptability of the latter. Ong continues by using imagery to reflect on the dying process as possibly 'transformative.'¹¹ She therefore supports palliative care as a better approach than assisted dying for patients at the end of life who are experiencing significant suffering.

Palliative care employs a multidisciplinary approach for patients at the end of life. It seeks to relieve suffering through effective pain management and psychological, social, and spiritual support. The care provided is not limited to the patient but is extended to patients' families as well. Widespread availability of palliative care in Australia could be the answer to end long-standing debate about euthanasia and assisted suicide. Palliative care practitioners have written about their own experience in literally thousands of cases of patients at the end of life who feel comfortable and are actively involved with decision-making about their care, along with families who feel confident with the care provided. Experiences like this of the strengths and positives of palliative care are paramount to ensure its widespread use and uptake.¹²

Dr Natasha Michael

Palliative care physicians are deeply and strongly committed to providing holistic and patient-centred care both to their patients and their patients' families and caregivers. I was fortunate to speak with Dr Natasha Michael and Dr Mark Boughey, two eminent physicians who have helped to shape and promote palliative care in Australia and overseas.

Dr Michael admits that her reasons for studying medicine were not entirely altruistic and were perhaps the choice of a rather naive school leaver. Even so, if she had to make this decision again, she would still make the same choice. An interest in geriatrics was the start of a career that has focused in palliative care and broadly in medical ethics.

For Dr Michael, palliative care is "fundamentally a philosophical approach to care... We care for the whole person – not just the physical being, but the spiritual and psychological emotional being [as well]. The unit of care... is the patient as well as the family... We ensure that we relieve suffering through the early identification and addressing of difficulties. We acknowledge that death is a natural process of life, and we neither hasten [death] nor do we prolong it."

Working overseas for a number of years gave Dr Michael a rich insight into how people of different cultures and faiths perceive death. In some parts of the world, death is a natural part of society and family, whereas Dr Michael observed that in the United Kingdom and Australia, the community is "death denying, [and] people are uncomfortable talking about [death]." However, there is now a concerted effort in the UK to acknowledge the place

of palliative care within public healthcare. Dr Michael thinks that Australia must follow this same approach if palliative care is to gain the recognition here that it deserves.

Dr Michael identifies three key statements at the end of life. They are: 'I want to die,' 'Let me die,' and 'Kill me.' 'I want to die' is an expression of distress where patients are overburdened by the symptoms of their illness. For these patients, offering better pain management should be the primary objective of care. Patients saying 'Let me die' are those who feel they have fulfilled their life's goals, and are keen for "nature to take its course." The third group is the minority, says Dr Michael. For these patients, the pain and suffering have become overwhelming, and 'Kill me' is seen by them as the only option. In Dr Michael's experience, this position should not be literally translated but a starting point to begin a conversation about end of life care and perhaps better pain management. Therefore, palliative care should be malleable to become shaped into a model of care that is best suited to individual patient needs. "The bread and butter of what we do is prepare people for dying at the end of life. And if we see people early in the illness, fifty percent of the patients in my unit are discharged home," Dr Michael said. Another common theme that emerges in the conversations that Dr Michael has with her patients are those patients who say that they don't want to overburden their children. To this she advises that by "allowing your children to care for you, you are giving the next generation a gift actually. When your grandchildren watch what your children do for you, they will do the same for their parents." We hope therefore in the coming generations that we will become more compassionate, and people won't feel that they are a burden. In line with this is offering meaning through conversation and contribution. Dr Michael says that her patients welcome the opportunity to speak with medical students and to contribute to research.

"The bread and butter of what we do is prepare people for dying at the end of life..."

Over the years and into the future, palliative care has and will continue to face many challenges. Dr Michael recognises that there remains a significant need to have palliative care as part of acute hospital admissions and a need for greater resourcing for community palliative care services. She also expresses the hope that as it endeavours to become a prominent specialty, palliative care will not lose sight of its fundamental philosophical basis of caring for the whole person. Specialty training programs in palliative care are enrolling more training doctors, Dr Michael says, but some younger health professionals may lack the life skills to manage this role. Dr Michael adds that this could potentially pose some concern. As healthcare continues to move forward, advance care planning is now a well-recognised step towards better end-of-life decision-making for the patient and their family. In a recent workshop, attendees were worried about some elderly parents who may have limited cognition and capacity to make these important choices, and they were especially concerned about what safeguards there are. In response, Dr Michael encouraged ongoing conversations and shared

decision-making. She also supported continuing to present palliative care within these forums in order to “demystify... some of these assumptions that people have about what we do and what we can offer.”

