Special Issue

End of Life Law, Ethics, Policy and Practice

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GUEST EDITORIAL: END OF LIFE LAW, ETHICS, POLICY AND PRACTICE

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The International Conference on End of Life: Law, Ethics, Policy and Practice was held at Queensland University of Technology, Brisbane, Australia in August 2014. It was co-hosted by the Australian Centre for Health Law Research, the Dalhousie Health Law Institute (Canada) and the Tsinghua Health Law Research Center (China). The conference attracted almost 350 delegates from 26 countries and included representation from over a dozen different disciplines with an interest in end of life care.

This issue contains seven articles which span the four conference themes of:

i) withholding and withdrawing potentially life-sustaining treatment;
ii) euthanasia and assisted suicide;
iii) palliative care and terminal sedation; and
iv) determination of death and organ donation.

We begin the issue with an article from Michael Ashby on how, from the palliative care perspective, we might or should die. The article, entitled 'How We Die: A View from Palliative Care', examines the experience of dying, especially with regard to the how, where and when of dying in Australia. While Australia has been ranked the second best country in the world in which to die,[1] the article notes that much remains to be done. Ashby then examines some of the remaining significant medical, legal, ethical and social barriers to care and decision-making at the end of life, including some legal issues, such as terminal sedation (see also McLean's article below). Other issues that are canvassed include the difficult social and cultural problems about attitudes towards death and dying, 'death talk' or communicating about death and dying, in preparing for death and in respect of death causation. The article advocates a move away from a focus on human agency and death causation towards non-obstruction of the dying process, something which palliative care can enable.

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[1] Economist Intelligence Unit, *The 2015 Quality of Death Index. Ranking Palliative Care Across the World* (2015) <http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015>.

The next article then shifts to the topic of withholding and withdrawing life-sustaining treatment and focuses in on a key area of debate in this field: futility. The article, '*Texas Advance Directives Act*: Nearly a Model Dispute Resolution Mechanism for Intractable Medical Futility Conflicts,' by Thaddeus Pope, analyses an early model for resolving futility disputes. Pope first examines the nature of medical futility disputes and why there is a need for a process to resolve them. He then shifts to examine the legislation and undertakes a detailed legal analysis of the conflict resolution process established by the Act. He reviews its purpose and history, and then considers the various procedural steps that form part of the Texan model. He also examines how this framework has operated in practice and the extent to which it has been used by hospitals and families. Pope concludes with a normative critique of the *Texas Advance Directives Act*. He argues that while there are benefits to the dispute resolution process, it fails to take sufficient account of fundamental notions of procedural due process and should be reformed accordingly.

A second futility article is 'Futility and the Law: Knowledge, Practice and Attitudes of Doctors in End of Life Care' by Lindy Willmott, Ben White, Eliana Close and colleagues. It reports on empirical research undertaken in Queensland into doctors' perceptions about the law that governs futile treatment at the end of life, and the role it plays in medical practice. The article begins by outlining the relevant law which is particularly complex in Queensland when compared with other Australian jurisdictions. The article then shifts to describe the empirical research that was undertaken which involved semi-structured interviews with 96 doctors from a range of specialties involved in end of life care. Key findings are that doctors have poor knowledge of the law in this area and their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the end of life. The attitudes of doctors interviewed were also largely negative towards the law and some reported that the law affected their clinical practice and either had or would cause them to provide treatment that they regard as futile. The article concludes with recommendations for law reform and education.

The next two articles report on overseas law and/or practice on assisted dying. The first is by Linda Ganzini on 'Legalised Physician-Assisted Death in Oregon'. Her article draws together the various empirical evidence available on the operation of the Oregon regime and examines demographic information about those who have sought assistance to die. She notes, for example, that 3 in 1000 deaths in Oregon are now from physician-assisted death, and most of those dying have cancer or amyotrophic lateral sclerosis. Access to the regime is mostly by educated people with health insurance, most of whom are receiving comprehensive end of life care through a hospice. Ganzini does note, however, that a small number of persons with depression do access the regime, pointing to the need for improved screening for mental illness. She concludes that concerns that legalisation would undermine palliative care and that the regime would be utilised disproportionately by patients without access to good end of life care have been unfounded.

The second article on assisted dying is Jocelyn Downie's 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions'. This article offers a unique perspective on what Downie describes to be the 'well-travelled terrain' of the voluntary euthanasia and assisted suicide debate. Rather than rehearsing the arguments in support of and opposing reform and describing the legislative models around the world that permit these practices, Downie's article considers a range of pathways to permissive regimes. By focusing on the experiences in five common law jurisdictions (the United States, the United Kingdom, Australia, New Zealand and Canada), Downie explores prosecutorial charging guidelines, court challenges, jury nullification, the exercise of prosecutorial discretion in the absence of offence-specific charging guidelines, and the exercise of judicial discretion, in

addition to legislative reform, as potential law reform avenues. The article concludes with some lessons that can be learnt from the recent experience in Canada which has witnessed the landmark decision of the Supreme Court of Canada in *Carter's case*[2] where provisions of the *Criminal Code* relating to physician-assisted dying were held to be void in some circumstances, as well as legislative reform in the province of Quebec.

While some practices in Australia are clearly lawful (such as withdrawing treatment which is not in the best interests of a patient) and some are clearly unlawful (such as providing medication to a patient with the sole intention of killing that patient), terminal sedation is a medical practice that cannot neatly be categorised as either lawful or unlawful. Opinions also differ about the ethics of the practice. Sheila McLean's article 'Terminal Sedation – Good Medicine? Good Ethics? Good Law?' explores the legal and ethical implications of terminal sedation including when it is combined with the removal or withholding of artificial nutrition and hydration. Remarkably, the legal and ethical dimensions of this practice have received little scrutiny despite the fact that the death of patients is the certain result.

In this article, McLean considers the kinds of practices that are encompassed by the phrase 'terminal sedation' as well as the circumstances in which it is provided, and how practice in this regard varies across jurisdictions, and even within the same country. McLean explores the various ethical and legal principles upon which terminal sedation could be justified, but concludes that the practice, particularly when it involves the withholding or withdrawing of artificial nutrition and hydration, rests on shaky ethical and legal foundations. The author argues that there is an urgent need for 'clarification, consistency, transparency and accountability' as the use of terminal sedation continues to grow.

This special issue concludes with a discussion of the United Kingdom position on deceased organ donation after the circulatory determination of death, and measures that can increase rates of solid organ donation. This is a timely contribution as this issue has become controversial in Australia in recent times.

Dale Gardiner's article, 'How the UK Overcame the Ethical, Legal and Professional Challenges in Donation after Circulatory Death', charts the return of donation after circulatory death ('DCD') in the United Kingdom after the practice had effectively been abandoned for approximately 25 years, following the rise of donation after brain death. Gardiner points out that, today, DCD accounts for 40 per cent of deceased solid organ donation in the United Kingdom. He attributes part of the success of DCD to the introduction of new measures aimed at increasing the number of families that are approached by intensive care staff with the offer of the opportunity to donate. Gardiner points out that even though the consent rate itself has not changed (the rate of consent has remained virtually the same over the last decade), these reforms have resulted in a staggering 311 per cent increase in the number of families approached, and this has translated into a 170 per cent increase in the number of actual DCD donors since 2007.

Gardiner also attributes the rise of DCD to a better ethical and legal framework for DCD in the United Kingdom, which has allowed organ donation following circulatory death to become a usual rather than unusual event in hospitals. In other words, donation conversation is now, where appropriate, a normal part of end of life care. In his article, Gardiner goes on to outline in detail the main factors which he believes brought these changes about.

[2] *Carter v Canada (Attorney General)* 2015 SCC 5.

The seven articles in this special issue traverse a breadth of end of life issues including withholding and withdrawing life-sustaining treatment, euthanasia and assisted suicide, palliative care and terminal sedation, and determination of death and organ donation. The articles look at these issues from both national and international perspectives and from legal, medical, bioethical and social science viewpoints. This collection also signals the important work that still needs to be done, and of the need for comparative understanding and interdisciplinary perspectives to advance end of life law, ethics, policy and practice.

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HOW WE DIE: A VIEW FROM PALLIATIVE CARE

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There is an ongoing global conversation about dying, particularly with regard to treatment abatement decisions, causation and responsibility for death, and relief of physical and existential suffering. There is rising international support for assisted dying. People now tend to die slowly in old age, as a result of multiple chronic illnesses, with more medical decision points and impaired cognitive capacity. This paper describes the dying process from the standpoint of palliative medicine and argues for an improved common recognition of the process of dying, in its contemporary spiritual and social contexts, by the public, medicine, ethics, public policy and the law.

I INTRODUCTION

There is an ongoing global conversation about death and the process of dying. Despite half a century of clinical, academic and public policy activity by specialist palliative care workers, as well as health administrators, academics, lawyers, artists and writers, it is still common to hear the same issues recycled with the oft-repeated comment that we 'do not do this well'. The pathways to death are changing: increasing numbers of people are dying in old age, slowly, over one to two years, with multiple co-morbidities, high incidences of dementia, and more significant medical decision points. On the one hand, the public (fed by a technically optimistic health industry) may have unrealistic expectations of curative capacity; on the other, they exhibit widespread concern about "bad dying". Clinicians still struggle with treatment abatement decisions, and issues related to causation and responsibility for death.

In contemporary discourse and policy, the main issues revolve around causation (euthanasia and assisted dying); causal responsibility by doctors and families (decision-making at the end of life, especially for those who lack capacity); relief of physical and psychological suffering; spiritual, existential and cultural dimensions associated with meaning and coping; and place of death (and dying).

In recent years, three prominent policy 'think-tanks': Demos, the Economist Intelligence Unit, and the Grattan Institute have been commissioned to study dying. In the report compiled by the Economist Intelligence Unit, Australia was recently ranked as the second best country in the world (after the UK) in which to die, albeit using crude global measures of the 'quality' of dying.[1] Clearly much remains to be done everywhere to improve care and decision-making at

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[1] Economist Intelligence Unit, *The 2015 Quality of Death Index. Ranking Palliative Care Across the World* (2015) <http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015>.

the end of life, both within health care systems and in the broader community. The Grattan Institute has pointed out the demographic and economic challenges of dying for an ageing population.[2] Palliative Care Australia has published a guidance document on system reform and care at the end of life,[3] and an updated National Palliative Care Strategy was promulgated in 2010.[4] The Australian Commission on Safety and Quality in Health Care has recently issued a consensus statement on care at the end of life for the acute sector.[5]

In the UK, Demos[6] has strongly criticised care of the dying, despite that country being rated as the global leader in palliative care by the Economist Intelligence Unit ('EIU').[7] The National Health Service ('NHS') End of Life Care Strategy was launched because there had never been a system-wide approach to palliative care, despite excellent care for over 50 years by some of the longest established pioneering specialist palliative care services in the world.[8] Of all NHS complaints in acute hospitals, 54 per cent were found to be related to care at the end of life and bereaved people.[9] A government commission for Healthcare Audit and Inspection found a major mismatch between actual place of death and peoples' preferences, usually for death in their own home.[10] It was estimated that only around one third of the population ever discusses death and dying issues with others. The General Medical Council also published comprehensive updated guidance for doctors on end of life care in 2010.[11]

Palliative care is defined by WHO (2002) as:

> an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.[12]

The work of palliative care can be sub-divided into:

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[2] Hal Swerissen and Stephen Duckett, 'Dying Well' (2014) Grattan Institute <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>.

[3] Palliative Care Australia, *Health System Reform and Guidance at the End of Life: a Guidance Document* (2010) <https://www.pcvlibrary.asn.au/download/attachments/2917053/Care+at+the+end+of+life.pdf?version=1&modificationDate=1327895181539>.

[4] Australian Government, Department of Health, *The National Palliative Care Strategy* (2010) <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>.

[5] Australian Commission on Safety and Quality in Health Care, *Safety and Quality of End-of-Life Care in Acute Hospitals: a Background Paper* (2013) < http://www.safetyandquality.gov.au/publications/safety-and-quality-of-end-of-life-care-a-background-paper/>.

[6] Charles Leadbetter and Jake Garber, *Dying For Change* (2010) Demos <http://www.demos.co.uk/publications/dyingforchange>.

[7] Economist Intelligence Unit, above n 1.

[8] Department of Health (UK), *End of Life Care Strategy* (National Health Service, 2008) <http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf>.

[9] Commission for Healthcare Audit and Inspection, *State of Healthcare 2007: Improvements and Challenges in Services in England and Wales* (2007) <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228524/0097.pdf>.

[10] Ibid.

[11] General Medical Council (UK), *Treatment and Care Towards the End of Life: Good Practice in Decision-Making* (2010) <http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp>.

[12] World Health Organisation, *WHO Definition of Palliative Care* (2015) <http://www.who.int/cancer/palliative/definition/en/>.

(i) biological aspects: pain and symptom management;
(ii) psychological and spiritual support: for patients, families, friends, and carers, and after death for the bereaved; and
(iii) communication and decision-making: especially so-called 'death-talk'.

Even from its early days palliative care services espoused multidisciplinary teamwork and whole person-centred care, seeing the patient in their mind-body-spirit and social/kinship context. This care is intrinsically relational in temperament and practice, and its practitioners need to have the necessary expertise, experience, and time to work effectively with their clients. However in order for palliative care to be appropriately accessed and deployed, there needs to be personal, clinical and societal recognition of death and the process of dying. There are barriers in all these domains despite many years of work by specialists in palliative care and many other disciplines, and by concerned politicians and citizens, especially those who have experienced the 'bad' deaths of those close to them.

Across the world, public policy, ethics and the law have all been engaged in trying to unravel the real and perceived difficulties of care and decision-making at the end of life. Personal (patient) autonomy is rightly the main guiding principle in all these deliberations, but it is often not adequately balanced, informed and supported by the realities of death and the dying process. Academic attempts to define, acknowledge, express and work with contemporary 'western' human dying have had limited success in policy and practice. There often seems to be over-investment in the concept of medical 'futility', which now sits in a hotly contested space and cannot be relied upon as a safe conceptual basis in ethics, law or practice for limitation of medical treatment as death approaches.[13]

The first steps in any attempt to clarify these matters is to make some clear observations and statements about the clinical nature of death and dying itself: what the dying process is like, and what can be done both to mitigate its effects on the person who is dying and support those around them. These are obvious questions to ask palliative care workers as their role is primarily to care for dying people.[14] While Part II of this paper describes the experience of dying from a clinical palliative care perspective, Part III will consider the clinical, ethical and legal barriers to good care and decision-making at the end of life. Each of these disciplines makes some contribution to obstructing the concept of a 'natural' dying process. This has consequences for dying people, families, carers, and the wider society.

II THE EXPERIENCE OF DYING

Dying can be broken down into subsidiary experiences: 'when?' (age at death), 'how?' (cause of death, epidemiology), 'where?' (place of care and eventual death), and 'why?' (existential/spiritual considerations). The first three of these will be examined here. The last, the existential and spiritual dimensions, despite their importance, are mostly beyond the scope of this paper.

[13] Michael Ashby, 'The Futility of Futility: Death Causation is the "Elephant in the Room" in Discussions about Limitation of Medical Treatment' (2011) 8 *Journal of Bioethical Inquiry* 151.
[14] See Michael Ashby, 'The Dying Human: a View From Palliative Medicine' in Allan Kellehear (ed), *The Study of Dying: From Autonomy to Transformation* (Cambridge University Press, 2009) 76.

A *When?*

It is now clear that most of the world's population is living longer than ever before in human history. In western countries most people can expect to live into their late 70s or early 80s. The average age of dying in Australia for men is 79.9 years and for women 84.3.[15] By the middle of this century it is predicted that about a quarter of the Australian population will be over 65 years old. It is not just the general proportion of older people that is growing inexorably: projections suggest that the elderly (ie those in their 80s and 90s) will make up more than 5 per cent of the population by 2040.[16] It is also clear that standardised mortality ratios now show that dying is 'saved up': dying for most people is 'compressed' into the years 70-85. It is now less common to die before the age of 65 than ever before.[17]

B *How?*

The cause of death has been shifting inexorably from acute and infective causes to a chronic 'burden of disease' picture for the last century. The ten leading causes of death, which account for just over 51.3 per cent of all deaths, are listed on the Australian Bureau of Statistics ('ABS') website chart, and show trends in 2003, 2007 and 2012.[18] Circulatory disease (heart attacks and strokes) was the main killer in the mid to late 20th century, and still accounts for 29.9 per cent of deaths, down from 36.9 per cent in 2003 (myocardial infarction accounted in 2012 for 13.6 per cent, stroke 6 per cent). Cancer (of all sorts) has been increasing in both incidence and prevalence and is now the leading single cause of death in Australia (with similar trends in most western countries), rising from 29 per cent in 2003 to 29.6 per cent in 2013.[19] While genetic, environmental and lifestyle causes are major causal factors, it is also clear that rising rates of cancer are a feature of an ageing population. The other clear trend is the rise of dementia as the third largest cause of death, having seen a 140.7 per cent increase between 2001-2010, now accounting for about 9000 deaths per annum.[20] The recognition of dementia as a fatal process and a cause of death in its own right is an ongoing task.[21] It is also striking that Australians, on average, now have 3.2 causes listed on their death certificates, as opposed to one sudden single cause such as infection, myocardial infarction or stroke. These causes more

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[15] Australian Bureau of Statistics, *Gender Indicators, Australia, Feb 2014 – Life Expectancy* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4125.0main+features3110Feb%202014>.

[16] The proportion of the Australian population aged over 65 years in 1901, 2012 and 2040 (projected) was/is/will be: 4, 14 and 20 per cent respectively; and aged over 85: 0.1, 2 and 4 per cent. See, Australian Bureau of Statistics, *Population Projections, Australia, 2012 (base) to 2101 – Media Release* (2013) <http://www.abs.gov.au/ausstats/abs@.nsf/lookup/3222.0Media%20Release12012%20%28base%29%20to%202101>.

[17] Swerissen and Duckett, above n 2.

[18] Australian Bureau of Statistics, *Causes of Death, Australia, 2012 - Overview* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Leading%20Causes%20of%20Death~10001>.

[19] Australian Bureau of Statistics, *Causes of Death, Australia, 2012* – Circulatory Diseases and Cancers (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Circulatory%20Diseases%20and%20Cancers~10037>.

[20] Australian Bureau of Statistics, *Causes of Death, Australia, 2010 - Overview* (2012) <http://www.abs.gov.au/ausstats/abs@.nsf/0/6BAD463E482C6970CA2579C6000F6AF7?opendocument>.

[21] Andrew Robinson et al, 'Who Knows, Who Cares? Dementia Knowledge Among Nurses, Care Workers, and Family Members of People Living With Dementia' (2014) 30 *Journal of Palliative Care* 158.

often occur as part of the increasing chronic disease burden, and the ABS now reports data on multiple causes of death.[22]

Joanne Lynn, a US public health expert, has described three model pathways of dying: (i) a rapid decline (often from incurable cancer), (ii) gradual deterioration with increasing frequent and severe crises (typically chronic obstructive airways disease and heart failure), and (iii) prolonged 'dwindling' (death in frail 'old' old age: 80s and 90s, gradual deterioration with very limited physiological reserve, and often seemingly relatively trivial final cause).[23]

The result is that, in 2015, people are living longer than ever before. This trend is ongoing and almost global. The nature of any limits on human longevity is controversial in gerontology,[24] but it does seem that it will continue to be unusual to exceed the age of 100, although even this great age is being reached by increasing numbers of Australians.[25] The downside to these expanding life spans, however, is that people live with increasing levels of morbidity and disability as they age, with concomitant symptom burdens and dependence levels. These, in turn, result in more frequent encounters with the health system and more clinical decision-making events. If death is not sudden or unexpected (eg, accident, myocardial infarction, suicide), the dying process or 'end of life' is now often one to two years. Murray has posited a 'no surprises' question in which primary care clinicians are asked the question: 'would you be surprised if the patient were to die in the next year?' If the answer is 'no', a shift of care to a palliative approach is implemented.[26] This question is the basis of the Gold Standard Framework ('GSF') in the UK National Health Service.[27]

While it is well accepted that it takes 18 years to grow to adulthood, there is no such socially accepted space to recognise a slow process of dying in old age. Indeed, most 'healthy ageing' emphasises positivistic approaches and attitudes that ignore or downplay the realities of death and dying. It is this that lies behind the seemingly oxymoronic health promotion concept of 'healthy' dying (see below).

There were 147 678 registered deaths in Australia in 2013.[28] It has been estimated that approximately three quarters of these can considered as 'anticipated' as they result from

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[22] Australian Bureau of Statistics, *Causes of Death, Australia, 2012 – Multiple Causes of Death – in Detail* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Multiple%20Causes%20of%20Death%20-%20In%20Detail~10025>.

[23] Joanne Lynn, 'Living Long in Fragile Health: The New Demographics Shape End of Life Care, Improving End of Life Care: Why Has It Been So Difficult?' (2005) 35(6) *Hastings Center Report Special Report* S14.

[24] See Tom Kirkwood's 2001 Reith Lectures: British Broadcasting Corporation, *The End of Age* (2001), <http://www.bbc.co.uk/radio4/reith2001/>.

[25] Australian Government, The Treasury, *2015 Intergenerational Report* (2015) <http://www.treasury.gov.au/PublicationsAndMedia/Publications/2015/2015-Intergenerational-Report> viii.

[26] See Martin Denvir et al,'Future Care Planning for Patients Approaching End-of-Life with Advanced Heart Disease: an Interview Study with Patients, Carers and Healthcare Professionals Exploring the Content, Rationale and Design of a Randomised Clinical Trial' (2014) 4(7) *BMJ Open* e005021; Scott Murray and Kirsty Boyd, 'Using the "Surprise Question" Can Identify People with Advanced Heart Failure and COPD Who Would Benefit From a Palliative Care Approach' (2011) 25 *Palliative Medicine* 382.

[27] See Gold Standards Framework website for details of the approach in the NHS (UK), a comprehensive set of tools and procedures to identify people reaching the end of life who needs a palliative approach to care, with an emphasis on primary care and culture change: NHS, *The Gold Standards Framework* (2015) <http://www.goldstandardsframework.org.uk>.

[28] Australian Bureau of Statistics, *Deaths Registered, Australia, Selected summary details – 2003, 2012 and 2013* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3302.0>.

chronic diseases such as cancer, dementia, heart and lung failure.[29] More than 31 500 patients accessed specialist palliative care services in 2013, and this number is rising annually, with, for example, an increase of 3.6 per cent in 2013 compared to 2012.[30] While this population of patients tends to be very debilitated, those patients on community programs are often ambulant and manage to retain significant levels of function, independence and comfort for weeks and often months before death. However as death approaches all of these parameters change, resulting for example in 10 per cent of patients in hospice/inpatient palliative care unit being comatose, and around 20 per cent totally bedridden. Even in community programs where most people are ambulant but require assistance, 11 per cent are in bed for 50 per cent of the time.[31]

Symptom burden is high. Most studies list pain, fatigue, impaired appetite, weight loss, bowel problems, nausea and shortness of breath as the most prevalent, intrusive or distressing.[32] While all diseases, even cancer, have specific symptom patterns but variable incidence and prevalence, comparative studies show that whatever the underlying diagnosis or diagnoses and hence cause of death, the final common pathway for most diseases has a cluster of core common symptoms in the pre-terminal and terminal phase. This has been demonstrated for advanced cancer, AIDS, heart disease, chronic obstructive lung disease and end stage renal failure.[33] The cluster consists of what might be termed generalised 'constitutional' symptoms of tiredness, lack of energy and appetite, coupled with shortness of breath, and pain (often vague, flitting and non-specific), to which one might add cognitive impairment. As death approaches, this constitutional capacity to carry out one's will reduces and eventually disappears altogether in the last hours or days of life. The will can fight against diminishing strength only for so long before it is overwhelmed and has no 'petrol in the tank' left to ignite.

Data provided by the Palliative Care Outcomes Collaboration ('PCOC')[34] for the palliative care service in southern Tasmania show that patients who are judged to be in a stable phase of their illness trajectory have significant levels of moderate fatigue (58.7 per cent) and pain (20.6 per cent), and these levels rise steeply for unstable patients: (moderate fatigue 75 per cent) and (pain 43.1 per cent). Pain is a significant driver (or reflection) of instability: 25.5 per cent of unstable patients have severe pain, as opposed to 1.9 per cent of stable patients. National figures suggest that approximately 50 per cent of patients who have an episode of moderate/severe pain at the beginning of an episode of palliative care will report no pain at the end of the episode of care.[35]

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[29] Palliative Care Australia, *Health System Reform and Care at the End of Life: A Guidance Document* (2010) 24 <https://www.pcvlibrary.asn.au/download/attachments/2917053/Care+at+the+end+of+life.pdf?version=1&modificationDate=1327895181539>.

[30] Australian Institute of Health and Welfare, *Palliative Care Services in Australia 2014* (2014) <http://www.aihw.gov.au/publication-detail/?id=60129548894>.

[31] Palliative Care Outcomes Collaboration (PCOC), *National Report on Patient Outcomes in Palliative Care in Australia* (Report 16, 2013) <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow169129.pdf>.

[32] Jean Potter et al, 'Symptoms in 400 Patients Referred to Palliative Care Services: Prevalence and Patterns' (2003) 17 *Palliative Medicine* 310.

[33] Joao Paulo Solano, Barbara Gomes and Irene J Higginson, 'A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease' (2006) 31 *Journal of Pain and Symptom Management* 58.

[34] See PCOC, above n 31.

[35] Ibid.

Recent trials have shown that referrals to a palliative care service can improve not just quality of life for patients with incurable lung cancer, and of those who survive them, but there could also be a small survival advantage for earlier referral as well.[36] Although length of survival was not the main reason for establishing palliative care services, these studies tend to debunk the idea that good palliative care (which proactively manages the dying process and acknowledges incurability as well as the inevitability of death) actually shortens life by demoralising people.

There are conceptual disagreements about what, if anything, may constitute a 'good' death. Research and experience of those in the field of death and dying reveal that dying people, and those who care for or about them, are able to have a rich conversation in the right settings, including in well designed and executed research studies. A simple landmark qualitative study conducted in Chicago in 2000 showed that patients and families fear bad dying more than death itself. Dying people indicated a strong sense of value in good pain and symptom management, clarity of decision-making, preparation for death, completion, and affirmation of the whole person. They placed a high priority on making contributions of gifts, time and money (meaning/role/usefulness). They also sought to decrease the family burden by planning ahead, arranging affairs, and saying goodbye. Doctors, perhaps understandably, given their core professional responsibilities, tended to emphasise biomedical aspects.[37]

C *Where?*

Place of death figures large in debates around the management of death and dying. This is primarily because those people surveyed when well tend to say that in the event of a foreseen dying process they would prefer to die at home. At first glance it may seem strange to interrogate this rational, emotional and social wish further, given that hospital and residential facilities have capacity limits, and hospital 'avoidance' is a major challenge for all health services. However the reality is not so straightforward. It is undisputed that death and the dying process became 'institutionalised' through the second half of the 20th century. It is equally clear that this process remains stubbornly embedded in western countries with high bed capacities and social structures that tend to 'outsource' care. For instance, in the three influential think-tank reports cited above,[38] it is acknowledged that hospital death rates remain high, and community capacity for care of sick, elderly and dying people is in need of further development and reform, with reorientation of existing services to accommodate the aspiration of dying at home. In the UK, where modern palliative care as it is now understood was first conceived, the home death rate has remained stubbornly low at under 20 per cent despite half a century of innovation and service development, and the UK being ranked by EIU as the world's best provider of such palliative care. Denominator is everything in these comparisons, and whole of jurisdiction data on place of death are hard to obtain. Palliative care service data are of course skewed towards home and hospice death. For instance, in Tasmania approximately 4000 people die each year, and of those who die in an inpatient bed, it is estimated that between 40 and 50 per cent are referred to the palliative care services.[39]

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[36] Ian Haines, 'Managing Patients With Advanced Cancer: the Benefits of Early Referral for Palliative Care' (2011) 194 *Medical Journal of Australia* 107.

[37] Karen E Steinhauser et al, 'In Search of a Good Death: Observations of Patients, Families and Providers' (2000) 132 *Annals of Internal Medicine* 825; Karen E Steinhauser et al, 'Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers' (2000) 284 *Journal of the American Medical Association* 2476.

[38] Economist Intelligence Unit, above n 1; Swerissen and Duckett, above n 2; Leadbetter and Garber, above n 6.

[39] Unpublished Work, Guy Bannink, Email to Michael Ashby, 1 March 2015.

It is clear that different cultures and health systems generate wide variations in place of death statistics, with an overall trend for institutional death rates to remain high in many countries, even where significant community palliative care capacity has been well established for many years. For citizens over 65, 2005 Australian data shows that 54 per cent of deaths occurred in hospitals, 32 per cent in nursing homes and 14 per cent at home or other sites (middle range in international ranking).[40] This can be compared to New Zealand in 2003-2007 with 34 per cent; 38 per cent and 28 per cent respectively (lowest hospital death rate in the world); and to comparable UK 2008 figures of 57 per cent, 21 per cent, and 23 per cent.[41] In Canada, 2006 data from Manitoba shows a middle range of 51 per cent, 32 per cent, and 17 per cent. Among developed countries, Japan and South Korea both have the highest hospital death rates of 69 per cent and 67 per cent respectively.[42]

Specialist palliative care services in Australia tend to operate a triangular care model with regard to location of care, accompanying people as they move around the health system according to needs and wishes, whether it is home (own home, another family home or residential facility), hospital, or inpatient palliative care unit. However, the capacity of specialist services to change location of death and the final terminal phase to home instead of hospital or nursing home is limited. The availability of another able-bodied person in the house around the clock is a real obstacle, as are social factors. Carer research indicates that much can be done to support carers, and there is no room for complacency.[43] Symptoms like incontinence, falls, wandering, delirium and insomnia all make home care difficult and tend to result in admissions. There is also a cultural and social expectation that serious illness and deterioration necessitates professional care, and home care recommendations may be seen as reckless or uncaring. Indeed the intervention of professional domiciliary services may de-skill and marginalise informal networks.[44]

The concept of the 'good enough' death attempts to deal with the idealisation potentially implicit in the 'good' death. It is about recognising that the realistic aim is the best death in the circumstances, as dying is a reflection of the life lived, coupled with the luck of biological fate. Just as birth can be unpredictable, so dying can be turbulent and challenging.[45]

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[40] Joanna Broad et al, 'Where Do People Die? An International Comparison of the Percentage of Deaths Occuring in Hospital and Residential Care Settings in 45 Populations, Using Published and Available Statistics' (2013) 58(2) *International Journal of Public Health* 58, 257-267

[41] Ibid.

[42] Swerissen and Duckett, above n 2.

[43] See various contributions in Peter Hudson and Sheila Payne (eds), *Family Carers in Palliative Care: a Guide for Health and Social Care Professionals* (Oxford University Press, 2008).

[44] Debbie Horsfall, Kerrie Noonan and Rosemary Leonard, *Bringing Our Dying Home: Creating Community at End of Life* (Research Report, University of Western Sydney and Cancer Council of NSW, 2011).

[45] This terminology is taken from the work of the English child psychotherapist DW Winnicott (1896-1971). See Donald W Winnicott, *Home is Where We Start From* (Penguin, 1986). For reflections on the good and good-enough death in hospice and palliative care, see the following: Beverley McNamara, Charles Waddell and Margaret Colvin (1994) 'The Institutionalisation of the Good Death' 39 *Social Science and Medicine* 1501; Beverly McNamara, Charles Waddell and Margaret Colvin, 'Threats to the Good Death: the Cultural Context of Stress and Coping Among Hospice Nurses' (1995) 17 *Sociology of Health and Illness* 222; Bethne Hart, Peter Sainsbury and Stephanie D Short, 'Whose Dying? A Sociological Critique of the "Good Death"' (1998) 3(1) *Mortality* 65.

III ACKNOWLEDGING THE PROCESS OF DYING IN MEDICINE, ETHICS, LAW AND SOCIETY

It is not possible to deploy appropriate and necessary palliative care unless there is assessment and acknowledgement of the dying process. Community expectations of the capacity of modern medicine to prolong life are often at variance with reality. Discussion of death, and preparation for it, do not occur easily in countries like Australia, and there are powerful forces at work that may present barriers to dealing with the realities of death and dying. The demographic trends as seen above not only show large life expectancy increases, but also diminish the reality of death.

Technological advances mean medicine can do so much more. Professionalism dominates medical matters in everyday life so that illness, death and dying, grief and loss are seen as being in the province of specialists. Religious and spiritual life is much more in the province of the individual, with post-modern and existential world-views replacing traditional communitarian denominational church-based structures, which are mostly in decline. Social lives are more individualistic, with increased national and international social mobility, the ever-changing nature of communities, and multiculturalism.[46] Care should be exercised in making these sweeping generalisations lest a misleading revisionist picture of death in history is painted as halcyon days when ordinary people knew how to 'do' dying. It seems doubtful that any modern person would want to return to the unrelieved suffering of the past when people had no alternative to death at home without medical help, particularly given the protracted chronic diseases journeys of most people today described earlier. However, it is important to question and, where necessary, move away from excessive 'medicalisation' of dying, especially where this over-emphasis of medical intervention occurs at the expense of other personal, social and spiritual aspects of life, and has negative and unsustainable consequences for the economy.

A *Barriers to Care and Decision-Making at the End Of Life*

There are a number of major attitudinal barriers to good end of life care for clinicians. Firstly, health professionals and families struggle with death 'talk'.[47] Based on the assumption that you cannot initiate talk of death because patients and families do not want it and you run the risk of precipitating death if you do ('don't talk about death; it will kill him') there is a widespread tendency to avoid it. Secondly, there is a pervasive view that you have to do everything to maintain and prolong life otherwise you are causing death ('you can never give up on a patient'). This is powerfully backed up by a perceived threat of ethical or legal sanction unless all possible treatment is given to patients, no matter how slim the odds of a favourable response or outcome. Thirdly, there is still a lingering doubt that the use of opioids and sedatives in palliative care may contribute to the cause of death, so symptom control is compromised. These barriers are not actually primarily medical in origin: they arise from social, ethical, religious and political considerations of death and dying that are deeply embedded in history, culture

[46] See Pat Jalland, *Australian Ways of Death: a Social and Cultural History 1840-1918* (Oxford University Press, 2002) and *Changing Ways of Death in Twentieth Century Australia: War, Medicine and the Funeral Business* (University of New South Wales Press, 2006) for magisterial accounts and analysis of historical trends in death and dying in Australia, and her other works for similar insights in England, especially with regard to the influence of war.

[47] See Brendan Murphy's 2008 editorial in the *Medical Journal of Australia* exhorting clinicians, especially medical unit heads to take the lead in decision-making at the end of life: Brendan Murphy, 'What Has Happened to Clinical Leadership in Futile Care Discussions?' (2008) 188 *Medical Journal of Australia* 418.

and politics. Nonetheless, preparation for death is an intrinsic spoken or unspoken part of most cultures and religions across time and geographical location.[48]

Catherine Mayer has suggested that it is not so much that we believe ourselves to be immortal, but that we behave as if death does not exist: that is, we are now 'amortal'. She posits the view that we tend not to want to act according to our ages. The narrative of middle life and old age is one of defying any 'natural' limitations that our bodies or society appear to impose upon us.[49] On the other hand, Isaiah Berlin, a Russian-born Jewish intellectual, student of the history of ideas and of the concept of liberalism, who grew up in England and held a chair at Oxford for many years, responded to the deportation of fellow Jews to death camps (usually without knowledge of their fates) by describing it as an affront to their human dignity because this ignorance robbed them of the chance to face death.[50] This is a confronting challenge for present times, suggesting that dealing with death is an existential responsibility for each mature adult.[51] The 'choice' then is not between one treatment and another, or opting in or out of life-prolonging interventions or life support at the margin of life, but whether to face up to and deal with one's own dying.

In the modern western world there is much more emphasis on the individual. In the post-modern existentialist construct each person is responsible for developing their own narrative and meaning. The body is predominant, and for those who have no religious faith, there is often an absence of channels for transcendence of suffering, especially that of the body, but also so-called existential' suffering. Kellehear has pointed out that dying has become part of the trials of 'here and now' of 'this-world' as opposed to 'other world' spirituality.[52] Palliative care, which adopts a holistic multidisciplinary care model and 'total' pain concept, attempts to help patients to deal not only with physical pain and symptoms, but also emotional, spiritual and social/relational issues as death approaches.

B *Preparing for Death: Advance Directives and Care Planning*

While considerable work is being done within health to improve care and decision-making at the end of life, it is clear that death and dying is everybody's business. The community does not speak with one voice on these issues: there is a wide spectrum of opinion and behaviour from 'keep me alive at all costs, no matter what the circumstances' through to 'let me die' and 'help me to die'. While on the one hand there are well-documented obstacles to the changing of goals of care as death approaches, on the other hand there is an on-going debate in most OECD countries about the legalisation of voluntary euthanasia and/or physician-assisted suicide, largely fuelled by public concern about the nature of the dying process.

It seems clear that much more public debate and education about end of life issues is needed, and that it is important to encourage all citizens to ensure that they make their wishes known

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[48] See for instance: Drew Gilpin Faust, *This Republic of Suffering: Death and the American Civil War* (Alfred A Knopf, 2008); Thomas Kselman, 'Death in the Western World: Michel Vovelle's Ambivalent Epic La mort et l'Occident, de 1300 à nos jours' (2004) 9(2) *Mortality* 168; Allan Kellehear, *A Social History of Dying* (Cambridge University Press, 2007).

[49] Catherine Mayer, *Amortality: The Pleasures and Perils of Living Agelessly* (Random House, 2011).

[50] Michael Ignatieff, *Isaiah Berlin: A Life* (Vintage, 2000).

[51] Failure to do so might be seen as 'mauvaise foi' (literally, 'bad faith') in Sartre's 'existentialist' world view: Jean-Paul Sartre, *Essays in Existentialism* (Citadel Press, 1993).

[52] Kellehear, above n 48.

for end of life care so that those around them will have the authority and confidence to stop treatment that is not working, and re-direct care to the goals of comfort, quality and dignity. Substitute decision-making and Advance Care Directives are important tools to ensure that patient wishes are carried out, and that the dying process is not drawn out in a way that benefits nobody, misuses health resources, and fails to address the real needs of patients, their families and carers. Health promotion techniques are needed to ensure that the whole community is engaged in reform and behavioural change.

Advance care planning needs to meet the challenges of limitation of medical treatment and the dying process head-on. Whilst capacity is important, broader action is required. Perhaps the writing of an Advance Care Directive using a format that addresses end of life issues as well as other preferences, beliefs, values and unacceptable treatment outcomes is more pertinent for those diagnosed with life threatening illnesses, or those reaching older ages such as those over 70 (the peak dying time for Australians is now 70-85 years), all adults should be encouraged to talk to those close to them about mortality and their wishes about unacceptable treatment outcomes. They should also be encouraged to appoint an Enduring Guardian (or equivalent substitute decision-maker). Enduring Guardian appointments, including those that specify aspects of personal care, should be actively sought and incorporated into a care plan if the person is admitted into hospital or aged care facility.

C *Communication and 'Death Talk'*

It is important to acknowledge that talking about death and dying, and specifically addressing limitations of medical treatment is both necessary and possible. Training medical practitioners in communication skills has been shown to improve technique, patient satisfaction and confidence.[53] It is always important to start by finding out what the patient and/or family/substitute decision maker understand about the current situation and realistic options available.

Open questions are often the best approach. Questions such as 'how do you see the future?' and 'what are your hopes/fears?' are often revelatory. Doctors often forget how frightened and apprehensive people are in their presence, especially where bad news is anticipated. The 'fight or flight' survival mechanism tends to be operating, and patients' deep listening, logic and learning abilities are shut down or compromised. This means that rational decision-making and information retention may be impaired. Patient and family behaviour may be erratic and tend to mirror the kind of non-linear oscillation that has been well described in the bereaved. In what is known as the Dual Process Model, grieving people move in and out of normal functioning and grief behaviour, often in seemingly random and unpredictable ways. So too, sick people dealing with the threat of impending death often appear to oscillate between reality and hope.[54] Much is also conveyed non-verbally in behaviour, and patients may make us feel things they struggle to tell us in words. There is clearly scope for more psychodynamic understanding in both palliative care and grief work. It is also now clear that dementia is increasing in both incidence and as a recognised principal or contributory cause of death. For most people, regardless of diagnosis, some degree of cognitive impairment is common as death approaches, and eventual terminal restlessness and frank delirium are also often seen prior to eventual coma

[53] See for example, Jonathan Silverman, Suzanne Kurtz and Juliet Draper, *Skills for Communicating With Patients* (Radcliffe Medical Press, 3rd ed, 2013) and University of Washington, *Oncotalk: Improving Oncologists' Communication Skills* <http://depts.washington.edu/oncotalk/>.

[54] Margaret Stroebe and Henk Schut, 'The Dual Process Model of Coping With Bereavement: Rationale and Description' (1999) 23 *Death Studies* 197.

in the final hours or days of life. It is therefore clear that impaired or absent capacity, and legal incompetence, must be anticipated as either a long-term executive issue, or a final terminal state.

D *Health-Promoting Palliative Care*

At first glance the term 'health-promoting' in reference to palliative care and end of life issues might seem almost oxymoronic. However, Allan Kellehear has pioneered the notion of public health promoting palliative care. He identifies major social barriers to dealing with death, and proposes that well-established and effective principles of public health, as laid out in the Ottawa Charter, be used to empower the whole community to deal with death in a more open, direct and 'healthy' way. Kellehear has summarised the goals of health-promoting palliative care as follows:

- provide education and information for health, death and dying
- provide both personal and social supports
- encourage interpersonal reorientation towards a 'natural' death
- encourage reorientation of palliative care services towards public health ideas of prevention, harm reduction and community participation
- combat death-denying health policies and attitudes.[55]

In Tasmania a 'Healthy Dying' initiative has been developed to improve care and decision-making at the end of life.[56] This consists of three components: a 'Goals of Care' framework, an Advance Care Directive for the End of Life, and a number of health-promoting professional and community interventions to raise awareness.

A Goals of Care form has replaced the 'NFR' form at several Australian hospitals and health services. It provides a clinical framework for setting realistic goals during an episode of care into one of three phases: curative/restorative, palliative and terminal. Limitations of medical treatment that are proportional to the assigned phase are transparently established and negotiated, and documented on a dedicated form in the notes. It is based on the 'Physician Orders for Life Sustaining Treatment' ('POLST') approach in the USA.[57] It is a medical order to clarify any limitations of medical treatment for a present condition, and is to be distinguished from advance directives that are usually made by people, in their own 'voice', to inform medical decision-making for future episodes of impaired capacity.[58]

E *Death Causation: Ethical and Legal Basis of Palliative Care*

Two opposing views of death causation, as it applies to care at the end of life, appear to be operating in western societies. On the one hand, modern medical practice, based on the Judaeo-Christian tradition of law and ethics, takes a forensic view of 'natural' death and does not permit human agency to be implicated. Consistent with this, palliative care practitioners hold

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[55] Alan Kellehear, *Health Promoting Palliative Care* (Oxford University Press, 1999); Alan Kellehear, *Compassionate Cities: Public Health and End-of-Life Care* (Routledge, 2005).

[56] Department of Health and Human Services, Tasmanian Government <http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0006/96378/Web_Healthy_Dying_info_combined.pdf>.

[57] POLST – Physician Orders for Life-Sustaining Treatment Paradigm (2015) <http://www.polst.org/>.

[58] Robyn Thomas et al, 'Goals of Care: a Clinical Framework for Limitation of Medical Treatment' (2014) 201 *Medical Journal of Australia* 452.

a position of causal 'neutrality', whereby the process of dying is stated to be neither hastened nor prolonged. On the other hand, there is widespread support for euthanasia, which explicitly allows death to be caused in certain circumstances, at the patient's request.