In society and in particular the media reporting of death and dying, the story rapidly escalates into the controversy about euthanasia. Dr Michael has been an invited speaker at parliamentary inquiries and public conferences on this topic, and has stated that the community has limited knowledge and little experience with death and dying, and that there is much fear and anxiety associated with the end of life. Dr Michael insists that these challenges can be overcome with education, awareness and open dialogue. Those who support euthanasia repeatedly use the phrase ‘dying with dignity.’ Dr Michael from her own research in the area says that dignity is interpreted in many different ways that are not limited to the physical dimension but must include aspects relating to personhood, identity, and meaning in relationships with others. She says that the phrase is too simplistic for the complex and emotive debate that still continues in our community.

Dr Michael often speaks of what she refers to as the “incredible moment when life gives way to death.” This poignant and vivid image perhaps best evokes this most important experience of life. When a patient is ‘actively dying,’ while their breathing and consciousness are wavering in that state, they remain a family member and presence in the room. However, there is “the moment they draw their last breath... When that moment occurs – the moment of death – everything changes...the physical presence [is gone]. You walk into a room and someone is not there anymore.” Dr Michael says that the time leading to this moment is perhaps the most precious time that patients and their family should experience together, as together they experience the transition whereby that person ceases to be a physical presence.

Dr Mark Boughey

Dr Boughey was uncertain about his career path after graduating from high school, but felt a strong affinity to medicine due to several family members being doctors themselves. After a three year gap and reapplying to study medicine, he began his studies. “I think there was a sense of wanting to connect with people...work with people and help them change and make them better at what they do and manage their own health,” he said. At this time, palliative care was only emerging as a medical speciality. For Dr Boughey, it was “holistic, direct, communicative, inclusive, [and] patient-centred.” He added that this was “the way I liked to practise healthcare and medicine, and it was a completely new field.”

For Dr Boughey, palliative care is an approach to healthcare that is not exclusively the domain for negotiating death and dying but rather patient-centred care that promotes multidisciplinary medical practice. It is an inclusive model that engages with patients and their families on an intimate level to respond appropriately to health needs. Dr Boughey believes that healthcare broadly should adopt and be sustained through embracing the “patient-centred, good communication skills, shared decision-making and advance care planning” features which are inherent in palliative

care. Although progress is being made in recognising the work of palliative care in medical training, there is limited progress in nursing and allied health training. This slows down “a complete integration into the health services.” Another challenge for palliative care is gaining the recognition from other medical specialties. “Talk therapy doesn’t get funded,” Dr Boughey said, because other “clinicians don’t see it as relevant.” As a result, the funding for other disciplines is much greater when compared to that for palliative care, and there is the expectation that therapies and policy can be developed within palliative care without purposeful funding. Although much of the work and advancements in palliative care can be attributed to individual physicians, Dr Boughey says that funding and resources could stimulate and allow for the rapid expansion and widespread use of palliative care.

Dr Boughey reports that the public health sector has made positive changes in end-of-life care with “good discharge planning...[and] effective communication... We teach communication [and] there is a whole lot of stuff that makes the health journey experience a lot more integrated.” Similarly from his experience in working various types of hospitals, Dr Boughey has observed a particular (positive) concern for palliative care in Catholic hospitals. Dr Boughey says that in Catholic hospitals, “generally there is a connection between mission and provision of end-of-life care. I think palliative care is significant: we are more recognised in the organisation [and] we are connected to the [hospital] Executive.”

When health professionals from other health disciplines attempt to categorise palliative care, Dr Boughey observes that oftentimes they regard it as only concerned with death and dying. This is far from the reality of contemporary palliative care. Dr Boughey is concerned that medicine broadly has “become so fragmented, [and] it has become so intervention-orientated... [that it has become] about giving the next new drug, giving treatments. A lot of clinicians have lost the ability to have the dialogue to contextualise what is the best care that is needed to be provided when deterioration and palliation are being considered.” Furthermore, as they become disengaged from the illness narrative and focus almost exclusively on therapy and treatment, clinicians are also oftentimes losing sight of their ethical responsibilities. Dr Boughey says that it is important to discuss with patients the “possibility of minimising intervention... [and] presenting the other side of the story.” Clinicians seek to provide hope, and patients appreciate this. However, Dr Boughey says that it takes an articulate patient to explore the non-curative or non-interventional therapies. The capacity to have informative dialogue that doesn’t step back from the nuances of the illness narrative is an important skill to have. “It is all about communicating effectively and you don’t need to be a ‘death specialist’ [laugh] to communicate effectively. You should be able to communicate effectively irrespectively of what discipline is involved and what they are trying to work towards.”