A study of medical, legislative, legal and parliamentary scrutiny of end of life issues in Australia 1983-1998, and in four comparable OECD countries: the United Kingdom, Canada, USA and New Zealand collated and analysed the arguments about death causation in palliative medicine. All the reports, judgments and parliamentary committee proceedings studied assume that palliative care interventions and treatment abatement decisions may constitute a cause of death. However, these are allowed in law in those jurisdictions due to the public policy imperative to relieve pain and suffering and avoid prolongation of the dying process.[59]

The incorporation of this causal assumption into law and public policy can be traced back to a famous passage of Justice Devlin's instructions to the jury in the case of *R v Adams*[60] in 1957. Devlin J used double effect reasoning to render lawful the use of escalating morphine and heroin doses which contemporary medical evidence had informed the court might have the incidental effect of shortening the life of a dying person.[61] The experience of the hospice and palliative care movement over the past three decades has shown that the safe and effective use of morphine, other opioids, and sedatives in pain and symptom control need not bring cause of death into question. Similarly, treatment abatement is undertaken when futility can clearly be demonstrated for dying persons. It is clear that there is no basis for fear of legal sanction by health professionals if the prevailing standards of palliative care are adhered to. The law takes a common sense and multifactorial view of causation, and will often not even apply a causal analysis, focusing more on legality of actions and presence or absence of duties instead.[62]

Causation can be an important analytical and reflective component of the process of determining whether palliative care is ethical and legal. However, neither the natural death concept, in the strictly forensic sense, nor the palliative care position of causal neutrality can be empirically defended in all cases, and it is not usually helpful or appropriate to do so. Natural death can be more fruitfully understood in a broader existential sense of inevitability, as a composite of causality, autonomy and dignity, and not solely in terms of the presence or absence of human agency. The goals and intentions of drug prescribing and principles of pharmacology in palliative care can and should be made clear.

The Ontario coroner Dr James Young has captured the essence of the basic underlying principles of therapeutic intervention in palliative medicine. He lay down four conditions that need to be satisfied for palliative care interventions to be legal in his jurisdiction:

> (1) The care must be intended solely to relieve suffering; (2) it must be administered in response to suffering or signs of suffering; (3) it must [be] commensurate with that suffering; and (4) it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively.[63]

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[59] Michael Ashby, *Natural Death? Palliative Care and Death Causation in Public Policy and the Law* (Doctor of Medicine Thesis, University of Adelaide, 2001) <http://digital.library.adelaide.edu.au/dspace/handle/2440/38237>.
[60] *R v Adams* [1957] Crim LR 365.
[61] Ibid.
[62] See also Ben White, Lindy Willmott and Michael Ashby,'Palliative Care, Double Effect and the Law in Australia' (2011) 41 *Internal Medicine Journal* 485.
[63] See Parliament of Canada, *Of Life and Death: Report of Special Senate Committee on Euthanasia and Assisted Suicide* (Minister of Supply and Services Canada, 1995) 26; also James Lavery and Peter Singer, 'The "Supremes" Decide on Assisted Suicide: What Should a Doctor Do?' (1997) 157 *Canadian Medical Association Journal* 405.

The intention is to relieve symptoms and suffering, not bring forward the time of death. Whilst this position is sustainable in the palliative phase, it is susceptible to challenge in the terminal phase when death is imminent. It should be acknowledged by practitioners that as death approaches, abatement of life-sustaining treatment and terminal sedation may indeed alter the time of death, although this matter cannot be verified scientifically, one way or the other, in a particular case, or in general. There are serious limitations to the use of clinical studies in this area, and, for obvious reasons, the causal question itself cannot be directly asked in any interventional study. In the absence of palliative interventions or treatment abatement, particularly during the final dying process, we cannot know when a particular patient would have died, and it would be unethical to design controlled trials to find out.

F *Treatment Abatement And Sedation For Incompetent Patients*

Legal scholars have recently argued that there is an uneasy status quo with regard to treatment abatement and terminal sedation - two standard practices in modern palliative care in countries such as Australia, New Zealand, Canada and the UK. Downie, Willmott and White reviewed the legal understanding of unilateral withdrawal of medical treatment for incompetent persons and concluded that the legal basis for such decisions is confused, unreliable and lacks transparency.[64] They argue for this area of law to be tightened up, especially in federal countries, with appropriate consistent legislation that ensures that the issue of consent is dealt with. McLean reviewed terminal sedation practices and concluded that sedation, particularly without medical provision of nutrition and hydration for incompetent persons, may similarly be found to be unlawful.[65] While the major argument is based on autonomy and patient consent, causation is also a concern for many in these two areas.

1 *Sedation*

Sedative drugs are commonly used in terminal care when death is believed to be imminent, in order to maintain comfort and dignity by alleviating agitation, anxiety and so-called terminal restlessness. They are used proportionately to the patient's distress; not to bring about death.[66] It is clear that there is robust disagreement, even within medicine itself, about whether such treatment contributes to the cause of death, and even about what the therapeutic goals are or should be. There are those who contend that within accepted palliative care practice patients are sedated, and the cause of death is either through central nervous system and respiratory depression, or dehydration and starvation. Certainly, palliative care practitioners rarely use morphine for its sedative properties at any stage of an illness, especially when patients are trying to function as normally as possible, and sedation is usually unwelcome. Morphine may even aggravate terminal restlessness in terminal care, probably due to metabolite accumulation. In terminal care sedatives are titrated against agitation and distress, but occasionally also

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[64] Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: a Case For Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26 *New Zealand Universities Law Review* 24.

[65] Sheila McLean, 'Terminal Sedation: Good Medicine? Good Ethics? Good Law?' (Keynote address delivered at the International Conference on End of Life: Law, Ethics, Policy and Practice, QUT, Brisbane, 14-15 August 2014) <https://www.youtube.com/watch?v=dYZrHUcvc-c>.

[66] Michael Ashby, 'The Fallacies of Death Causation in Palliative Care' (1997) 166 *Medical Journal of Australia* 176; Danuta Mendelson, 'Quill, Glucksberg and Palliative Care – Does Alleviation of Pain Necessarily Hasten Death?' (1997) 5 *Journal of Law and Medicine* 110.

against another symptom (eg pain or shortness of breath) where other measures have failed and the patient may wish to be less aware of what they are going through. If patients are conscious they are consulted and asked if they wish to be more sedated, but they are often unable to give consent due to incompetence. It should be noted that patients are usually unconscious and/or cognitively impaired, and therefore incompetent, at this stage. Therefore it is clearly not possible to state categorically that such sedation has no effect on time of death. However this is not the really important question, being superseded by the comfort and dignity of the person. The precise timing of death is unpredictable, and verification of the relative causal contributions to that timing of disease, together with physiological and pharmacological factors, is not usually measurable. Outside the setting of terminal care, the use of sedatives to the point of sleep or deep coma for the relief of suffering, sometimes known as 'pharmacological oblivion', is not part of accepted palliative care practice, especially not as a way of ending a patient's life.

2 *Treatment Abatement*

Abatement of burdensome and purposeless treatment during the process of dying does not constitute a cause of death: it is an integral component of palliative care practice. Treatment-related toxicity is diminished or abolished, and the process of dying is not unnecessarily prolonged. Nonetheless, in certain treatment abatement decisions concerning imminently dying persons, for example in the case of *Bland*,[67] death is the intended outcome of treatment abatement. However justified, agreed, appropriate and necessary, this is not part of palliative care practice for dying people.

Downie et al[68] and McLean[69] rightly state that law and clinical practice are inconsistent, at times confused and confusing, and may lack transparency. As a result they warn us that, if tested at law, treatment abatement decisions and terminal sedation episodes may indeed lead to adverse outcomes for practitioners and their employers. This is of course alarming, as defensive clinicians (and substitute decision-makers), fearful of real or inaccurate perceptions of what is required by law, and ethics, will tend not make the decisions necessary to ensure peaceful, unobstructed dying. Seeking a legislative remedy, especially in federal countries where it is difficult to introduce uniform legislation, is a slow and uncertain monumental undertaking which runs the risk of reducing flexibility or creating new unintended legal problems.[70] Where actual medical treatment choices are limited, and pain and distress require immediate action, a more timely remedy would be to alter clinical practice to ensure that a process of contemporaneous 'bedside' consensus is established about treatment abatement and symptom management for people in the terminal phase who lack capacity.[71] This process needs to be based on trust, best interests, and sound clinical assessment delivered by competent clinicians trained to communicate in the necessary conversations.

Using the 'goals of care' approach described earlier, it is suggested that in phase D – the last hours or days of life – a form of 'therapeutic privilege', well established to save life in emergency situations, is permitted for the care of incompetent and imminently dying persons.

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[67] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.
[68] Downie, Willmott and White, above n 64.
[69] McLean, above n 65.
[70] White, Willmott and Ashby, above n 62.
[71] Michael Ashby, Alan Kellehear and Brian Stoffell, 'Resolving Conflict in End-of-Life Care' (2005) 183 *Medical Journal of Australia* 230.

Depending on the jurisdictional requirements, the onus would be on medical practitioners to communicate with, and consult, any substitute decision-makers or persons responsible, and to demonstrate, if need be, to a tribunal or court, that the dying process was underway.[72] It should also be established, in both medical practice and law, that the 'necessaries of life' provisions are suspended in this imminent dying phase, and any legally perceived requirement for medical provision of hydration and nutrition is also dismissed. The basis of the finding in the *Re BWV* case[73] was that medical provision of hydration and nutrition is indeed medical treatment and should be subject to the same evaluative process before deployment as any other. The question is, do hydration and nutrition, on balance, confer benefit on the patient?[74] For an imminently dying person the answer to this is negative: it is a normal part of the dying process for oral intake to slow and stop, and for absorption and digestive processes to cease operation.[75]

It is not the intention of this paper to suggest that need for consent and respect for personhood and autonomy cease before life lapses, nor to restore some kind of medical ascendancy or paternalism, but rather to propose a common sense attempt to remove barriers to dying in the twilight between life and death at the point where decision-making capacity is either minimal or permanently gone. A 'collective gaze' provides transparency and appropriate, timely and necessary terminal care consistent with what is known of the dying person and the realities of the situation, and is framed in ethics rather than avoidance of potential legal sanction.

The last word on this should lie with Justice Thomas, a New Zealand judge, who made the following statement in his judgment in the case of *Auckland Area Health Board v Attorney-General*,[76] where the court was being asked to consider the removal of ventilator support from a patient with very severe Guillain-Barré syndrome:

> Medical science and technology has advanced for a fundamental purpose: the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred, but it need not be postponed indefinitely.[77]

IV CONCLUSION

The process of dying has probably never been easy unless it is sudden, and despite substantial progress in pain and symptom relief, the chronic disease trajectories of the early 21st century bring new challenges. The (usually) short episodes of unrelieved suffering in the dying of the past have been replaced with longer periods of deterioration and 'area under the curve' of symptom burden, dependence and both global physical and mental deterioration.

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[72] It is not suggested that this exemption be deployed for non-dying persons where life support withdrawal authorisation is being sought. Such decisions do need to be considered, but may require more scrutiny, including legal processes, as death is not imminent.

[73] *Gardner; re BWV* [2003] VSC 173 (29 May 2003).

[74] Michael Ashby and Danuta Mendelson, 'Gardner; Re BWV: Victorian Supreme Court Makes Landmark Australian Ruling on Tube Feeding' (2004) 181 *Medical Journal of Australia* 442.

[75] Pamela Van der Riet, Denise Brooks and Michael Ashby, 'Nutrition and Hydration at the End of Life' (2006) 14 *Journal of Law and Medicine* 182.

[76] *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 253.

[77] Ibid 253; The court allowed the cessation of ventilatory support.

In care and decision-making at the end of life the deliberative processes and discourse should move away from the almost exclusive focus on human agency and death causation (important though this is) and embrace non-obstruction of the dying process and self-determination so that natural death is seen as having a composite meaning embracing both forensic and existential senses. In the final analysis all would surely agree that there is more to a 'good' or 'good enough' death than causality. If we take Isaiah Berlin's existential challenge and accept that it is an important attribute of humanity and dignity to deal with our own dying, then it is also incumbent upon us to accept that just as we come into the world needing help, as we leave it we will probably need the help of others.[78] We will need to surrender to the inevitable and let the natural forces take us from the world. Even though it may be hard to look at death directly,[79] some preparation is usually required unless the proverbial bus gets us first. There is a time to rage against the dying of the light, and a time to accept the inevitable. Palliative care is a means by which the realities of dying can be dealt with. We need to ensure that individuals, societies and health systems are orientated towards care that meets the real needs and wishes of people as the end of life approaches, and that law and ethics also recognise death and modern patterns of ageing, chronic illness and dying. Causation and choice are important aspects, but ultimately we do not choose whether we die or not; but we can have a substantial say in how we die. Palliative care is a key enabler of this agency, provided it is well backed up by public policy, ethics and law. Lastly, all societies will need to address growing international public support for medical assistance in dying according to their public processes and traditions. There will probably never be universal agreement about this issue due to the deep religious and ethical differences at stake. Palliative care needs to be available for all, regardless of belief about assisted dying, but it also needs to be acknowledged that palliative care, however good and available, does not meet the needs or autonomous wishes of all people.[80]

[78] For a deep political discussion on caring, see Michael Ignatieff, *The Needs of Strangers* (Vintage, 1994).

[79] See *Les Maximes* of Francois de la Rochefoucauld to the effect that 'death, like the sun, cannot be directly looked at' in La Rochefoucauld, *Maxims* (Stuart D Warner and Stephane Douard, English and French Edition, St Augustine Pr Inc, 2009) [trans of *Les Maximes* (first published 1678)], and TS Eliot, 'Humankind cannot stand very much reality' in TS Eliot, *Four Quartets* (Harcourt, 1943).

[80] See *Carter v Canada (Attorney General)* 2015 SSC 5 and *Seales v Attorney-General* [2015] NZHC 1239 (4 June 2015).

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TEXAS ADVANCE DIRECTIVES ACT: NEARLY A MODEL DISPUTE RESOLUTION MECHANISM FOR INTRACTABLE MEDICAL FUTILITY CONFLICTS

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Increasingly, clinicians and commentators have been calling for the establishment of special adjudicatory dispute resolution mechanisms to resolve intractable medical futility disputes. As a leading model to follow, policymakers both around the United States and around the world have been looking to the conflict resolution provisions in the 1999 Texas Advance Directives Act ('TADA'). *In this article, I provide a complete and thorough review of the purpose, history, and operation of* TADA. *I conclude that* TADA *is a commendable attempt to balance the competing goals of efficiency and fairness in the resolution of these time-sensitive life-and-death conflicts. But TADA is too lopsided. It is far more efficient than it is fair.* TADA *should be amended to better comport with fundamental notions of procedural due process.*

I INTRODUCTION

Conflicts over the appropriateness of continuing life-sustaining medical treatment ('LSMT') at the end of life are disturbingly common.[1] Dominant among these conflicts are 'medical futility disputes.' In this type of end of life treatment conflict, intensive care unit clinicians determine that it is medically and ethically appropriate to stop LSMT and focus on comfort measures only. But the patient's surrogate decision maker will not consent to that treatment plan. Because LSMT can (or might be able to) sustain at least the patient's biological life, the surrogate wants it continued.

Fortunately, most of these medical futility disputes can be resolved through informal consensus-building approaches.[2] Eventually, with intensive communication, negotiation, and mediation; the parties reach agreement. Nevertheless, a significant and growing number of these medical futility conflicts remain intractable.[3]

Few jurisdictions in the world have developed an adequate mechanism to handle this expanding

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[1] See below Part II C.

[2] See below Part II D - II E.

[3] See below Part III A.

subset of stalemate cases. But the few that have designed and implemented such mechanisms seem to enjoy some measure of success.[4] Accordingly, many clinicians and commentators elsewhere are calling for the establishment of similar special adjudicatory dispute resolution mechanisms.[5]

The paradigm adjudicatory dispute resolution mechanism is a court of law. But almost nobody thinks that is an appropriate model for this type of conflict.[6] First, litigation is cumbersome, being both time-consuming and expensive. Thus, it cannot usefully address complex, urgent medical issues. Moreover, because courts are adversarial and open to the public, they are an unwelcome forum in which to resolve sensitive medical treatment disputes worthy of privacy.

In contrast, the dispute resolution mechanism in the *Texas Advance Directives Act* (*'TADA'*) is tailor designed for medical futility disputes. It has been in operation for over sixteen years. And policymakers both around the United States and around the world have been looking to *TADA* as a model to follow.[7]

Because *TADA* is so frequently held up as a model to follow, it merits a careful and thorough examination. The purpose of this article is to critically evaluate *TADA* and answer three questions. 1) How do *TADA*'s dispute resolution provisions work? 2) Should other jurisdictions adopt them? 3) What changes are required to make *TADA*'s dispute resolution provisions sufficiently fair?

I will proceed in seven stages. In Part II, I provide a brief background on medical futility conflicts. I describe their nature and prevalence. I explain how they can usually be prevented and resolved informally. But, as the growing attention on *TADA* indicates, medical futility disputes cannot always be prevented or resolved informally. In a significant subset of cases the parties can find no common ground. So, there are, and will continue to be, intractable medical futility disputes.

In Part III, I review the need and demand for dispute resolution mechanisms for these remaining stalemate cases. The status quo is for clinicians to cave-in to surrogate demands for LSMT, even when they think that the administration of such interventions is medically and ethically inappropriate, or even cruel. Clinicians are legally risk averse and reluctant to cause a patient's death without consent. But many clinicians are unhappy with this status quo. Both individual clinicians and hospitals are eager to implement adjudicatory mechanisms to resolve these cases. They see *TADA* as a leading model.

In Part IV, I turn from explaining the context and motivation for *TADA* to an examination of the statute itself. First, I provide a brief history of *TADA*. Second, I summarise *TADA*'s dispute resolution provisions. I walk the reader, step-by-step, through the operation of all six stages of the dispute resolution process. Then, in Part V, I turn from the statutory text to examine *TADA* in operation on the ground. I describe how Texas hospitals have used *TADA* over the past sixteen years.

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[4] See, eg Mark Handelman and Bob Parke, 'The Beneficial Role of a Judicial Process When "Everything" Is Too Much?' (2008) 11(4) *Healthcare Quarterly* 46.
[5] See below Part III B.
[6] See generally, Alan Meisel, Kathy Cerminara and Thaddeus Pope, *The Right to Die: The Law of End-of-Life Decisionmaking* (Aspen Publishers, 3rd ed, 2004) section 3.26.
[7] See below Part III C.

In Part VI, I turn from a descriptive approach to a normative approach. While *TADA* is extremely controversial, I argue neither for nor against the core idea that healthcare providers may withhold or withdraw LSMT without patient or surrogate consent. In other words, I am not evaluating 'whether' clinicians should be able to stop LSMT without consent. Instead, I am evaluating 'how' the law authorises them to do that.

Specifically, I evaluate how well *TADA* comports with notions of procedural due process, the 'oldest of our civil rights.'[8] This is not a constitutional analysis but rather a use of constitutional principles to evaluate fundamental fairness. The requirements of procedural due process under the Fifth and Fourteenth Amendments to the US Constitution embody 'tenets of fundamental fairness.' Accordingly, they provide a useful 'template to help measure' the propriety and fairness of *TADA*'s dispute resolution procedures.[9]

Finally, in Part VII, I conclude that *TADA* is not now sufficiently fair. But state legislatures could easily remedy these defects with modest amendments that have already garnered widespread support among relevant stakeholders.

II BACKGROUND: MEDICAL FUTILITY DISPUTES

To appreciate the motivation for, and purpose of, *TADA*'s dispute resolution provisions, it is first necessary to understand the nature of medical futility disputes. Accordingly, in this section I explain: 1) what is a medical futility dispute; 2) that they are common; and 3) that they can often be prevented. Furthermore 4) even when they cannot be prevented, medical futility disputes can almost always be informally resolved. *TADA* is designed to address the small, yet significant, subset of cases that remain intractable to communication, negotiation, and mediation.

A *What Is a Medical Futility Dispute?*

A medical futility dispute is one in which the parties disagree over whether a current or proposed medical intervention is beneficial.[10] The paradigmatic medical futility dispute is one in which the patient's substitute decision maker (surrogate) requests aggressive treatment interventions for an imminently dying or catastrophically chronically ill patient. However, that patient's health care providers consider such treatment to be medically or ethically inappropriate.

Medical futility disputes can concern any type of medical intervention. But most of the relevant legislative and judicial activity, as well as most of the academic commentary, involve disputes over LSMT. There are three distinctive features of such disputes.

First, disputes over LSMT involve life-and-death stakes. They usually concern patients in a hospital ICU. LSMT utilises mechanical or other artificial means to sustain, restore, or supplant an individual's spontaneous vital function. LSMT procedures include: assisted ventilation, renal

[8] Edward L Rubin, 'Due Process and the Administrative State' (1984) 72 *California Law Review* 1044, 1044.
[9] Thomas J Balch, 'Are There Checks and Balances on Terminating the Lives of Children with Disabilities? Should There be?' (2009) 25 *Georgia State University Law Review* 959, 963.
[10] Thaddeus M Pope, 'Dispute Resolution Mechanisms for Intractable Medical Futility Disputes' (2014) 58 *New York Law School Law Review* 347, 351.

dialysis, cardiopulmonary resuscitation ('CPR'), antibiotics, chemotherapy, and artificial nutrition and hydration.[11] Typically, withholding or withdrawing LSMT will result in the patient's death.

Second, ICU patients dependent on LSMT almost never have decision making capacity. They lack the 'ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.'[12] They cannot direct their own medical treatment. Consequently, medical treatment decisions for ICU patients must be made by a substitute decision maker or surrogate.[13]

Third, the typical futility dispute is between the attending physician and the surrogate. The clinician says 'stop,' but the surrogate says 'go.' The clinician thinks that LSMT is no longer medically indicated and that the appropriate treatment plan is for comfort measures only. The surrogate, on the other hand, rejects this proposed treatment plan, and directs the clinician to continue LSMT.[14]

B *The Move from Definitions to Process*

Since the late 1980s, writers and policymakers have articulated four main definitions of 'medical futility.' Two are narrowly circumscribed and defined by objective clinical criteria: 1) physiological futility and 2) medical ineffectiveness. Two other positions also purport to 'appear' neutral and scientific like the first two: 3) quantitative futility and 4) qualitative futility. But they actually include value-laden criteria.[15]

Finding consensus on these two definitions proved problematic and elusive. Lawyers, bioethicists, health care providers, and policymakers have had enormous difficulty defining treatment that is 'futile' or 'medically inappropriate.' Years of debate have failed to produce any consensus.

So, by the mid-1990s, many institutions, professional associations, and commentators abandoned a definitional approach. They abandoned delineating clinical indications that would 'define' medical futility. Instead, paraphrasing Justice Potter Stewart's comment on pornography, many concluded that we can only 'know it' when we 'see it.'[16] They instead espoused a procedural, process-based approach.[17]

A recent policy statement from five leading critical care medical associations reconfirms this procedural approach.[18] First, the policy statement recognises that medical futility conflicts involve

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[11] See, eg Texas Health & Safety Code § 166.002(10).
[12] Pope, above n 10.
[13] Ibid.
[14] Ibid.
[15] Thaddeus M Pope, 'Medical Futility Statutes: No Safe Harbor to Unilaterally Stop Life-Sustaining Treatment' (2007) 75 *Tennessee Law Review* 1.
[16] *Jacobellis v Ohio*, 378 US 184 (1964).
[17] Thaddeus M Pope and Douglas B White, 'Medical Futility and Potentially Inappropriate Treatment', in Stuart Younger and Robert Arnold (eds), *Oxford Handbook on Death and Dying* (Oxford University Press, published online Sept 2015).
[18] Gabriel T Bosslet et al, 'An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units' (2015) 191(11) *American Journal of Respiratory and Critical Care Medicine* 1318.

'contested value judgments about what is appropriate treatment.'[19] So, it would be problematic to give all decision-making authority either to surrogates or to individual clinicians.

Second, the statement maintains that a process-based approach can incorporate multiple perspectives to minimise the risk that the values of any one individual will carry undue weight. Third, it concludes that a process-based approach better fulfills democratic ideals for resolving conflicts involving fundamental interests. Fourth, the policy statement predicts that a process-based approach may allow mutually agreeable solutions to emerge as the conflict-resolution process unfolds over time.

In short, the multi-society policy statement agrees with *TADA* that a procedural, and not a definitional, approach is appropriate. But the policy statement specifically rejects the particular procedural approach in *TADA* as insufficiently compatible with fundamental fairness. A core objective of this article is to more fully explain why.

C *Medical Futility Disputes Are Common*

Conflicts over LSMT in the ICU are common.[20] Indeed, they have recently been characterised as reaching 'epidemic proportions.'[21] A large portion of these end of life treatment conflicts are medical futility disputes.[22]

The problem has been well measured and documented in several different ways. One is from the perspective of ethics consultation services. For example, several leading US medical centres have reported that medical futility disputes comprise a significant percentage of their annual ethics consults: 13 per cent at Memorial Sloan Kettering;[23] 33 per cent at the University of Michigan Health System;[24] and 50 per cent at Stanford's Lucile Packard Children's Hospital.[25] The Mayo Clinic has reported similar percentages.[26]

The frequency of medical futility conflicts is equally high when measured from the perspective of ICU clinicians. Several recent surveys of critical care specialists demonstrate significant levels of conflict over LSMT. For example, a widely-discussed 2014 study from UCLA found that 20 per cent of the medical interventions in five of its ICUs were either futile or probably futile.[27]

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[19] Ibid 1320.
[20] See, eg Terrah J Paul Olson et al, 'Surgeon Reported Conflict with Intensivists about Postoperative Goals of Care' (2013) 148 *JAMA Surgery* 29, 29.
[21] AC Long and J Randall Curtis, 'The Epidemic of Physician-Family Conflict in the ICU and What We Should Do about It' (2014) 42(2) *Critical Care Medicine* 461.
[22] James Downar et al, 'Non-Beneficial Treatment Canada: Definitions, Causes, and Potential Solutions from the Perspective of Healthcare Practitioners' (2015) 43(2) *Critical Care Medicine* 270.
[23] Andrew G Shuman et al, 'Clinical Ethics Consultation in Oncology' (2013) 9(5) *Journal of Oncology Practice* 240.
[24] Lauren B Smith and Andrew Barnosky, 'Web-Based Clinical Ethics Consultation: a Model for Hospital-Based Practice' (2011) 37(6) *Physician Executive Journal* 62.
[25] David Magnus, 'Organizational Needs Versus Ethics Committee Practice' (2009) 9(4) *American Journal of Bioethics* 1.
[26] Keith M Swetz et al, 'Report of 255 Clinical Ethics Consultations and Review of the Literature' (2007) 82 *Mayo Clinic Proceedings* 686, 689-90.
[27] Thanh N Huynh et al, 'The Frequency and Cost of Treatment Perceived to be Futile in Critical Care' (2013) 173(20) *JAMA Internal Medicine* 1887.

Furthermore, not only is the volume of futility disputes already high but it is also likely to rise even further. There are three main reasons for this. First, the number of patients who are the subject of futility disputes will increase with continued growth: 1) in the ageing population, 2) in the burden of chronic illness, and 3) in the technology used to support vital organ function.[28]

Second, not only is the number of patients growing but also the rate of conflict is increasing. Physicians are increasingly more likely to recommend comfort measures only, instead of continuing aggressive, curative treatment. This is the result of shifts both in training and in reimbursement incentives.[29]

Third, at the same time that physicians are increasingly recommending comfort measures only, surrogates are increasingly likely to resist those recommendations. Largely for cultural, religious, and ethnic reasons, a growing proportion of Americans say that doctors should 'do everything possible to keep patients alive.'[30]

D *Many Futility Disputes Can Be Prevented*

It is better to prevent futility disputes from arising in the first place than to work at resolving them after they have already arisen. In fact, prevention is not terribly complicated or difficult. Most patients do not even want aggressive treatment at the end of life.[31] Suppose that these patients still had capacity and could make their own treatment decisions. They and their clinicians would generally agree on the appropriate treatment plan. There would be no conflict.[32]

But the patients who are the subjects of futility disputes almost always lack decision making capacity and cannot make their own treatment decisions. In such circumstances, they are presumed to want LSMT unless they have adequately rebutted that presumption. Unfortunately, most patients have not 'opted out' of pro-life default rules. As a result, they receive treatment that they would not have wanted and that their clinicians do not want to administer.

Fortunately, rapidly expanding initiatives are helping patients to better understand their options and to better document their treatment preferences.[33] In short, most patients do not want continued LSMT when they are chronically critically ill. If these patients had adequately documented their treatment preferences, most futility disputes could be avoided.

E *Almost All Futility Disputes Can Be Informally Resolved*

While prevention is a first choice approach, it is not always successful. If prevention has failed and conflict arises, informal and internal dispute resolution mechanisms available within the

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[28] Downar et al, above n 22.
[29] See Thaddeus M Pope, 'Medical Futility Statutes: No Safe Harbor to Unilaterally Stop Life-Sustaining Treatment' (2007) 75 *Tennessee Law Review* 1, 10-19.
[30] Pew Research Center, *Views on End-of-Life Medical Treatments* (21 November 2013) <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.
[31] Ibid.
[32] Pope, above n 10, 353.
[33] Ibid 353-55.

hospital work almost all of the time.[34] Through further communication and mediation, consensus is reached in over 95 per cent of medical futility cases.[35]

If the treatment team is not getting anywhere with the surrogate, it can invite the intervention of ethics consultants, social workers, chaplains, palliative care clinicians, the ethics committee, external second opinions, and other experts. These other hospital resources are quite effective at achieving consensus.[36] Indeed, only around five per cent of disputes remain intractable.

Clinicians do not want to act contrary to their professional judgment. Nor do they want to act without patient or surrogate consent. In a medical futility dispute, these two objectives come into conflict. But they are not irreconcilable or mutually exclusive. Consistent with both of these objectives, there are three ways to reach consensus in a futility dispute.

First, as discussed above, the clinician might eventually get consent from the surrogate. With intensive communication and mediation, the physician and surrogate might find some common ground.

Second, consensus might be reached by 'replacing' the objecting clinician with a substitute. Sometimes, the treating clinician can find a new health care provider willing to provide the treatment that the surrogate wants.[37] While the current health care provider may be unwilling to administer the surrogate-requested treatment, it is sometimes possible to transfer the patient to another physician or facility that is willing to provide the disputed treatment.

Third, if neither of these solutions is possible, the clinician is often able to replace the current surrogate with a new surrogate who will consent to the recommended treatment plan. This is the mirror image of the second path to consensus. Instead of transferring the patient to a new health care provider who agrees with the surrogate, the clinician replaces the current surrogate with a new surrogate who agrees with the clinician.[38]

But while an effective mechanism for many disputes, surrogate selection cannot resolve some significant categories of conflict. In many cases it will be difficult for providers to demonstrate that surrogates are being unfaithful to patient instructions or preferences. Since too few individuals engage in adequate advance care planning, applicable instructions and other evidence regarding patient preferences are rarely available. Therefore, it is often impossible to demonstrate surrogate deviation. Other times, the available evidence shows that the surrogate is acting faithfully and making decisions consistent with the patient's instructions, preferences, and values.[39]

In short, most futility disputes can be resolved through reaching consensus in one of three ways: 1) clinicians obtain consent from the current surrogate, 2) clinicians obtain consent from a new

[34] Downar, above n 22.
[35] Pope, above n 10, 355-56.
[36] Lance Lightfoot, 'Incompetent Decisionmakers and Withdrawal of Life-Sustaining Treatment: A Case Study' (2005) 33 *Journal of Law Medicine and Ethics* 851, 851.
[37] See below section IV C 5.
[38] Pope, above n 10, 356-59; Thaddeus M Pope, 'Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes' (2010) 3 *St Louis University Journal of Health Law and Policy* 183.
[39] See, eg Cuthbertson v Rasouli, 2013 SCC 53.

surrogate, or 3) the clinicians and surrogate find another clinician or facility willing to provide the requested treatment.

But some conflicts are not amenable to any of these solutions. '[E]ven impeccable communication and relational skills may not resolve conflicts that arise from fundamental difference in values between families and clinicians.'[40] In these intractable disputes, the clinician and surrogate are 'stuck' with each other.

III *TADA* IS VIEWED AS A MODEL DISPUTE RESOLUTION MECHANISM

Unable to obtain the surrogate's consent to the proposed treatment plan, most clinicians 'cave-in' to surrogate demands. Physicians in most US jurisdictions are afraid to refuse surrogate requested treatment that they deem inappropriate or even cruel.[41]

In contrast, *TADA* has proven effective at allowing (or empowering) physicians to avoid providing medical treatment that they judge medically or ethically inappropriate. Accordingly, other jurisdictions have been looking to *TADA* as a model to follow.

A *Clinicians Want Safe Harbor Legal Immunity*

Medical facilities across the United States have developed policies for dealing with medical futility. Indeed, among other professional medical organisations, the American Medical Association ('AMA') recommended a process-based approach. The AMA process includes seven steps: four aimed at 'deliberation and resolution,' two aimed at securing alternatives in cases of 'irresolvable differences,' and a final step aimed at closure when all alternatives have been exhausted. But with respect to this final step, the AMA correctly noted that 'the legal ramifications of this course of action are uncertain.'[42]

This uncertainty is 'chilling' and deters clinicians from proceeding without surrogate consent.[43] 'Immunity… is critical in the view of most, if not all, practicing physicians.'[44] It is unclear how effective medical futility dispute resolution guidelines can be in the face of legal uncertainty.[45]

One Texas physician observes:

> In my near 10-year experience with consults related to medical futility, many a physician, nurse, and even hospital ethics committee member felt that certain treatments in a given case were futile

[40] Robert D Truog, 'Tackling Medical Futility in Texas' (2007) 357 *New England Journal of Medicine* 1.
[41] Thaddeus M Pope and Ellen A Waldman, 'Mediation at the End-of-Life: Getting Beyond the Limits of the Talking Cure' (2007) 23 *Ohio State Journal on Dispute Resolution* 143.
[42] American Medical Association Council on Ethical and Judicial Affairs, 'Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs' (1999) 281(10) *JAMA* 937.
[43] Pope, above n 29.
[44] Robert L Fine, 'Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes about Medical Futility' (2009) 136(4) *Chest* 963, 965.
[45] Amir Halevy and Amy L McGuire, 'The History, Successes and Controversies of the Texas Futility Policy' (2006) 43(6) *Houston Lawyer* 34.

and should be stopped; however, few were willing to do so in the face of potential legal jeopardy.[46]

B *Most Clinicians Accede to Surrogate Demands*

In short, for clinicians, safe harbor legal immunity is not just attractive, it is essential. It allows providers to avoid practicing what they judge to be 'bad' or 'wrong' medicine.[47] In contrast, without legal safe harbor immunity, most clinicians usually 'follow the path of least resistance'[48] and just provide the treatment.[49] Without legal protection, they 'cave-in' to surrogate demands.[50]

But clinicians do not want to provide non-beneficial treatment.[51] So, many have been working to obtain legal safe harbor immunity like that provided by *TADA*.

C *Attempts and Recommendations to Copy* TADA

In a recent survey of over 700 clinicians, 82 per cent agreed that current dispute resolution mechanisms for medical futility disputes were inadequate.[52] They want better and more effective mechanisms. Specifically, most responding clinicians agreed that empowering a committee to arbitrate medical futility conflicts was a good option.[53] While it is not the only option, a majority of clinicians want a non-judicial tribunal with adjudicatory power.

Many view *TADA* as a model or paradigm of what this type of dispute resolution mechanism should look like.[54] Consequently, it is no surprise that other US states have been looking to copy it.

1 *Legislative and Judicial Efforts to Copy* TADA

Two US states have taken material, concrete steps to copy *TADA*. Idaho took a legislative approach. New Jersey tried to adopt *TADA* through the courts. Neither attempt was successful. But these undertakings themselves demonstrate the attractiveness of *TADA*.

In February 2009, Idaho state Senator Patti Anne Lodge introduced SB 1114, which was closely patterned after *TADA*.[55] While the bill unanimously passed the Idaho Senate in March 2009, Idaho has a bicameral legislature. The bill was never favorably reported from a House committee.

In New Jersey, the attempt to copy *TADA* did not take the form of a legislative bill but rather the

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[46] Robert L Fine, 'Medical Futility and the Texas Advance Directives Act of 1999' (2000) 13(2) *BUMC Proceedings* 144, 145.
[47] Thaddeus M Pope, 'Physicians and Safe Harbor Legal Immunity' (2012) 21(2) *Annals Health Law* 121.
[48] Fine, above n 44.
[49] Tom Blackwell, 'Doctors More Reluctant to Clash with Families over End-of-Life Decisions in Wake of Supreme Court Ruling', *National Post* (Canada), 5 September 2014.
[50] Thomas William Mayo, 'The Baby Doe Rules and Texas "Futility Law" on the NICU' (2009) 25 *Georgia State University Law Review* 1003, 1009.
[51] Pope, above n 29.
[52] Downar, above n 22.
[53] Ibid.
[54] Pope, above n 29, 68-69 and 79-80.
[55] SB 1114, 60th Leg, 1st Reg Sess § 5(7) (Idaho 2009).

form of an appellate brief. The brief was authored by the New Jersey Hospital Association, the Medical Society of New Jersey, and the Catholic Healthcare Partnership of New Jersey. These organisations asked the Appellate Division of the state Superior Court to judicially adopt provisions closely patterned on *TADA*.[56] As in Idaho, this attempt was unsuccessful. The Court dismissed the case as moot after the patient died.[57]

2 *Professional Organisations Endorse Copying* TADA

Apart from formal judicial and legislative action to copy *TADA*, a significant number of professional organisations have endorsed copying *TADA*. These include medical associations, bar associations, and others.

Medical societies in at least four states have passed resolutions calling on their legislatures to copy *TADA*. Medical associations in California,[58] North Carolina,[59] Washington,[60] and Wisconsin[61] considered such resolutions.

Legal associations have done the same. For example, the New York State Bar Association published a similar recommendation.[62] At a less formal level, major organisations in Maryland[63] and Connecticut[64] have held conferences and workshops exploring whether and how to follow *TADA*.

Furthermore, still others are looking to copy *TADA*, though in a less open and transparent manner. The authors and architects of *TADA* report that they get calls from around the country from lobbyists and advocates.[65] Plans, strategies, and bills are being drafted and devised.[66]

3 *Academic Commentary Recommends Copying* TADA

In addition to the efforts of legislatures, policymakers, and professional organisations, a number of commentators have argued that other states should follow *TADA*. For example, one author

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[56] Brief of Amici Curiae New Jersey Hospital Association, Catholic Healthcare Partnership of New Jersey, and Medical Society of New Jersey, *Betancourt v Trinitas Hospital*, No. A-003-849-08T2 (NJ Super AD Aug 7, 2009).
[57] *Betancourt v Trinitas Hospital*, 1 A 3d 823 (NJ Super AD 2010).
[58] California Medical Association, 2009 House of Delegates, *Resolution 506-09: End-of-Life Care and Futile Treatment*.
[59] AE Kopelman et al, 'The Benefits of a North Carolina Policy for Determining Inappropriate or Futile Medical Care' (2005) 66(5) *North Carolina Medical Journal* 382.
[60] Washington State Medical Association, 2010 House of Delegates, Resolution A-2: WSMA Opinion on Medical Futility in End-of-Life Care.
[61] Wisconsin Medical Society, *Resolution 1-2004*.
[62] New York State Bar Association Health Law Section, *Summary Report on Healthcare Costs: Legal Issues, Barriers and Solutions* (September 2009) <https://www.nysba.org/Sections/Health/Health_Law_Section_Report/Health_Law_Section_Reports.html>.
[63] Thaddeus M Pope, 'Medical Futility and Maryland Law', *Mid-Atlantic Ethics Committee Newsletter* (Maryland) Winter 2011, 1-3.
[64] Hartford Hospital Ethics Committee, *Summit - Medical Futility: Medicine, Law and Ethics* (Oct 21, 2010) <http://www.harthosp.org/portals/1/images/6/ethics_summit_program.pdf>.
[65] Mayo, above n 50.
[66] Texas Hospital Association, Key Messages on Texas Advance Directives Act (2011).

concludes that 'the Texas model offers an excellent blueprint for other states to follow.'[67] Others similarly assess *TADA* as a 'thoughtful approach' and an 'admirable project.'[68]

Not surprisingly, those involved in innovating *TADA* believe that the

> extra-judicial dispute resolution mechanism found in the Texas Advance Directives Act should… serve as a national model that appropriately balances the interests of all involved parties in these difficult cases while still leading to a defensible solution.[69]

But even independent scholars have similarly encouraged 'other jurisdictions in the United States [to] consider codifying a procedure similar to the one in Texas.'[70] These recommendations have been widely published in medical journals,[71] in law journals,[72] and in bioethics journals.[73]

IV *TEXAS ADVANCE DIRECTIVES ACT*

Now that we have established the reasons for examining *TADA*, we can turn to an examination of the statute itself. After providing a brief history of the legislation, I walk through all six steps of its dispute resolution process.

A *What Is* TADA*?*

The focus of this article is on the unique dispute resolution mechanisms in the *TADA*. But these provisions are just a small part of the *TADA*. While *TADA* spans over 15 000 words, the dispute resolution provisions consist of just around 700 words. *TADA* is a comprehensive healthcare decisions statute comprised of 71 separate statutory sections. The dispute resolution provisions

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[67] Jacob M Appel, 'What's So Wrong with Death Panels?' *Huffington Post* (Online), 22 November 2009 <http://www.huffingtonpost.com/jacob-m-appel/whats-so-wrong-with-death_b_366804.html?ir=Australia>.

[68] Michael Kapottos and Stuart Youngner, 'The Texas Advanced Directive Law: Unfinished Business' (2015) 15(8) *American Journal of Bioethics* 34.

[69] Fine, above n 44; Amir Halevy, 'Medical Futility, Patient Autonomy, and Professional Integrity: Finding the Appropriate Balance' (2008) 18(2) *Health Matrix* 261; Kelley Shannon, 'End-of-Life Legislation Dies in Texas House', *Houston Chronicle* (Houston) 23 May 2007; Robert L Fine, 'A Model for End-of-Life Care', *Washington Times* (Washington), 6 September 2009.

[70] John M Zerwas, 'Medical Futility in Texas: Handling 'Reverse Right to Die' Obstacles without Constitutional Violation' (2007) 43 *Tulsa Law Review* 169, 198.

[71] See eg, HC Jacobs, 'The Texas Advance Directives Act - Is It a Good Model?' (2009) 33(6) *Seminars in Perinatology* 384; Arthur E Kopelman, 'The Benefits of a North Carolina Policy for Determining Inappropriate or Futile Medical Care' (2005) 66(5) *North Carolina Medicine Journal* 392; Matthew H Armstrong et al, 'Medical Futility and Non-beneficial Interventions: An Algorithm to Aid Clinician' (2014) 8(12) *Mayo Clinic Proceedings* 1599.

[72] See eg Patrick Moore, 'An End-of-Life Quandary in Need of a Statutory Response: When Patients Demand Life-Sustaining Treatment that Physicians are Unwilling to Provide' (2007) 48 *Boston College Law Review* 433, 468; Mary Johnston, 'Futile Care: Why Illinois Law Should Mirror the Texas Advanced Directives Act' (2014) 23 *Annals of Health Law Advance Directive* 27; Lisa Dahm, 'Medical Futility and the Texas Medical Futility Statute: A Model to Follow or One to Avoid' (2008) 20(6) *Health Lawyer* 25.