Teaching about death and dying and encouraging conversations about this amongst families and in the community is to portray death and dying in a “positive way and part of the natural cycle.” Experience of death and

dying itself only becomes a reality when there is direct connection with someone who is actually going through this experience. Dr Boughey recognises that for some people fully engaging in decisions about end of life is only relevant when they themselves or someone close to them are dying. Otherwise, those people are likely to see these decisions as being outside their comfort zone, which, Dr Boughey appreciates, is a fairly natural reaction.

In one sense, the very title of 'palliative care' helps to create the distance that many people have towards it. Dr Boughey wistfully says that if he could change the name, it would be "clinically supportive ethical care" because "I think we focus primarily on the person with the serious illness, and not just the disease causing the illness, and we become, by necessity, the most ethically-driven part of the healthcare system in our considerations surrounding current, appropriate, best care. That is not just about our perspective but from the patient's perspective – that sort of holistic care." Reflecting on a family meeting from that day, Dr Boughey says that when patients come to realise the limitation that their illness poses – which can sometimes mean moving into a palliative care bed in hospital— the family need to support the patient in this transition. Positive outcomes like this can have a ripple effect on the care staff as well. "It is also satisfying for our younger doctors and nurses to see that conversation facilitated so you walk away from that family meeting feeling like you have achieved something."

Reflecting on the wish to hasten death, Dr Boughey says that "people are having longer lives and we have to accept that but it is just that people don't tend to think about the psychological impacts or the care impacts... You can be well and in remission but you still [have] the physical and emotional needs." Also with the resurgence of new treatments, patients are becoming more assertive in making decisions for themselves, and that includes taking steps to hasten death or at least to communicate this to their doctors. Disregarding the advice and expertise of health professionals can have a negative impact on the way that patients are able to make decisions. They can readily become over-burdened by the choices and ultimately express a wish to hasten death. In these instances, it becomes vitally important, Dr Boughey says, to involve palliative care at the earliest possible time to ease some of the burden and engage in a dialogue that shares with the patient other viable options at the end of life that aren't as dramatic or definite as death. The place for palliative care is to make patients feel valued, and to feel they have some control.

... it becomes vitally important, Dr Boughey says, to involve palliative care at the earliest possible time to ease some of the burden and engage in a dialogue that shares with the patient other viable options at the end of life that aren't as dramatic or definite as death.

Conclusion

The ambiguity between expression of a desire to hasten death and explicit action to end one's life is complex. This article sought to review the experiences and attitudes of patients, carers and health professionals about end of life care, and specifically the wish to hasten death. On the whole, the explicit action to hasten death is rare; however, patients with terminal illness and those caring for them are faced with negotiating pain management, preserving life, and affirming patient identity. The expression of the wish invites open discussion about end-of-life care perhaps through palliative care services. Addressing aspects of psychological distress, spiritual distress, loss of control, and dependency on others should be seen as a welcome part of compassionate care for patients and their families. The expressed desire to hasten death is an opportunity for the healthcare team to provide a greater supportive environment for the patient at the end of life.

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ENDNOTES

¹ Catholic Health Australia states that "at the very heart of Catholic health and aged care is a distinctively person-centred vision based on belief in the essential dignity of each human person. Catholic services above all seek to foster a healing environment that promotes a culture of life." For this, see Catholic Health Australia (CHA), "Ethics," CHA, <http://www.cha.org.au/mission/ethics>.

² Beverley McNamara, "Good enough death: autonomy and choice in Australian palliative care," *Social Science & Medicine* 58 (2004): 989-938.
³ *Ibid.*, 936.

⁴ Cathy Siebold, *The Hospice Movement: easing death's pains* (New York: Twayne, 1992), 16. Siebold added that "careful listening" is therefore an "important skill in determining the best way to reduce patient discomfort."

⁵ Cristina Monforte-Roya et al., "What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients," *PLoS ONE* 7 no.5(May 2012): e37117, 1–16 at 1,5–7,10,12-15.

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