[73] See, eg, Nancy S Jecker, 'Futility and Fairness: A Defense of the Texas Advance Directives Law' (2015) 15(8) *American Journal of Bioethics* 43; Laurence B McCullough, 'Professionally Responsible Clinical Ethical Judgments of Futility 15(8) *American Journal of Bioethics* 54; Kappatos and Younger, above n 68; Thaddeus M Pope, 'Legal Briefing: Medical Futility and Assisted Suicide' (2009) 20(3) *Journal of Clinical Ethics* 274.

comprise just four sections.[74]

B *History of* TADA*: 1993 to 1999*

In 1993, representatives from most of the major hospitals in Houston, Texas formed the Houston Citywide Taskforce on Medical Futility.[75] They developed a nine step procedure for resolving futility disputes. The goal of the taskforce was to create a common policy, because the members thought that would be more ethically and legally defensible than individual facilities proceeding on their own.

But this was still insufficient. Making the protocol citywide made it seem more reasonable. But it still did not give the protocol the force of law. The guidelines had 'no legal standing.'[76] And without a 'positive statement in the law . . . the threat of malpractice litigation would force most physicians to honor families' requests for even the most inappropriate aggressive treatment.'[77] As discussed above, safe harbor legal immunity is critical.[78]

Four years later, the state legislature was considering comprehensive *TADA* legislation. The Houston procedures were largely incorporated into this bill. In February 1997, Senator Mike Moncrief introduced *TADA* in SB 414. By April, the bill passed the Senate. By May, it passed the House. But when the final version of SB 414 was sent to Governor Bush, in June 2007, he vetoed it.[79]

Governor Bush's veto proclamation noted that SB 414 contained 'several provisions that would permit a physician to deny [LSMT] to a patient who desires them.' Indeed, opponents had charged that SB 414 would 'encourage medical professionals to participate in euthanasia…by denying life-saving medical treatment…to patients whose lives they independently decide are not worth living.'[80] The Governor was concerned about these 'potentially dangerous defects.'[81]

To address the Governor's concerns, at least 24 interested organisations formed the Texas Advance Directives Coalition.[82] Its membership included advisors from the legislative and executive branches. It included medical groups like Texas Hospital Association and Texas Medical Association. It even included pro-life groups like Texas Right to Life and Texas Alliance for Life. Despite this heterogeneous composition, the Coalition was able to reach a 'watershed compromise.'[83] The Coalition reached consensus on safeguards and protections designed to resolve the 'defects' that concerned Governor Bush.[84]

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[74] Texas Health & Safety Code §§ 166.045, 166.046, 166.052, 166.053.
[75] Amir Halevy and Baruch Brody, 'A Multi-Institutional Collaborative Policy on Medical Futility' (1996) 276(7) *JAMA* 571.
[76] Elizabeth Heitman and Virginia Gremillion, 'Ethics Committees under Texas Law: Effects of the Texas Advance Directives Act' (2001) 13(1) *HEC Forum* 82, 90.
[77] Ibid 88.
[78] See above Part III C.
[79] Heitman and Gremillion, above n 76, 90-92.
[80] Texas House Research Organization, *Bill Analysis of SB 414* (May 23, 1997), 2.
[81] Proclamation by the Governor of the State of Texas (June 20, 1997), 75th Texas Legislature, *Senate Journal* 4926.
[82] Robert L Fine, 'The Texas Directives Act of 1999: Politics and Reality' (2001) 13 HEC Forum 59, 63-67; Heitman and Gremillion, above n 76, 92-94.
[83] Halevy and McGuire, above n 45.
[84] Emily Ramshaw, 'Bills Challenge Care Limits for Terminal Patients', *Dallas Morning News* (Dallas, Texas), 15

So, when the legislature reconvened in 1999, Senator Moncrief used the Coalition's language to amend the vetoed 1997 legislation. He again introduced *TADA*.[85] By April, it passed the Senate. By May, it passed the House. Governor Bush signed the bill on 18 June 1999. *TADA* went into effect on 1 September 1999.[86]

C *Dispute Resolution Provisions of* TADA

The *TADA* dispute resolution provisions address the situation in which 'an attending physician refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient.'[87]

With respect to LSMT, this can happen in two basic ways. First, the surrogate may be requesting LSMT that the physician thinks is inappropriate. Second, the surrogate may be refusing LSMT that the physician thinks should be provided. The former situation (a medical futility dispute) is the far more common situation and the one on which this article focuses.

TADA encourages the 'physician's refusal' to 'be reviewed by an ethics or medical committee.'[88] This review process is comprised of six basic steps that proceed in a roughly chronological order:

1) The attending physician refers the dispute to a review committee.
2) The hospital provides the surrogate with notice of committee review.
3) The review committee holds an open meeting.
4) The review committee makes its decision and provides a written explanation.
5) The hospital attempts to transfer the patient to a willing facility.
6) The hospital may stop LSMT.

TADA mandates that hospitals continue to administer disputed LSMT during the first five steps of this review.[89] In addition, *TADA* specifies two situations under which the process can be shortened or extended.

1 *The Attending Physician Refers the Dispute to a Review Committee*

In a futility dispute, at some point, the attending physician determines that one or more forms of LSMT are inappropriate. Since the default presumption is that all physiologically effective LSMT will be provided, the physician ordinarily seeks the consent of the patient's surrogate to a proposed plan to withhold or withdraw treatment. The surrogate refuses consent.

While not required by *TADA*, the attending physician will typically work on obtaining the

February 2007.
[85] Tex SB 1260 (1999).
[86] Added by Acts 1999, 76th Leg, ch 450, Sec 1.02, eff Sept. 1, 1999.
[87] Texas Health & Safety Code § 166.046(a).
[88] Texas Health & Safety Code § 166.046(a).
[89] Texas Health & Safety Code § 166.046(a). TADA was recently amended to exempt clinically assisted nutrition and hydration from the types of affected LSMT Tex HB 3074, 84th Legis. (2015) (Springer), enacted Tex House J 6047 (June 12, 2015).

surrogate's consent through additional family meetings and the intervention of other specialists like chaplains and ethics consultants.[90] Such communication and mediation typically resolves the dispute.[91] But if none of this works (or even if it was never tried), then the attending physician may invoke *TADA*'s formal dispute resolution provisions.

TADA's dispute resolution procedures are written such that the attending physician is the only one who can invoke them.[92] They are triggered when the attending physician 'refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient.'[93] The attending physician notifies the review committee of her refusal, effectively asking or petitioning it to adjudicate the dispute.

2 *The Hospital Provides the Surrogate with Notice of Committee Review*

Once the attending physician refers the case to the review committee, the committee will convene a 'meeting' to consider the case. Presumably to enable the surrogate to attend and meaningfully participate at the committee hearing, the hospital must inform the surrogate of the committee review process at least two days in advance. Specifically, this notice must be provided 'not less than 48 hours before the meeting called to discuss the patient's directive, unless the time period is waived by mutual agreement.'[94]

At the same time that it provides notice of the review committee meeting, the hospital must also provide the surrogate with two written documents: 1) a statutorily mandated written 'statement' of rights[95] and 2) a state-maintained list of health care providers and referral groups.[96] *TADA* encourages, but does not require, the hospital to provide a third document, 3) that describes its committee review process.

(a) The Hospital Provides the Surrogate with a Written Statement of Rights

While not in the original 1999 *TADA*, a 2003 amendment added specific language that hospitals must provide to surrogates.[97] The required written statement basically summarises the surrogate's rights in plain, less legalistic, language.[98]

In cases in which the attending physician refuses to comply with an advance directive or treatment decision requesting LSMT, the statement shall be in substantially the following form:

> **When There Is a Disagreement about Medical Treatment: the Physician Recommends against Life-Sustaining Treatment That You Wish to Continue**

[90] Several bills aimed to amend *TADA* to first require an advisory ethics consultation. See, eg, SB 439 (2007) (Deuell); HB 3474 (2007) (Delisi); SB 303 (2013) (Deuell).
[91] See above Part II E.
[92] Texas Health & Safety Code § 166.046. See also Mayo, above n 50, 1005 n.8.
[93] Texas Health & Safety Code § 166.046(a).
[94] Texas Health & Safety Code § 166.046(b)(2).
[95] Texas Health & Safety Code § 166.046(b)(2)(A).
[96] Texas Health & Safety Code § 166.046(b)(3).
[97] Texas Health & Safety Code § 166.052. Added by Acts 2003, 78th Leg, ch 1228, Sec 5, eff June 20, 2003.
[98] Texas Health & Safety Code §§ 166.046(b)(3)(A) & 166.052.

> You have been given this information because you have requested [LSMT] which the attending physician believes is not appropriate. This information is being provided to help you understand state law, your rights, and the resources available to you in such circumstances. It outlines the process for resolving disagreements about treatment among patients, families, and physicians…[99]

A similar statement must be provided when there is a disagreement about medical treatment in which the physician recommends LSMT that the surrogate wishes to stop.[100]

(b) The Hospital Provides the Surrogate with the State Registry List

In addition to the 'statement' of rights,[101] the hospital must also provide a copy of a state-maintained list of health care providers and referral groups that have volunteered their readiness either to consider accepting transfer or to assist in locating a provider willing to accept transfer.[102]

This list is maintained by the Texas Health Care Information Council ('THCIC'), an agency of the Texas Department of State Health Services. *TADA* requires the THCIC to 'maintain a registry listing the identity of and contact information for health care providers and referral groups, situated inside and outside [Texas], that have voluntarily notified the council they may consider accepting or may assist in locating a provider willing to accept transfer of a patient…'[103]

As of September 2015, the list includes only three healthcare providers.[104] It also includes four law firms and two advocacy groups. While the 'registry list of health care providers and referral groups' is maintained by the THCIC, the State of Texas does not endorse or assume 'any responsibility for any representation, claim, or act of the listed providers or groups.'[105] Furthermore, the listing of a provider or referral group in the registry 'does not obligate the provider or group to accept transfer of or provide services to any particular patient.'[106]

(c) The Hospital Provides the Surrogate with a Description of Its Review Process

While *TADA* requires hospitals to provide the 'statement of rights' and the 'registry list,' it merely suggests and recommends that the hospital provide the surrogate with a third document: 'a written description of the ethics or medical committee review process and any other policies and procedures related to this section adopted by the health care facility.'[107] Since *TADA* provides almost no direction on how a review committee is to operate, the process will vary from hospital to hospital.

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[99] Texas Health & Safety Code § 166.046(a).
[100] Texas Health & Safety Code § 166.052(b).
[101] Texas Health & Safety Code § 166.046(b)(3)(A).
[102] Texas Health & Safety Code § 166.046(b)(3)(B).
[103] Texas Health & Safety Code § 166.053(a).
[104] Texas Department of State Health Services, *Registry List of Health Care Providers and Referral Groups* <http://www.dshs.state.tx.us/thcic/Registry.shtm>.
[105] Texas Health & Safety Code § 166.053.
[106] Texas Health & Safety Code § 166.053(b).
[107] Texas Health & Safety Code § 166.046(b)(1).

3 *The Review Committee Holds an Open Meeting*

At this point, at least 48 hours before the review committee hearing, three things have happened. First, the attending physician has refused to honour the treatment decision for continued LSMT. Second, the physician has referred the case to the hospital review committee. Third, the surrogate has been apprised of her rights.

TADA does not authorise physicians to act unilaterally. The attending physician's refusal must be reviewed by an 'ethics or medical committee.'[108] But hospitals have significant discretion here. *TADA* is mostly silent as to the composition or training of the committee that reviews the dispute between the surrogate and clinician.[109] The statute provides only that 'the attending physician may not be a member of that committee.'[110]

With respect to the meeting itself, *TADA* provides that the surrogate is entitled to attend.[111] But it does not specify any other rules or procedures. *TADA* is silent on who else the surrogate may bring (eg an attorney, a religious adviser). It is silent on the scope of the surrogate's participation (eg right to ask questions).

While not specified in the statute, the review committee meeting typically proceeds in two stages. It 'begins with a presentation from the attending physician and other members of the health care team.'[112] During this presentation, clinicians 'provide reasoning and evidence to support why they believe further curative care would be medically futile.'[113] Most committees then 'allow the patient and family to present their arguments and evidence.'[114]

4 *The Review Committee Makes Its Decision and Provides a Written Explanation*

After the meeting, the review committee will usually deliberate in private, separate from the treating clinicians and family. Once it reaches a decision, the committee must prepare a 'written explanation of the decision reached during the review process.'[115] It must provide the surrogate with a copy. This 'written explanation' must also be included in the patient's medical record.[116]

The review committee consideration of a medical futility dispute results in one of three main outcomes. First, the committee can agree with the surrogate. Second, it can agree with the referring physician. Third, sometimes the conflict is mooted by the patient's death or by subsequent family-clinician agreement.

First, if the review committee agrees with the surrogate, then the physician must make a reasonable

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[108] Texas Health & Safety Code § 166.046(a).
[109] Texas Health & Safety Code § 166.002(6).
[110] Texas Health & Safety Code § 166.046(a).
[111] Texas Health & Safety Code § 166.046(b)(4)(A).
[112] Robert W Painter, 'Developments in Texas Advance Directives' (2009) *Houston Lawyer* 20 <http://www.thehoustonlawyer.com/aa_sep09/page20.htm>.
[113] Ibid.
[114] Ibid.
[115] Texas Health & Safety Code § 166.046(b)(4)(B).
[116] Texas Health & Safety Code § 166.046(c).

effort to transfer the patient to a physician who is willing to comply with the surrogate. Hospital personnel must assist the physician in arranging the patient's transfer: 1) to another physician, 2) to an alternative care setting within that facility, or 3) to another facility.[117]

Second, if the committee agrees with the referring physician (and it usually does), then the dispute resolution process may continue. Published studies indicate that review committees agree with referring physicians in more than 70 per cent of cases.[118]

Third, sometimes the conflict is mooted, because the patient dies during the review process.[119] Other times, conflict is mooted, because surrogates are persuaded by the fact that the review process affirms the attending physician's decision that LSMT is inappropriate treatment.[120] These surrogates are happy that the committee takes the burden of decision making off their shoulders.[121] On the other hand, some surrogates may consent because they experience the *TADA* process as *fait accompli*.[122]

But while some disputes are resolved by or during the review process, others are not. Some surrogates continue to request LSMT that both the attending physician and the ethics or medical committee concluded was inappropriate.

5 *The Hospital Attempts to Transfer the Patient to a Willing Facility*

If the review committee agrees with the referring physician and the surrogate does not agree with that decision, then 'the physician shall make a reasonable effort to transfer the patient to a physician who is willing to comply with the directive.'[123] In fact, it is unlikely that another physician at the same facility will accept a transfer at this point in the process. So, *TADA* further provides: 'If the patient is a patient in a health care facility, the facility's personnel shall assist the physician in arranging the patient's transfer: 2) to an alternative care setting within that facility; or 3) to another facility.'[124]

The surrogate may concurrently look for a transfer on her own. She can use the 'registry list' of health care providers and referral groups that have volunteered their readiness to consider accepting transfer, or to assist in locating a provider willing to accept transfer. Surrogates may contact providers or referral groups on the list or others of their choice to get help in arranging a

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[117] Texas Health & Safety Code § 166.046(d).
[118] See, eg Richard J Castriotta, 'Protecting Patients: the TADA, and the Limits of Surrogate Directives' (Paper presented at the American College of Chest Physicians Annual Meeting, Chicago, Illinois, 26-31 October 2013); Becca Aaronson, 'A Texas Senate Bill Would Revise the State's End-of-Life Procedure', *New York Times* (New York) 30 March 2013.
[119] See below Part V.
[120] Robert L Fine, 'The History of Institutional Ethics at Baylor University Medical Center' (2004) 17(1) *Proceedings of Baylor University Medical Center* 73.
[121] Fine, above n 120, 71; Robert D Truog, 'Medical Futility' (2009) 25 *Georgia State University Law Review* 985, 999.
[122] Tom Mayo, 'Medical Futility in Texas: Myths and Misconceptions' (8 April 2014) <http://repositories.tdl.org/utswmed-ir/handle/2152.5/1405>.
[123] Texas Health & Safety Code § 166.046(d).
[124] Texas Health & Safety Code § 166.046(d).

transfer. The patient is responsible for any costs incurred.[125]

After being served with the review committee's 'written explanation,' the surrogate has at least ten days to accomplish a transfer. But this is a difficult task. Few hospitals are willing to accept the transfer of a patient after another hospital's review committee has already determined that continuing LSMT is inappropriate.[126] But transfer is not impossible.[127] For example, the family of Spiro Nikolouzos transferred him from St. Luke's Episcopal Hospital to Avalon Place, a long-term care facility.[128]

More recently, a June 2011 case at Texas Children's Hospital garnered significant media attention. A fourteen-year-old boy had been diagnosed months earlier with inoperable glioblastoma, a particularly lethal cancer. The boy's parents were able to transfer him, five days into the ten day waiting period, to Atrium Medical Center, a nearby long-term acute-care facility.[129]

In these cases in which the surrogate is requesting LSMT 'that the attending physician has decided, and the review process has affirmed is inappropriate treatment, the patient shall be given available [LSMT] pending transfer.'[130] But the transfer period is not indefinite.

6 *The Hospital May Stop Life-Sustaining Treatment*

The patient must continue to be given LSMT until he or she can be transferred to a willing provider. But the waiting period to find a transfer lasts for only 10 days from the time the surrogate was given the committee's 'written explanation' that LSMT is not appropriate. If a willing provider cannot be found within 10 days, then LSMT may be withdrawn.

Neither the physician nor the health care facility are 'obligated to provide [LSMT] after the tenth day after the written decision' is provided to the surrogate.[131] The inability to transfer is intended to serve as confirmation of the review committee's decision. The refusal of other facilities to provide the disputed LSMT supposedly indicates or confirms that the review committee was correct. Accordingly, LSMT 'under this section may not be entered in the patient's medical record as medically unnecessary treatment until the ten day waiting period has expired.'[132]

7 *Special Adjustments to Timing*

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[125] Texas Health & Safety Code § 166.046(e).
[126] See, eg Bosslet et al, above n 18, 1325; Leigh Hoper and Todd Ackerman, 'Inside of Me, My Son Is Still Alive', *Houston Chronicle* (Houston) 16 March 2005; Mary Ann Roser, 'Time Running Out for Baby on Life Support', *Austin American Statesman* (Austin) 8 April 2007.
[127] Martin L Smith et al, 'Texas Hospitals' Experience with the Texas, Advance Directives Act' (2007) 35 *Critical Care Medicine* 1271.
[128] AP, 'Man in Center of Life-Support Debate Dies in San Antonio', *Houston Chronicle* (Houston) 1 June 2005, B5.
[129] Todd Ackerman, 'Teen's Move Sidesteps Futile-Care Controversy', *Houston Chronicle* (Houston) 30 June 2011; L Frillici, 'Family Fights to Keep Teen Alive as Hospital Decides to End Life Support', *KHOU 11 News* (Houston), 30 June 2011.
[130] Texas Health & Safety Code § 166.046(e).
[131] Texas Health & Safety Code § 166.046(e).
[132] Texas Health & Safety Code § 166.046(f).

The previous six steps fully describe the *TADA* dispute resolution mechanism. But *TADA* also specifies two situations under which this standard dispute resolution process can be shortened or extended. First, the process can be shortened, if the patient has already been the subject of a committee review. Second, the transfer period can be extended by court order.

(a) Prior Committee Review Can Shorten the Process

If, during a previous admission to a facility, a patient's attending physician and the review process have determined that LSMT is inappropriate, and the patient is readmitted to the same facility within six months, the hospital does not need to follow any of the above six steps.

This makes sense. Suppose the patient is transferred from the hospital to a long-term care facility. Then, the patient suffers an emergent issue such as respiratory distress and returns to the hospital. If the patient is in substantially the same condition, why start the entire dispute resolution process all over again? The result would probably be the same.

To bypass the dispute resolution process in such cases, the patient's attending physician and a consulting physician who is a member of the facility's review committee must confirm that the previous review committee decision is still applicable. They must document on the patient's readmission that the 'patient's condition either has not improved or has deteriorated since the review process was conducted.'[133]

(b) Courts Can Sometimes Extend the Transfer Waiting Period

Just as *TADA* permits special circumstances to shorten the dispute resolution process, it also permits special circumstances to lengthen the process. While *TADA* gives the surrogate only ten days to find a facility willing to provide disputed LSMT, the surrogate may ask the 'appropriate district or county court' to extend this ten-day period.

But the surrogate's ability to obtain a judicial extension of the transfer period is extremely limited. *TADA* permits the court to grant such an extension only if there is a 'reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the time extension is granted.'[134]

Despite these restrictive standards, in several cases, surrogates have been able to obtain temporary restraining orders or preliminary injunctions.[135] Hospitals have also agreed to an extension just before a pending hearing.[136] However, in many other cases the courts have denied requests for

[133] Texas Health & Safety Code § 166.046(e-1).
[134] Texas Health & Safety Code § 166.046(g).
[135] See, eg, *Gonzales v Daughters of Charity Health Services of Austin*, No 86427 (Travis County Probate Court May 18, 2007) (Second Extension of Temporary Restraining Order); *Hudson v Texas Children's Hosp*, 177 SW 3d 232 (Tex App 2005); *In re Nikolouzos*, 179 SW 3d 581 (Tex App 2005); Kristina Herrndobbler, 'Court Keeps Woman on Life Support', *Beaumont Enterprise* (Texas), 11 August 2006, A.1; Bill Murphy, C*omatose Surgeon Would Prefer Death*, *Houston Chronicle* (Houston), 21 March 2001, 26; Emily Ramshaw, 'Children Fight to Save Mom', *Dallas Moring News* (Dallas), 18 August 2006.
[136] See, eg, Todd Ackerman, 'Transfer Resolves Latest Futile Care Case', *Houston Chronicle* (Houston) 31 July 2006; Todd Ackerman, 'Family Vows to Fight Futile Care Law', *Houston Chronicle* (Houston) 9 May 2006;

extensions.[137]

D TADA *Provides Safe Harbour Legal Immunity*

Importantly, *TADA* not only outlines a dispute resolution mechanism but also offers safe harbour legal immunity for following it. The statute provides:

> A physician, health professional acting under the direction of a physician, or health care facility is not civilly or criminally liable or subject to review or disciplinary action by the person's appropriate licensing board if the person has complied with the procedures outlined in Section 166.046.[138]

This legal protection is important. Without it and unable to secure surrogate consent to stopping LSMT, providers generally continue to comply with requests that they consider inappropriate.[139] Moreover, the requirements for earning immunity under *TADA* are clear, measureable, and precise. So, healthcare providers can be sure about when they are qualified for safe harbour protection. Legal immunity is effective only when providers have confidence and certainty about when they have it.[140]

E *The* TADA *Process Is Optional*

While *TADA* outlines a six-step dispute resolution process with specific written disclosures and other details, using that process is optional. Hospitals may refuse requested LSMT without following these six steps. And they may still have liability protection.

TADA explicitly anticipates this situation in three separate sections. First, '[i]f an attending physician refuses to comply with a directive or treatment decision and does not wish to follow the procedure established under Section 166.046, [the physician may].' *TADA* simply requires that LSMT 'be provided to the patient … only until a reasonable opportunity has been afforded for the transfer of the patient to another physician or health care facility willing to comply.'[141] The physician's liability is limited, so long as she complies with the professional standard of care.[142]

Second, a separate section of *TADA* confirms that clinicians may also have rights under common law. 'This subchapter does not impair or supersede any legal right or responsibility a person may have to affect the withholding or withdrawal of [LSMT] in a lawful manner.' This section imposes only one affirmative obligation: LSMT 'is required to be provided the patient … until a reasonable opportunity has been afforded for transfer of the patient to another physician or health care facility willing to comply.'[143]

Third, *TADA* recognises that LSMT may be denied to a patient in a triage situation. 'This chapter

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Hudson v Texas Children's Hosp, 177 SW 3d 232, 233 (Tex App 2005).

[137] See, eg, Lightfoot, above n 36, 854; *Hudson v Texas Children's Hosp*, No 352,526 (Probate Ct, Harris County, Tex Mar 14, 2005); *Nikolouzos v St Luke's Hosp*, 162 SW 3d 678, 679-80 (Tex App 2005).

[138] Texas Health & Safety Code § 166.045(d). *See also id* § 166.044.

[139] See above Part III A.

[140] Pope, above n 47; Pope, above n 29.

[141] Texas Health & Safety Code § 166.045(c).

[142] Texas Health & Safety Code § 166.044.

[143] Texas Health & Safety Code § 166.051.

may not be construed to require the provision of LSMT that cannot be provided to a patient without denying the same treatment to another patient.'[144]

V HOSPITAL EXPERIENCE WITH *TADA*

Now that we have examined how *TADA* works, we can turn to look at how hospitals have used it. Unfortunately, *TADA* has never included any reporting requirements.[145] Consequently, there are no thorough and systematic data on how Texas hospitals have used *TADA* over the past fifteen years. Nevertheless, there are some small scale studies. Some were conducted right after *TADA* went into effect in 1999. Some were conducted in the 2000s. And a few more recent studies were conducted since 2010.

A *Early Hospital Experience with* TADA *(1999 to 2004)*

Baylor University Medical Center reported that in the 12 months before *TADA*, it had 14 futility cases. Of these, two patients died during the consultation and process even with maintenance of LSMT. In the other 12 cases, the family agreed to withdraw LSMT. But in one case it took the family about a month to agree.[146]

In the first 16 months after *TADA*, Baylor reported 36 futility cases. In 29, the family promptly agreed to withdraw LSMT and focus on comfort care. Five cases were pursued through the *TADA* dispute resolution process. In three of these, the family agreed after receiving the review committee's report. In the other two cases, the patient died during the ten day waiting period.[147]

B *Later Hospital Experience with* TADA *(2005 to 2010)*

By the mid-2000s, several studies went beyond the walls of a single facility and measured the use of *TADA* more broadly. For example, a 2004 study surveyed 200 Texas hospitals. Respondents reported reviewing 256 futility cases over the first five years of *TADA* (1999 to 2004).[148]

The families of 71 patients agreed to discontinue treatment. Thirty patients were transferred to another facility. And 78 patients died before the end of the 10-day waiting period. Eight patients improved and appropriateness of treatment was reassessed. After the 10 day period, 78 patients were still alive. Hospitals discontinued treatment for 33. And despite review committee decisions, hospitals continued treatment for 45.

A second study looked at five years' of information from eleven large hospitals and two years' worth of data from five other large hospitals. The surveyed hospitals reported a total of 974 medical futility cases. But they used *TADA* in only 65 of those cases. The hospitals actually withdrew

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[144] Texas Health & Safety Code § 166.009.
[145] Mayo, above n 50. Several bills have tried to add such a requirement. See, eg, SB 439 (2007) (Deuell).
[146] Fine, above n 120, 79.
[147] Robert L Fine, 'The Texas Advance Directives Act of 1999: Politics and Reality' (2001) 13 *HEC Forum* 59, 81; Robert L Fine and Thomas William Mayo, 'Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act' (2003) 138 *Annals of Internal Medicine* 743, 745.
[148] Smith et al, above n 127.

treatment in only 27 of those cases. Twenty-two patients died receiving treatment as they awaited transfers.[149]

C *Recent Hospital Experience with* TADA *(2010 to 2015)*

The most recent available data suggest that hospitals rarely use *TADA*. The Texas Hospital Association ('THA') surveyed its members in 2010, 2011, and 2012. THA reports that in 2009, the *TADA* dispute resolution process was initiated just two times at two multi-hospital systems. In 2010, the *TADA* process was initiated only one time at one hospital system. In 2011, usage ticked up. The THA survey shows that *TADA* was used 21 times by 16 hospitals or hospital systems.[150]

In 2012, the Texas Hospital Association again surveyed its member hospitals. The 202 respondents reported that *TADA* had been used 30 times between 2007 and 2012. Of those cases, ten patients died during the ten day period, six patients were transferred to another provider, and four continued treatment past the 10-day period. Extrapolating from this sample of one-third of Texas hospitals, one might estimate that *TADA* is used 15 times per year statewide. And one can estimate that treatment is actually withdrawn only five times per year.[151]

On the other hand, the THA data may not be accurate or representative. A single hospital study at Memorial Hermann examined its *TADA* experience from 2000 to 2013.[152] The hospital reported that it had 34 cases during this time period (about 2.4 per year). The committee agreed with the referring physician in thirty of the 34 cases. Of these, the families of three agreed to discontinue treatment. Four were transferred. Seven died during the ten day waiting period. The hospital discontinued treatment for fifteen.

D *Summary of Hospital Experience with* TADA

While available studies suggest that Texas hospitals rarely use *TADA*, these understate the impact and effect of *TADA*. First, the more recent unpublished studies indicate far lower usage rates than the published studies. They may be neither statistically valid nor reliable. For example, it is unclear whether THA member hospitals are representative of all Texas hospitals. Second, focusing on only hospitals' actual use of *TADA* fails to account for its 'shadow effect.'[153] If families know the hospital has this 'weapon,' they may (reluctantly) consent to the recommended treatment plan, precluding the need to formally resort to the *TADA* mechanism.[154]

VI *TADA* FAILS TO AFFORD ADEQUATE PROCEDURAL DUE PROCESS

I have now established the purpose, operation, and usage of *TADA*. In this section, I turn from a descriptive account to a normative account. Specifically, I evaluate and assess whether *TADA*

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[149] Fine, above n 44.
[150] W Gardner Selby, 'Texas Right to Life Exaggerates on Claim of "Faceless Hospital Panel" Determining Treatment', *Politifact* (Texas) 30 May 2014 <http://www.politifact.com/texas/statements/2014/may/30/texas-right-life/texas-law-gives-hospital-panels-sway-over-cutting-/>.
[151] Becca Aaronson, 'A Texas Senate Bill Would Revise the State's End-of-Life Procedure', *New York Times* (New York), 30 March 2013.
[152] Castriotta, above n 118.
[153] Pope and Waldman, above n 41.
[154] Mayo, above n 122.

affords adequate procedural due process. I conclude that it does not. *TADA* is not sufficiently fair.

I am not alone. *TADA* is often described as a 'due process' approach.[155] But many charge that this due process 'is more illusory than real.'[156] Some legal commentators have colourfully observed that *TADA* affords hospital patients with fewer protections than other Texas law affords either to tenants facing eviction from rental property or to automobile owners threatened with repossession.[157] Even Texas hospital lawyers have conceded *TADA*'s weaknesses.[158] So have *TADA*'s primary authors.[159]

Despite being framed as a matter of 'due process,' the focus of the present inquiry is on fundamental fairness. As US law students quickly learn, Constitutional Fourteenth Amendment procedural due process analysis requires 'state action.'[160] So, it may not be directly applicable to private, non-governmental hospitals. To be sure, some writers have assessed whether even a private hospital's use of *TADA* constitutes 'state action' such that constitutional protections are triggered.[161] But that is not our present concern.

In this article, we look to constitutional requirements only as guideposts to assess *TADA* from an ethical and public policy perspective. The elements of due process have been well developed in hundreds of court opinions. And they provide a cogent framework for our fairness analysis.[162]

Before we begin assessing how well *TADA* satisfies specific elements of due process, we must first be mindful of two overarching principles. First, more extensive due process is required when a more significant interest is impacted.[163] Here, where the stakes are literally 'life and death,' particularly careful due process is required.[164]

Second, more due process is required when the 'risk of error' is high.[165] Due process rules are 'meant to protect persons not from the deprivation [itself] but from the mistaken or unjustified deprivation of life, liberty, or property.'[166] Here, there is an especially high risk error because futility determinations are not purely medical judgments but are the product of 'exceedingly complex value judgments.'[167] And even to the extent they are medical judgments, there are significant limits to accurate prognostication.[168]

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[155] See, eg Fine and Mayo (2003), above n 147.
[156] Truog, above n 40, 3.
[157] Nora O'Callaghan, 'Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act' (2008) 60(2) *Baylor Law Review* 527, 555.
[158] Testimony of Michael Regier on SB 439 (2007) (at 170:00); Texas Hospital Association, *Key Messages on Texas Advance Directives Act* (2011).
[159] Mayo, above n 50, 1013, 1013-1017. Fine, above n 44.
[160] Brentwood Academy v Tennessee Secondary School Athletic Assn, 531 US 288 (2001).
[161] See, eg Nora O'Callaghan, 'When Atlas Shrugs: May the State Wash Its Hands of Those in Need of Life-Sustaining Medical Treatment?' (2008) 18 *Health Matrix* 291.
[162] See, eg, O'Callaghan, above n 157, 559.
[163] *Joint Anti-Fascist Refugee Comm v McGrath*, 341 US 123, 168 (1951) (Frankfurter J, concurring).
[164] *Matthews v Eldridge*, 424 US 319, 335 (1976).
[165] Ibid.
[166] *Carey v Piphus*, 435 US 247, 259 (1978).
[167] Bosslet et al, above n 18.
[168] Keith M Swetz et al, 'Ten Common Questions (and Their Answers) on Medical Futility' (2014) 89(7) *Mayo*

In the following six subsections, I examine how well *TADA* comports with the following elements of procedural due process.

a) Neutral and Independent Decision Maker
b) Appellate Review
c) Notice
d) Statement of Decision
e) Criteria to Guide Decision
f) Other Due Process Concerns

A TADA *Lacks a Neutral and Independent Decision Maker*

The US Supreme Court has held that 'it is axiomatic that a . . . fair tribunal is a basic requirement of due process.'[169] A fair tribunal is one with a 'neutral and detached judge.'[170] '[A]n impartial decision maker is essential.'[171] Indeed, the neutrality of the decision maker is widely thought to be the most important part of due process.[172]

Perhaps the most significant fairness problem with *TADA* is its delegation of decision making power to the hospital's very own internal review committee. Since the committee is comprised of hospital clinicians and administrators, it is hardly a neutral and independent decision maker.[173] It is 'predisposed' to find for the hospital.[174]

In one survey of 200 Texas hospitals, 56 per cent reported having a 'medical appropriateness review committee distinct from their ethics committee.' Half of these committees had five or fewer members.[175] Most were wholly comprised of physicians and hospital administrators. Hardly any included community representatives. There is a significant risk that such committees may be biased towards the interests of hospital management.[176]

Harvard Professor Robert Truog has lamented the *TADA* review committee's lack of neutrality in a long series of prominent articles. 'This is hardly an impartial tribunal.'[177] He has observed that review committee members 'are unavoidably "insiders".'[178] Truog is concerned that *TADA* 'gives an unwarranted amount of power to the clinicians and hospitals over patients and families who

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Clinic Proceedings 943.
[169] Caperton v AT Massey Coal Co, 556 US 868 (2009).
[170] *Ward v Monroeville*, 409 US 57, 61-62 (1972).
[171] *Goldberg v Kelly*, 397 US 254, 271 (1970).
[172] *Hamdi v Rumsfeld*, 124 S Ct 2633 (2004).
[173] Cameron Stewart, 'Futility Determination as a Process: Problems with Medical Sovereignty, Legal Issues and the Strengths and Weaknesses of the Procedural Approach' (2011) 2(1) *Journal of Bioethical Inquiry* 4; O'Callaghan, above n 157, 596-99.
[174] *Marshall v Jerrico*, 446 US 238, 242 (1980).
[175] Smith et al, above n 127.
[176] Morten Magelssen, Reidar Pedersen and Reidun Førde, 'Sources of Bias in Clinical Ethics Case Deliberation' (2014) 40 *Journal of Medical Ethics* 678.
[177] Truog, above n 121, 1000.
[178] Truog, above n 40, 2.

hold unpopular beliefs or values.'[179]

Truog argues that *TADA*'s placement of the life-and-death decision in the hands of hospital review committees is too-provider friendly because '[m]ost of these committee members are doctors, nurses, and other clinicians from the hospital community... [thus] involvement of the hospital ethics committee fails to bring the diversity of the community into the deliberative process.'[180] It runs the risk of 'becoming a rubber-stamp mechanism' that does not respect diversity.[181]

Truog is not alone. I have also warned of the dangers of giving life and death adjudicatory power to hospital committees.[182] I will not repeat those arguments here. Suffice it to say that hospital review committees are overwhelmingly internal and intramural bodies. They are comprised of professionals employed directly or indirectly by the very same institution whose decision the review committee adjudicates. When the decision maker has a pecuniary interest in the outcome, it is not sufficiently neutral and independent.[183]

Committee members cannot be fair and impartial when the propriety of administering expensive LSMT must be weighed against a financial loss to the very hospital that provides those committee members with privileges and a source of income.[184] 'Actual futility cases are almost always intertwined with questions about saving money.'[185] Uninsured patients are more likely to be perceived as receiving futile treatment.[186] Even *TADA*'s staunchest supporters concede: 'I can't promise you there's not some rogue hospital or committee out there.'[187] Indeed, there have been specific allegations of corruption.[188]

For example, Kalilah Roberson-Reese underwent a cesarean section at Memorial Hermann Hospital in Houston. But amniotic fluid began to leak into her lungs, forcing providers to put her on a ventilator. Later, her tracheal tube fell out and she went without oxygen for twenty minutes, which caused serious brain damage.[189] Within days, the hospital initiated the *TADA* dispute

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[179] Jeffrey P Burns and Robert D Truog, 'Futility: A Concept in Evolution' (2007) 132 *Chest* 1987, 1991.
[180] Robert D Truog, 'Counterpoint: The Texas Advance Directives Act Is Ethically Flawed: Medical Futility Disputes Must Be Resolved by a Fair Process' (2009) 136 *Chest* 968, 969.
[181] Robert D Truog, 'Rebuttal from Dr. Truog' (2009) 136 *Chest* 972, 972-73.
[182] Thaddeus M Pope, 'Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism' (2009) 31 *Campbell Law Review* 257; Thaddeus M Pope, 'The Growing Power of Healthcare Ethics Committees Heightens Due Process Concerns' (2014) 15 *Cardozo Journal of Conflict Resolution* 425.
[183] See, eg, *Ward v Monroeville*, 409 US 57, 61-62 (1972); *Tumey v Ohio*, 273 US 510, 523 (1927); *Gibson v Berryhill*, 411 US 564, 579 (1973).
[184] *Gonzales v Seton Family of Hospitals*, No. A07CA267 para 47 (WD Tex Filed 4 April 2007).
[185] Truog, above n 121, 990.
[186] Thanh H Neville et al, 'Differences Between Attendings' and Fellows' Perceptions of Futile Treatments in the Intensive Care Unit at One Academic Health Center: Implications for Training' (2015) 90(3) *Academic Medicine* 324, 327.
[187] Selby, above n 150.
[188] See, eg *Davis v Memorial Hermann Hosp*, No 2009-07079 (Harris Cty Dist Ct, Tex Feb 4, 2009) (Order granting TRO); *Dunn v Methodist Hosp*, No 2015-69681 (Harris Cty Dist Ct, Tex Dec 4, 2015) (Order of abatement); Mimi Swartz, 'Not What the Doctor Ordered', *Texas Monthly* (Texas) March 1995; *Estate of Bland v CIGNA Health Plan of Texas*, No 93-52630A (Harris Cty, Tex 1995).
[189] Todd Ackerman, '"Texas" Patient Care Law at Hub of Houston Dispute', *Houston Chronicle* (Houston), 9 July 2006, A1.

resolution procedures. But the review committee was conflicted. The patient had exhausted her Medicaid benefits and it appeared that the hospital was trying to 'bury mistakes' and avoid exposure both to liability and to uncompensated treatment.[190] Another case from the same hospital involved similar allegations. The family of Sabrina Martin alleged that 'Memorial Hermann and the doctors and nurses working on the case utilised the *TADA* process because they 'wanted Sabrina to die to bury the evidence of malpractice and limit the potential damages in court.'[191]

To address the review committee's lack of neutrality, some have proposed mandating certain minimum composition requirements. One example is to require that the review committee include 'significant membership external to and outside the hospital.'[192] One Australian court recommended that since such a hospital review committee should have 'independence … from the treating doctors … it would probably need to have interstate members.'[193]

Other specific membership composition solutions include making at least one quarter of the committee non-hospital staff, or mandating the inclusion of members from disability and aging advocacy organisations. More radically, hospitals could use an entirely independent and external oversight committee otherwise unconnected to the hospital.[194] The key goal is to balance between embeddedness and detachment.[195]

B TADA *Lacks Appellate Review*

In addition to a neutral decision maker, the US Supreme Court has also held that procedural due process requires 'meaningful appellate review.'[196] Review is deemed 'meaningful' if it prevents the arbitrary deprivation of life or liberty. If a court or state agency could review the decision of the hospital review committee, such review could largely 'cure' the neutrality problem.[197]

But *TADA* has a real accountability problem. It denies substantive judicial or agency review, making the hospital committee the forum of last resort.[198] A court may only grant a definite extension of time. And it may do even that only when there is a preponderance of evidence that a transfer will be accomplished.[199] This means that *TADA* gives hospitals near-absolute (unreviewable) power over when to terminate treatment.[200]

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[190] *Texas Right to Life v Memorial Hermann Healthcare System*, No 365099-401 para 17 (Harris County Probate Court, Tex, July 5, 2006) (Petitioner's Original Petition for Declaratory Judgment, Temporary Restraining Order and Motion to Extend Time).
[191] Chris Vogel, 'Doctors v Parents: Who Decides Right to Life?' *Houston Press* (Houston), 29 April 2008 <http://www.houstonpress.com/2008-05-01/news/doctors-vs-parents-who-decides-right-to-life/>.
[192] Smith et al, above n 127, 1274.
[193] Inquest into the death of Paulo Melo [2008] NTMC 080.
[194] Diane Coleman, *Disability Rights Leadership Institute on Bioethics* (April 2014) <http://dredf.org/drlib/wp-content/uploads/sites/5/2014/06/DRLIB-Withholding-of-Treatment.ppt>.
[195] Magelssen, Pedersen and Førde, above n 176.
[196] *Parker v Dugger*, 498 US 308, 321 (1991).
[197] Bosslet et al, above n 18, 1325.
[198] Truog, above n 40, 2.
[199] See above IV C 7.
[200] Painter, above n 112.

Some have suggested that courts can review hospital committee decisions under *TADA*.[201] But the dominant position is that substantive judicial review is not available.[202] '*TADA* immunises all denials of LSMT under its review process, whether they are entirely arbitrary, negligent, reckless, or made with malice and the intent of harming or killing the patient.'[203]

This is the better reading for two reasons. First, the legislative purpose and intent was to provide the legal certainty and finality that the Houston protocol lacked. Second, this interpretation is well-supported in formal executive, judicial, and legislative branch interpretations.[204]

When *TADA* first went to Governor Bush in 1997, he vetoed the bill because it 'eliminate[d] the objective negligence standard for reviewing whether a physician properly discontinued the use of [LSMT]. And replaces it with a subjective good faith standard.'[205] In one of the rare cases in which a case was litigated, the court refused to reach the substantive question of whether LSMT was appropriate. It found submitted medical evidence 'irrelevant' since the 'hospital's ethics committee has determined the care is inappropriate.'[206]

The state legislature has also confirmed that the role for the courts is a narrow one. 'The court considers whether another provider who will honor the patient's directive is likely to be found; it does not address the issue of whether the decision to withdraw life support is valid.'[207]

External oversight is essential. But that does not mean the appropriateness of LSMT should be determined by courts instead of hospital review committees. There is broad consensus that courts lack the requisite expertise and responsiveness necessary to engage in *de novo* review of these medical treatment decisions.[208]

On the one hand, *TADA* provides appellate review that is too little. On the other hand, a non-deferential and more detailed review would be too much. We must aim for a middle ground. Fortunately, we can look to well-established rules used in judicial review of agency actions. One particularly relevant model is the Health Care Quality Improvement Act ('HCQIA').[209]

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[201] Mayo, above n 50, 1010-13; Anne L Flamm, 'The Texas "Futility" Procedure: No Such Things as a Fairy-Tale Ending' (2004) Lahey Clinical Medical Ethics Journal.

[202] Todd Ackerman, 'Care Can End in Two Days: Family of Man on Life Support to Fight Ruling', Houston Chronicle (Houston) 1 March 2005; In re Nikolouzos, 162 SW 3d 678, 682 (Tex App 2005) (Fowler J, concurring); Halevy and McGuire, above n 45; Lightfoot, above n 36, 854; Fine, above n 46, 146; Gonzales v Daughters of Charity Health Services of Austin, No 86247 (Travis County Probate Court, Tex May 4, 2007) (Medical Defendants' Reply Brief in Further Support of their Opposition to Application for Temporary Restraining Order) 2; O'Callaghan, above n 157, 539 and 545; Cynthia S Marieta, The Debate Over The Fate of the Texas 'Futile-Care' Law: Is It Time for Compromise 3 <law.uh.edu/healthlaw/perspectives/2007>; Truog, above n 121.

[203] Anne L Flamm, 'Is the Baby in the Bathwater? A Defining Moment for the Texas Advance Directives Act Review Process for Medical Futility Judgments' (2008) 18 Health Matrix 229.

[204] Zerwas, above n 70, 179.

[205] Tex Legis J 4926 (June 20, 1997), vetoing Tex S Bill 414, 76th Leg (1997); see also House Committee on Public Health, Texas House of Representatives, Interim Report 2006 (Nov 15 2006) 33, 34.

[206] Nikolouzos v St Luke's Episcopal Hosp, 162 SW 3d 678, 683 (Tex App 2005).

[207] Interim Report, above n 205, 35.

[208] Meisel, Cerminara and Pope, above n 6.

[209] 42 USC §§ 11101-52.

When hospitals review their physicians in a manner consistent with the same procedural due process principles described here, they have immunity from civil money damages. So, if a hospital, with adequate notice and hearing procedures, took action that adversely impacted a physician's clinical privileges or membership in a professional society, that physician would have no monetary claim against the hospital. A court reviewing the hospital's actions would determine only if the hospital followed fair procedures and whether its decision is supported by substantial evidence. If so, the court would not reach the merits of the underlying matter.[210]

C TADA *Affords Inadequate Notice*

In addition to having a neutral decision maker and appellate review, another 'elementary and fundamental requirement of due process' is notice.[211] Notice must be 'reasonably calculated, under all the circumstances, to apprise interested parties of the pendency of the action and afford them an opportunity to present their objections.'[212] Notice must reasonably convey this information. And it must afford a reasonable time for those interested to make their appearance.[213]

The surrogate must have an opportunity to acquaint herself with the facts of the case.[214] But *TADA*'s 48 hours allows insufficient time for the surrogate: (a) to obtain the medical records, (b) to consult with an expert, and (c) to meaningfully prepare for the review committee meeting.[215]

As significant legislative activity between 2007 and 2015 demonstrates, the short notice periods in *TADA* have been a central focus of reformers.[216] 'Civil libertarians and patient rights advocates argue that [*TADA* fails to] provide sufficient time for the complicated and technical requirements that are thrust onto the patient and family.'[217] Those who represent patients report that the 48-hour period is 'extremely difficult.'[218] Even key authors of *TADA* support more notice.[219]

In one case that challenged the validity of *TADA* under federal law, the court appointed a guardian *ad litem* for a patient, Stephen Jody Helman. Mr Helman submitted a fifty-page trial brief to the court observing that *TADA* 'is by no means perfect and could certainly be improved to make it fairer and less burdensome to patients and their representatives.'[220] Mr Helman pointed specifically to the 'short notice period.'[221]

In practice, hospitals may exceed the minimum notice requirements.[222] For example, one study

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[210] Gabaldoni v Washington County Hospital Association, 250 F 3d 255 (4th Cir 2001).
[211] Mullane v Central Hanover Bank & Trust, 339 US 306, 314 (1950).
[212] Ibid.
[213] Ibid.
[214] Powell v Alabama, 287 US 45, 59 (1932).
[215] Bob Deuell, 'Respecting Every Life', Dallas Morning News (Dallas) 2 April 2007.
[216] See, eg SB 439 (2007) (Deuell); HB 3474 (2007) (Delisi); SB 303 (2013) (Deuell).
[217] Painter, above n 112.
[218] Mary Ann Roser, 'Futility Law Gives Doctors too Much Power, Groups Charge', Austin American Statesman (Austin) 8 May 2006.
[219] Mayo, above n 50, 1016.
[220] Gonzales v Daughters of Charity Health Services of Austin, No 86,427 (Travis County Probate Court, Tex Mar 6, 2007) (Guardian Ad Litem's Trial Brief on Legal Issues, 35).
[221] Ibid 35, n 17.
[222] Craig Myers, 'Section 166.046 of the Texas Futile Care Law: Supplying Health Care providers a Procedural

suggests that the average notice given to a surrogate prior to a review committee meeting was 7.9 days.[223] But nothing in *TADA* requires more than the 48-hour 'floor.' Some hospitals offer no more. Indeed, hospitals sometimes provide notice on a Friday afternoon for a Monday morning meeting.[224]

D TADA *Fails to Assure a Meaningful Statement of Decision*

While perhaps not in the same hierarchy as a neutral decision maker, appellate review and notice; another core element of procedural due process recognised by the US Supreme Court is a 'written statement' of decision.[225]

This requirement serves several purposes. First, it helps assure that a factual basis supports the deprivation (or dispossession) of life, liberty, or property.[226] Second, it enables the affected individual to understand the grounds for the deprivation.[227] Third, it provides a record upon which to prepare for appeal. By enabling an appellate tribunal to review the review committee's reasons, a written statement that sets out all the relevant facts and evidence protects against arbitrary and capricious deprivations.

Unfortunately, *TADA* places no requirements on the extent of the explanation provided. While some hospitals provide detailed explanations, others do not.[228] In one case, the hospital used a preprinted single-page form titled 'Decision of the Committee for the Determination of Inappropriate/Futile Treatment.' The form includes no field for an explanation of why the review committee judged interventions to be inappropriate. And no reasons or explanations are provided.[229]

Hospital review committees 'like judges, will give more careful consideration to the problem if they are required to state not only the end result of their inquiry, but the process by which they reached it.'[230] Requiring a more complete written decision sharpens the decision makers' internal

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Framework Regarding a Difficult Decision' Health Industry Online (Strasburger) 18 October 2006; Andy Hogue, 'Hughes Bill Tackles End of Life Dilemmas', Dallas Blog (Dallas), 20 April 2009; 'Texas Act Formalizes Ethics Committee Role in Disputes', Medical Ethics Advisor, 1 April 2006; Mayo, above n 50, 1015.

[223] Email from Lance Lunsford, vice president for advocacy communications, Texas Hospital Association, 21 May 2014, cited and linked as a source; W Gardner Selby, 'Texas Right to Life exaggerates on claim of "faceless hospital panel" determining treatment' 30 May 2014, <http://www.politifact.com/texas/statements/2014/may/30/texas-right-life/texas-law-gives-hospital-panels-sway-over-cutting-/>.

[224] *Gonzales v Seton Family of Hospitals*, No. A07CA267SS para 24 (WD Tex Apr 4, 2007) (Complaint); *Texas Right to Life v Memorial Hermann Healthcare System*, No. 365099-401 para 7 (Harris County Probate Court, Tex, July 6, 2006) (Petitioner's Original Petition for Declaratory Judgment, Temporary Restraining Order, and Motion to Extend Time).

[225] *Morrissey v Brewer*, 408 US 471, 489 (1972).

[226] *Black v Romano*, 471 US 606, 614 (1985).

[227] *Haymes v Regan*, 525 F2d 540, 544 (2d Cir 1975).

[228] *Gonzales v Seton Family of Hospitals*, No A07CA267 (WD Tex Filed 4 April 2007) (Complaint) (Exhibit B to Affidavit of Catarina Gonzales (Feb 19, 2007)) & Exhibit D to Affidavit of Catarina Gonzales (Mar 9, 2007)).

[229] *Texas Right to Life v Memorial Hermann Healthcare System*, No 365099-401 (Harris County Probate Court, Tex, July 6, 2006) (Exhibit A to Petitioner's Original Petition for Declaratory Judgment, Temporary Restraining Order, and Motion to Extend Time). See also *Davis v Memorial Hermann Healthcare System*, No 2009-07079 (Harris County District Court, Tex (Feb 4, 2009) (Petition); see also Robert L Painter, 'Introduction to the Texas Advance Directives Act' <https://www.youtube.com/watch?v=TlX4J0TQFwY>.

[230] *United States v Merz*, 376 US 192, 199 (1964).

thought processes.[231] Moreover, written statements of decision show families that the committee seriously considered their arguments and facilitates judicial review.

What exactly review committees should include in their written statements of decision brings us to the next due process concern.

E TADA *Fails to Provide Criteria to Guide Committee Review*

Closely related to *TADA*'s failure to assure a meaningful statement of decision is its failure to provide any criteria to guide the review committee. The Supreme Court has warned about vague statutes that fail to provide explicit standards for those who apply them. Such statutes increase the risk that the decision maker will resolve the case 'on an ad hoc and subjective basis with the attendant dangers of arbitrary and discriminatory application.'[232]

This risk is especially high with *TADA*. Not only does *TADA* have no oversight, monitoring, or accountability but it also has no consistency or standardisation.[233] Without any guidepost anchors or criteria, there may be significant variability both in when and how hospitals invoke *TADA*. Enormous variability has already been well-documented across US intensive care units.[234] Moreover, this variability is expressly presumed by the transfer requirement.

The statute neither contains nor suggests any ascertainable standard for determining the propriety of continuing LSMT.[235] This creates three problems. First, it means that the decisions of review committees may not be as informed or reasoned as necessary. Second, the lack of guiding standards means that a single hospital review committee may disparately treat similarly situated patients. Third, it means that review committees at different hospitals may be deciding similar cases differently.

Now, the reader may ask how *TADA* could include substantive criteria, when its very genesis lies in the inability of clinicians and philosophers to identify any such criteria. First, illegitimate bases for refusing treatment (such as the patient's race) could be specifically excluded. Second, while a universal definition of 'futility' has proven elusive, specific futile scenarios have garnered widespread support.

For example, many clinicians deem LSMT inappropriate: 1) when the burdens of treatment significantly outweigh the benefits, 2) when treatment can never achieve the patient's goals; 3) when death is imminent, 4) when the patient will never be able to survive outside of an ICU, and

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[231] Douglas E Abrams, 'But "Will It Write?" How Writing Sharpens Decision-Making' (2009) 3(2) *Precedent* 61.
[232] *Grayned v City of Rockford*, 408 US 104, 108-09 (1972).
[233] Testimony of Colleen Horton on SB 439 (2007) (211:10).
[234] Dominic J Wilkinson and Robert D Truog, 'The Luck of the Draw: Physician-Related Variability in End-of-Life Decision-making in Intensive Care' (2013) 39(6) *Intensive Care Medicine* 1128.
[235] *Gonzales v Seton Family of Hospitals*, No A07CA267 para 48 (WD Tex Filed 4 April 2007); Maureen Kwicinski, 'To Be or Not to Be, Should Doctors Decide? Ethical and Legal Aspects of Medical Futility Policies' (2012) 7(2) *Marquette Elder's Advisor*, 313, 349; O'Callaghan, above n 157, 529, 543, 564-66 and 589-96; David M Zientek, 'The Texas Advance Directives Act of 1999: An Exercise in Futility' (2005) 17(4) *HEC Forum* 245; Heitman and Germillion, above n 76.

5) when the patient is permanently unconscious.[236]

These principles cannot be automatically or mechanically applied in an algorithmic fashion. But neither must they be wholly disregarded. These and similar definitions, rules, and paradigm cases can productively inform and guide review committee deliberation and analysis.

F *Other Due Process Concerns*

While the above five elements of procedural due process are those that present the most serious problems with *TADA*, they are not the only ones.[237] The quality of *TADA* review committee decisions is also materially adversely affected by: 1) the review committee's lack of diverse membership, 2) the review committee's lack of training and competence, 3) the absence of standard meeting and hearing procedures, and 4) the absence of a requirement assuring the surrogate's participation.

First, *TADA* omits several key issues relating to the review committee.[238] In stark contrast to federal regulations governing Institutional Review Boards in the research context, *TADA* includes no details or guidelines concerning how a hospital composes its ethics committee.[239] *TADA* is silent as to: a) the overall number of committee members required, b) the inclusion of members from different professional disciplines c) the inclusion of lay or community members, and d) the inclusion of members with different gender, race, and disability status.[240]

Second, *TADA* is silent as to the training or qualifications of the review committee members.[241] Many bioethics leaders have expressed "growing concern" about the practice of healthcare ethics consultation and how it is practiced.[242] The field is moving toward certification based on educational achievements and examination performance. Here, where the review committee acts as a decision maker, not as a mere advisor or consultant, the need to assure that it has the right knowledge and skills is even higher.

Third, *TADA* fails to define the 'rules by which an ethics committee must operate.'[243] Committees have neither quorum requirements nor a system of review.[244] They do not report whether their decisions are unanimous or by a slim majority or whether dissent existed.[245] Some surrogates have

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[236] Thanh N Huynh et al, 'The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care' (2013) 173(20) *JAMA Internal Medicine* 1887.
[237] The right to representation by counsel is another essential element of a fair hearing. *Thompson v Board of Education of Henderson County*, 838 SW 2d 390, 393 (Ky 1992). But TADA also does not assure the surrogate a right to have legal counsel present.
[238] Testimony of Michael Rieger before House Committee (April 25, 2007) (446:00); Texas Hospital Association, *Key Messages on Texas Advance Directives Act*; Heitman and Gremillion, above n 76, 95; Fine and Mayo, above n 147, 744.
[239] 45 CFR § 46.107.
[240] Painter, above n 112, 20; Zientek, above n 235, 253-54.
[241] Texas Act Formalizes Ethics Committee Role in Disputes, Medical Ethics Advisor (1 April 2006).
[242] Ellen Fox, 'Developing a Certifying Examination for Health Care Ethics Consultants: Bioethicists Need Help' (2014) 14(1) *American Journal of Bioethics* 1.
[243] Fine, above n 46, 146.
[244] Robert's Rules of Order Newly Revised (11th ed Da Capo Press, 2011).
[245] Hearing before Texas HR Comm on Public Health Interim Rep, 80th Legis (2006) (Statement of Richard Mullin).

even reported that they were stopped in the hall of the hospital, and later learned that brief and informal encounter constituted the review committee meeting.[246]

Fourth, the 'right of confrontation and cross-examination is an essential and fundamental requirement' of due process.[247] But *TADA* assures only the surrogate's right to 'attend' the meeting. It does not assure the surrogate a right to ask questions of the attending physician.[248] Many hospitals voluntarily allow this.[249] But there is no provision in *TADA* that guarantees the right.

VII CONCLUSION

Striking the right balance between efficiency and fairness is difficult. These two goals are in tension. Dispute resolution procedures that better achieve one goal entail a tradeoff that correspondingly disrespects the other. On the one hand, the cost of less process is undermining deeply held principles of fundamental fairness.[250] On the other hand, the cost of more process is maintenance of the status quo, the continued administration of potentially non-beneficial treatment.[251]

TADA is a commendable attempt to 'steer a course between the Scylla of judicial review and the Charybdis of unfettered, unexamined physician discretion.'[252] But *TADA* places too much weight on efficiency at the cost of fairness.

The recalibration that I have defended in this article would not change the fundamental power of hospital review committees to authorise the withholding or withdrawal of inappropriate LSMT. Instead, the changes would be minor, affecting only 1) who is on the review committee, 2) how the committee conducts its meeting and makes its decision, and 3) the extent to which that decision can be reviewed. If *TADA* is used as infrequently as recent reports indicate, the costs of more process are circumscribed and determinate. This is a small price to pay to properly respect notions of due process, fundamental fairness, and fair procedure.

See also, Hearing before Texas HR Comm on Public Health, 80th Legis (2007) (Statement of Gregory Hooser); Hearing before Texas HR Comm on Public Health, 80th Legis (2007) (Statement of Colleen Horton, Univ of Tex Ctr for Disabilities Studies).

[246] Testimony of Robert Painter on SB 439 (2007) (261:20); Texas Health & Safety Code § 161.031(b).

[247] *Lee v Illinois*, 476 US 530, 540 (1986).

[248] *Gonzales v Seton Family of Hospitals*, No A07CA267 para 46 (WD Tex Filed 4 April 2007); Testimony of Adam Black on SB 439 (2007) (269:30).

[249] *Gonzales v Seton Family of Hospitals*, No A07CA267 (WD Tex Filed 4 April 2007) (Complaint, Exhibit A to Affidavit of Catarina Gonzales).

[250] Truog, above n 121.

[251] Stewart 2011, above n 173.

[252] Mayo, above n 50, 1010.

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FUTILITY AND THE LAW: KNOWLEDGE, PRACTICE AND ATTITUDES OF DOCTORS IN END OF LIFE CARE

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Despite the potential harm to patients (and others) and the financial cost of providing futile treatment at the end of life, this practice occurs. This article reports on empirical research undertaken in Queensland that explores doctors' perceptions about the law that governs futile treatment at the end of life, and the role it plays in medical practice. The findings reveal that doctors have poor knowledge of their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the end of life; their attitudes towards the law were largely negative; and the law affected their clinical practice and had or would cause them to provide futile treatment.

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I INTRODUCTION

Futile treatment, which is treatment that brings no benefit to a patient,[1] is a concerning issue in end of life care. Research from other countries suggests that dying patients receive futile treatment for a number of reasons, including fear of legal liability, and disputes between the patient or family and doctors over whether active treatment should continue.[2] The provision of futile treatment is problematic because it does not benefit a patient, can cause harm through unnecessary pain or discomfort and can prevent a 'good death'.[3] The provision of futile treatment can also cause distress to families and treating health professionals.[4] Doctors play a critical role in making decisions about whether or not to persist with treatment that is futile.[5] When doctors make decisions about whether or not to withhold or withdraw treatment at the end of life, they do so, knowingly or unknowingly, within a broader regulatory framework of laws and policies.

Despite the adverse outcomes associated with futile treatment, there has been no empirical research in Australia investigating why doctors provide such treatment, including the role the complex legal environment plays in their decisions to provide it. The extent to which doctors are aware of or are influenced by the law on futile treatment in the course of their clinical practice is not clear. A recent large-scale survey suggests that doctors lack accurate knowledge about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity.[6] One of the aims of this research is to explore doctors' understanding of the law that governs the provision of futile treatment at the end of life, and whether they believe it will support them in their decision-making.

The research findings reported in this article form part of a larger project, which explores how doctors understand futile treatment, why and how often they provide it (including the impact of laws and policies), and the cost of doing so. Data for this stage of the project were collected through a series of in-depth interviews with doctors at three public hospitals.

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[1] National Health and Medical Research Council, *An Ethical Framework for Integrating Palliative Care Principles into the Management of Advanced Chronic or Terminal Conditions* (September 2001), 17 <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/rec31_ethical_framework_palliative_care_terminal_110908.pdf>.

[2] See eg Robert Sibbald, James Downar and Laura Hawryluck, 'Perceptions of "Futile Care" Amongst Caregivers in Intensive Care Units' (2007) 177(10) *Canadian Medical Association Journal* 1201; Valerie Palda et al, '"Futile" Care: Do We Provide It? Why? A Semi-Structured, Canada-wide Survey of Intensive Care Unit Doctors and Nurses' (2005) 20(3) *Journal of Critical Care* 207; Seth Rivera et al, 'Motivating Factors in Futile Clinical Interventions' (2001) 119 *Chest* 1944.

[3] Richard Smith, 'A Good Death' (2000) 320 *British Medical Journal* 129.

[4] Randall J Curtis and Robert A Burt, 'Why Are Critical Care Clinicians So Powerfully Distressed by Family Demands for Futile Care?' (2003) 18(1) *Journal of Critical Care* 22.

[5] Ben White et al, 'The Legal Role of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 1 (New South Wales)' (2011) 18 *Journal of Law and Medicine* 498; Lindy Willmott et al, 'The Legal Role Of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 2 (Queensland)' (2011) 18 *Journal of Law and Medicine* 523 ('The Legal Role Of Medical Professionals (Queensland)'); Lindy Willmott et al, 'The Legal Role Of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 3 (Victoria)' (2011) 18 *Journal of Law and Medicine* 773 ('The Legal Role Of Medical Professionals (Victoria)').

[6] Ben White et al, 'Doctors' Knowledge of the Law on Withholding and Withdrawing Life-Sustaining Medical Treatment' (2014) 201(4) *Medical Journal of Australia* 229.

The primary goal of this article is to present what these interviews revealed about doctors' knowledge of and attitudes to the law on futile treatment at the end of life, for patients with and without capacity. Prior research demonstrates that doctors who know the law are more likely to protect patients' rights and less likely to practise defensive medicine.[7] It is also important that doctors know the law to protect themselves against legal sanction. Further, doctors who have positive attitudes towards the law might be more open to knowing and complying with it. To provide context for these findings, Part II of the article describes the law in Queensland. This is important because the law in Queensland is particularly complex, and presents a challenge to doctors who regularly grapple with end of life decision-making in practice. In Queensland, a doctor's authority to cease futile treatment unilaterally (that is, without obtaining consent) turns on whether or not a patient has the capacity to make a treatment decision, and therefore whether the situation is governed by the common law or guardianship legislation, respectively. Part III then details the interview method, including recruitment, sample, and qualitative analysis techniques. Part IV presents the results of doctors' knowledge of the law on futile treatment, their attitudes towards it and the extent to which they report that the law affects their clinical practice. The article concludes with recommendations for law reform and education to address issues raised by the results.

II QUEENSLAND LAW

A *General Duties To Provide Medical Treatment*

In Queensland, as in most (if not all) common law jurisdictions, duties are imposed on doctors to provide medical treatment in certain circumstances. Some of these are civil law obligations. For example, a doctor is required by the general law of negligence to use reasonable care and skill when making treatment decisions in relation to his or her patient.[8] If withholding or withdrawing life-sustaining treatment falls short of reasonable care, then that duty may be breached. The criminal law also gives rise to duties to provide life-sustaining treatment in certain circumstances. The duty that has been identified in Queensland as the principal source of potential criminal responsibility for those involved in decisions to withhold or withdraw life-sustaining treatment is that imposed by section 285 of the *Criminal Code* (Qld) to provide the 'necessaries of life'.[9] That duty will arise if a doctor has the care or charge of a person, and that person is unable to care for him- or herself.[10]

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[7] Ibid.

[8] *Rogers v Whitaker* (1992) 175 CLR 479; see also Des Butler, Tina Cockburn and Jennifer Yule, 'Negligence' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) 255 for more detail on the content of this duty and how civil liability legislation has altered, and in some instances, replaced, the common law.

[9] See eg, *Re RWG* [2000] QGAAT 2, [55]-[63]; *Re HG* [2006] QGAAT 26, [101]-[107]; *Re SAJ* [2007] QGAAT 62, [54].

[10] For further discussion of this provision and its possible application in the end of life setting, see Ben White, Lindy Willmott and John Allen, 'Withholding and Withdrawing Life-Sustaining Treatment: Criminal Responsibility for Established Medical Practice?' (2010) 17 *Journal of Law and Medicine* 849.

B *Treatment Being 'Futile' Relieves These Duties*

Under the common law, a determination by a doctor that treatment is 'futile' relieves him or her of these duties to provide it. This is so even if the adult patient or his or her family wants treatment to be provided. The courts have relied on two alternative approaches in reaching this conclusion. The first is that there is no duty to provide futile treatment because doing so would not be in the patient's best interests.[11] Where a patient is an adult who lacks capacity, and the family wants to challenge this decision, the matter could be decided by the Supreme Court exercising its *parens patriae* jurisdiction. If the Court, in assessing a patient's best interests, agrees with the doctor's assessment of futility, it will not interfere with the proposed non-treatment plan. A similar position arises where the patient is an adult with capacity, as the courts have concluded that a person cannot demand treatment that is not clinically indicated.[12]

The second approach is that not providing treatment that is futile would not breach the doctor's obligation under the criminal law to provide the necessaries of life. If treatment is futile, it could not be regarded as a 'necessary of life'.[13] Further, even if the medical treatment were regarded as a necessary of life, it might be argued that there is a 'lawful excuse' for not providing the treatment if such a course would be consistent with good medical practice.[14]

C *Guardianship Legislation Changes This Position In Queensland*

In Queensland, the legal landscape described above was altered for adults lacking capacity, as a result of the enactment of guardianship legislation which is comprised of the *Powers of Attorney Act 1998* (Qld) *('PAA')* and the *Guardianship and Administration Act 2000* (Qld) *('GAA')*.[15] This is because, under the *GAA* and *PAA*, 'health care' is defined to include withholding and withdrawal of a life-sustaining measure if the commencement or continuation of the measure would be inconsistent with good medical practice.[16] As not providing treatment is 'health care', consent must be obtained from a substitute decision-maker (or other authority) for treatment to be withheld or withdrawn.[17] This is the case even if the life-sustaining measure is regarded as futile.

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[11] *Application of Justice Health; Re a Patient* [2011] NSWSC 432, [2]; *Melo v Superintendent of Royal Darwin Hospital* (2007) 21 NTLR 197, [27]; *In the matter of Herrington; Re King* [2007] VSC 151, [24]; *Messiha v South East Health* [2004] NSWSC 1061, [26] and [28]. For a consideration of 'best interests' in the context of decisions to withhold and withdraw treatment from individuals who lack decision-making capacity, see Lindy Willmott, Ben White and Malcolm K Smith, '"Best Interests" and Withholding and Withdrawing Life-Sustaining Treatment from an Adult Who Lacks Capacity in the Parens Patriae Jurisdiction' (2014) 21(4) *Journal of Law and Medicine* 920.

[12] *R (on the application of Burke) v The General Medical Council* [2006] QB 273, 301-302.

[13] While there is no direct Queensland authority for this proposition, it is likely that the same approach would be taken to this issue as the New Zealand High Court in *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235.

[14] Again, there is no direct Queensland authority, but it is possible to advance the reasoning regarding 'lawful excuse' which was applied by the New Zealand High Court in *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235. For a more detailed discussion of Queensland's criminal law framework in the context of decisions about life-sustaining treatment, see White, Willmott and Allen, above n 10.

[15] Cf the law in the other Australian jurisdictions, which reflects the common law. See Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and Withdrawal of 'Futile' Life-Sustaining Treatment: Unilateral Medical Decision-Making in Australia and New Zealand' (2013) 20(4) *Journal of Law and Medicine* 907.

[16] *GAA*, Sch 2, s 5(2). See also the definition of 'life-sustaining measures': *GAA*, Sch 2, s 5A.

[17] Section 79 of the *GAA* makes it an offence for a health provider to carry out 'health care' for an adult with impaired capacity unless the appropriate consent (or some other authorisation) is obtained.

Where the treating team and the family disagree about treatment (and the family refuses consent to withhold or withdraw the life-sustaining measure), various mechanisms are available under the legislation to resolve this dispute. In an appropriate case, a decision about whether to withhold or withdraw treatment may be made by the Public Guardian (formerly the Adult Guardian),[18] the Queensland Civil and Administrative Tribunal[19] or the Supreme Court.[20]

Although there is considerable commentary on the operation of the legislation,[21] there is relatively little judicial or quasi-judicial authority on the operation of the legislation in the context of potentially futile treatment. Nevertheless, some observations were made about the Queensland framework in the 2009 Coronial decision, *Inquest into the case of June Woo.*[22] In that case, the Queensland State Coroner considered the above interpretation of the *GAA*, and concluded that 'the patient or a person authorised under the *GAA* must consent to the withholding of life-sustaining measures.'[23] Mrs Woo was 82 years of age and had a significant history of pulmonary fibrosis and chronic respiratory failure. She had lost capacity shortly after being admitted to hospital. A 'not for resuscitation' (NFR) order was made and so resuscitation was not attempted when she died a day later. While the Coroner concluded that Mrs Woo received appropriate medical care, he expressed concern about the decision-making process in relation to the NFR order. The treating doctor believed that resuscitation was futile and so 'did not consider the decision was one the relatives could consent or object to'.[24] However, given the legal position outlined above, this was not the case and the Coroner found that the order was not made with the family's consent as was required by the guardianship legislation. Although the Coroner concluded that by the time of Mrs Woo's death the family had given tacit consent to the NFR order, he noted that had she died at an earlier time and without that consent that 'significant legal consequences may have followed'.[25]

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[18] Pursuant to s 43 of the *GAA*, the Public Guardian is empowered to make a decision about a health matter if a substitute decision-maker refuses to make a decision or makes a decision that the Public Guardian believes is contrary to the health care principle. The 'health care principle' is set out in Schedule 1 of the legislation and requires the person making the decision to exercise power in a particular way including in a way that is least restrictive of the adult's rights and in the adult's best interests.

[19] Pursuant to ss 81(1)(f) and 115 of the *GAA*, the Tribunal can consent to the withholding or withdrawal of a life-sustaining measure if an application is brought before it.

[20] The *parens patriae* jurisdiction of the Supreme Court of Queensland is retained by s 240 of the *GAA* under which the Court could authorise the withholding or withdrawal of treatment. It is not an offence for a health provider to withhold or withdraw treatment on the basis of such authority: *GAA*, s 79(1)(c).

[21] There has now been a decade of academic and other commentary on this aspect of the law: see, eg, Ben White and Lindy Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (QUT Printing Services, Brisbane, 2005) 69-72 <http://eprints.qut.edu.au/7093/>; Willmott et al, 'The Legal Role of Medical Professionals (Queensland)', above n 5; Sean Lawrence et al, 'Autonomy Versus Futility? Barriers to Good Clinical Practice in End-Of-Life Care: A Queensland Case' (2012) 196(6) *Medical Journal of Australia* 404; Cameron Stewart, 'A Defence of the Requirement to Seek Consent to Withhold and Withdraw Futile Treatments' (2012) 196(6) *Medical Journal of Australia* 406; Willmott, White and Downie, above n 15; Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) 543, [14.240]; Malcolm Parker, 'Futile Choices: Wooing Doctors to Acknowledge the Law in Queensland' (2010) 18 *Journal of Law and Medicine* 32.

[22] *Inquest into the death of June Woo* (unreported, Queensland Coroner's Court, 1 June 2009).

[23] *Inquest into the death of June Woo* (unreported, Queensland Coroner's Court, 1 June 2009) 23.

[24] *Inquest into the death of June Woo* (unreported, Queensland Coroner's Court, 1 June 2009) 6.

[25] *Inquest into the death of June Woo* (unreported, Queensland Coroner's Court, 1 June 2009) 21.

Doctors' understanding of this legal complexity in Queensland and their attitudes about it have not been explored, nor has the extent to which they believe this law (or the law in general) affects their own practice with patients at the end of life. This study aims to address these knowledge gaps, and the next part of the article describes the way in which the data about legal knowledge, attitudes towards the law and the effect of law on medical practice was obtained and analysed.

III METHOD

A *Ethics*

Human research ethics committees at the Royal Brisbane & Women's Hospital (multi-centre approval), the Queensland University of Technology and the University of Queensland approved the research.[26] Protecting the confidentiality of the research participants was of utmost importance to the research team. A database that included names of research participants was kept during the recruitment period to ensure that invitations were not sent to people more than once. At the time of interview, participants were assigned a participant ID number. Interviews were digitally recorded and participants were encouraged not to mention names while the recorder was on. Once the interviews were transcribed, participants were given the opportunity to review their transcript and request amendments. When the final transcript was approved, the participant's name was removed from the database, leaving only the participant ID and demographic details.

B *Recruitment*

Doctors were recruited from three public hospitals in Brisbane, Queensland from specialties who routinely encounter patients at or near end of life. The recruitment strategy was developed in consultation with the Futility Research Group ('FRG'), a locally-based group of clinicians with research interests in futility. Purposive maximum variation sampling was used to recruit a wide variety of participants to obtain a diverse range of views.[27] This technique allowed the research team to build up a picture of futility by considering the perspectives of different specialists, and is particularly suitable for gaining an understanding of complex problems such as futile treatment at the end of life.

C *Sample Description*

Interviews were conducted with 96 doctors at the three participating hospitals. Table 1 shows the number of doctors from each specialty interviewed (listed in descending order).

Interviews were conducted with 68 men and 28 women. The sample was made up of experienced doctors; the vast majority of participants were consultants (87), and only 9 were registrars. This is because participants who had direct responsibility for making decisions about end of life care were actively sought. The sample spanned a wide range of ages from 30 to over 70, with a mean age of 49 years. The amount of time the doctors had spent working as a doctor in Australia ranged from

[26] Metro South Hospital and Health Service Human Research Ethics Committee, Approval number: HREC/13/QPAH/651; University of Queensland Medical Research Ethics Committee, Approval number: 2014000909; Queensland University of Technology UHREC Research Ethics Unit, Approval number: 1400000541.
[27] Michael Quinn Patton, *Qualitative Evaluation and Research Methods* (Sage, 2nd ed, 1990).

1 year to 49 years; the average amount of time was 19 years. Most interviews were conducted in the emergency, intensive care unit ('ICU'), palliative care and oncology departments (10-15 interviews in each), followed by renal, respiratory, internal medicine, surgery, cardiology, geriatrics and medical administration (4-9 interviews in each).

Table 1: Number of Doctors Interviewed By Specialty

DEPARTMENT	TOTAL
Emergency	15
ICU	12
Palliative care	10
Oncology	10
Renal	9
Respiratory	9
Internal medicine	9
Surgery	8
Cardiology	5
Geriatrics	5
Medical administration	4
TOTAL	**96**

D *Interviews*

The chief investigators prepared an interview guide (Appendix A), designed to address the key research questions and to allow the interviewer to follow up on ideas raised by the participant. The convergent interviewing technique was used.[28] This is a method of in-depth interviewing that is particularly useful when exploring issues that are difficult to define. The questioning strategy involves asking a general question at the beginning of the interview, in order to allow the participants to raise issues without prompting, before (where necessary) prompting for the topics specified in the interview guide. The convergent interviewing process also encourages analysis to occur throughout the data collection phase. The researchers' developing understanding is tested with each subsequent interview, by looking for convergence or divergence with previous interviewees on specific topics. Interviews are conducted until a stable pattern of agreements and disagreements is evident, and no new issues are revealed – a point known as saturation of ideas.[29]

In this study, a broad question about doctors' experience with futile treatment started the interview. Doctors were asked to recall one or more experiences of care or treatment provided, which in their view did not benefit the patient. In addition, they were asked to recall cases where futile treatment had been avoided, or cases where treatment was given that might be considered futile but, in their opinion, was beneficial. As they described and reflected on these experiences, the interviewer prompted them when appropriate about their understanding of the concept of futile treatment, their

[28] Robert Dick, *Convergent Interviewing* (Chapel Hill, 1990); Michelle Driedger et al, 'Finding Common Ground in Team-Based Qualitative Research Using the Convergent Interviewing Method' (2006) 16(8) *Qualitative Health Research* 1145.
[29] Dick, above n 28.

reasons for providing it, ways to avoid and reduce it, as well as how the legal and policy framework operated and whether or not it was helpful in these cases. At the end of the interview, doctors responded briefly to a hypothetical case in which there was family pressure to provide treatment that doctors believed did not benefit the patient. Following the format of convergent interviews, the doctors were encouraged to describe their experiences in as much detail as they could, and prompt questions were used only when interviewees did not address them spontaneously.

Doctors were very willing to give their views, and most described experiences of particular cases in great detail. The interviews took between 30 minutes and 2 hours, with the duration of most interviews being about an hour.

E *Analysis*

All interviews were transcribed verbatim, and the transcripts were imported into QSR International's NVivo qualitative data analysis software (Version 10). Initial analysis employed the framework approach. This is an analytic technique which combines thematic and case based analysis, using a systematic approach to summary and synthesis.[30] In addition to a more standard thematic analysis, a matrix was created by writing short summaries of what each participant said about themes of key interest to the investigators. This avoided the fragmentation that can result from using thematic analysis only. A matrix of summaries condensing the key themes raised by participants was brought along to team meetings for discussion. This process allowed the whole research team to be familiar with the main ideas emerging from the data, improving the analytical depth that could be achieved. Furthermore, new themes in addition to those explored in the interview guide emerged from the analysis.

To investigate doctors' knowledge of the law, most were asked whether or not they needed to obtain a patient or substitute decision-maker's consent before withholding or withdrawing life-sustaining treatment. Due to the nature of the interviews and time constraints, this question was explored in a variable amount of detail by different participants. Questions about legal issues and attitudes were asked in all interviews except two (the two initial interviews, before the investigators had refined the interview guide). These two interviews were excluded from the analysis in Part IV below.

Slightly different approaches were used to code the different data described in the results; the choice of approach was grounded in the nature of participants' responses. As discussed below,[31] each participant's responses were analysed as a whole to determine whether the participant understood the law or not. Each participant was assigned a single score for their knowledge of each of the common law and guardianship law accordingly. The precise scoring method used is outlined in more detail in Part III(F) below. As discussed below in Part IV(B), the participants' responses were analysed as a whole to come up with an overall score, and each mention of a particular kind of attitude was also coded, in order to capture the diversity of doctors' attitudes. A single participant may have expressed a number of different attitudes (positive and negative); in this case, each attitude was coded separately. In these instances, to come up with the participant's

[30] Jane Ritchie and Liz Spencer, 'Qualitative Data Analysis for Applied Policy Research' in Alan Bryman and Robert G Burgess (eds), *Analyzing Qualitative Data* (Routledge, 1994) 173, 173.
[31] See Part IV(A) below.

overall attitude the transcript was examined to determine that doctor's dominant attitude towards the law (positive or negative). The same method was used in Part IV(C), to code doctors' responses about their approaches towards law in practice.

F *Assessing Knowledge of the Law*

To capture doctors' knowledge of the law on futile treatment (Part IV(A) below), participants' explicit references to their legal obligations were coded with NVivo by the authors who possess legal expertise (LW, BW, and EC). These three authors initially discussed what the law governing futile treatment in Queensland is and what types of statements represented adequate knowledge of the various aspects of it. One of us (EC) then did the initial coding, and flagged cases in which participants' knowledge was not immediately obvious or was unclear (13 cases). These cases were coded in discussion with the other authors with legal expertise (all with LW and difficult cases also with BW) to ensure consensus about the way the transcripts were coded. When the NVivo extracts did not provide enough detail to assess the participant's knowledge of the law, the entire transcript was reviewed to uncover implicit references to the participant's understanding of relevant legal principles.

Doctors were scored as having correct (score of 1) or incorrect (score of 0) knowledge of the law in two domains: (a) the common law, and (b) the guardianship legislation. These scores were added, and resulted in an overall score ranging from 0 to 2 for each participant. Participants who simply cited the common law principle 'doctors do not have to provide treatment when it is futile' were given a correct score on the common law (1 point), even though they did not know or did not specify that this only applied to patients with capacity to make decisions. Similarly, doctors who said they must have the consent of the *patient* or substitute decision-maker to withhold or withdraw life-sustaining treatment were given a point for knowing the guardianship legislation, even though they were applying it incorrectly to patients with capacity. Only participants who scored 2 out of 2 could be said to be correct about the law as a whole.

Given the lack of specificity in some responses to interview questions, combined with the complexity of the law in this field, the researchers scored the responses generously and participants were given the benefit of the doubt when it was unclear whether they understood the law or when they were *substantially* correct about the substance and framework of the law. For example, as explained in the previous paragraph, respondents were awarded a point if they correctly described the common law (or guardianship law) even if they did not expressly say that the law applied to patients who had (or lacked) capacity. However, when participants made contradictory statements about the law, their knowledge was scored as incorrect. Participants were also scored as incorrect if they acted in a way that was consistent with the law, but did so under a misunderstanding of the legal rule that applied to the situation. For example, when asked what the law required when there was a futility dispute between the treating team and a family for a patient without capacity, one doctor responded:

> Interviewee: Look, I think if there's difficulties like that, then we go to the legal guardian and we use them as our substitute decision-maker. So we then involve the law, if you like.
>
> Facilitator: Okay, and that's because you want to involve them as a mediator or you can't do it without the family's consent? Or…

> Interviewee: We actually can do it without the family's consent but it's unwise to. So I come back and say the law says that you can't force medical and nursing staff to do things that they generally believe are futile and you don't want to traumatise families by doing things that they believe are terribly wrong, either. So yes the legal guardian does become both the person that takes on that role of looking at the legal aspects but also can deal with the mediation and is also just an independent person to try and deal with conflict. (Participant 413074 – Emergency Medicine Consultant)

Although this doctor knew that futility disputes could be escalated to the Public Guardian (incorrectly referred to by the doctor as the 'legal guardian'), this participant was deemed to have incorrect knowledge of the guardianship legislation because she or he was under the impression that treatment could be lawfully withdrawn without family consent and that involvement of the Public Guardian was a matter of good practice or helpful in conflict resolution as opposed to being required.

IV RESULTS

This Part comprises an analysis of doctors' knowledge of the law on futile treatment, their attitudes towards it, and the extent to which they reported that this law affects their clinical practice.

A *Knowledge of the Law*

Overall, doctors had a poor knowledge of both the common law and guardianship law, but more were familiar with the former than the latter. Doctors' varying levels of knowledge of the common law and the guardianship law is summarised in the following table:

Table 2: Doctors' Knowledge of the Law Regarding Futile Treatment in Queensland[32]

Knowledge of the law	Common law (proportion)	Guardianship law (proportion)
Correct	47 (50.0%)	34 (36.2%)
Incorrect	33 (35.1%)	60 (63.8%)
Did not answer/not raised	14 (14.9%)	0 (0.0%)
Total number of doctors	94 (100%)	94 (100%)

Half of the doctors cited the common law position that they did not have to provide treatment if they thought it was futile. However, more than a third of doctors held incorrect beliefs about the common law. For example, many conflated their obligations under the guardianship law with the common law, and believed that they needed a patient's consent to withhold or withdraw life-sustaining measures, whether or not the patient had capacity:

> … doctors live constantly under the fear of litigation… I believe it's a particular problem in Queensland, where the patient, or interested parties, have the direct right to demand therapy, even

[32] Note that two participants were excluded from this part of the analysis as they had not discussed the law at all: see Part III(E) above.

> if futile. So we're very conscious of patient or interested parties' views. (Participant 413008 – Renal Consultant)

Fourteen doctors (14.9 per cent) did not comment or were not specifically asked about the common law position, typically because of time constraints in the interview and because the discussion had focused on examples of patients without capacity to whom the guardianship law applied.

Approximately one-third of doctors understood their obligations to seek a substitute decision-maker's consent under the guardianship law. Of the two-thirds who did not have correct knowledge of these duties, some believed that the common law principle applied whether or not a patient had capacity, while others simply said they did not know whether consent was required. The following excerpts are illustrative of participants' responses where the doctors had an incorrect understanding of their obligations under the guardianship law, or were uncertain about them:

> I'm quite comfortable that when something's medically inappropriate then it – you've got legal grounds not to provide it. So doctors cannot always define or - this is why it's a bit of a grey zone, doctors define what's medically appropriate. If it's not medically appropriate, it doesn't get offered. So you should only be offering medically appropriate treatment. (Participant 413012 – Internal Medicine Registrar)

> …it's also absolutely clear in the law that doctors are not obligated to provide treatment they believe is completely futile. (Participant 413074 – Emergency Consultant)

> The letter of the law does say that if it's futile you don't have to do it. It also wants you to talk to people about it and I interpret that. Is that a fair way to put it? I would not, whether the letter of the law said so or not, if I knew someone should not be resuscitated I wouldn't give them a choice in that. (Participant 413004 – Palliative Care Consultant)

Significantly, of the doctors who discussed both areas of law, the majority (56 doctors, 70 per cent) were familiar with *either* the common law position *or* their obligations under the guardianship law, but not both (see Table 3). Only 11 per cent of those who answered were aware of the whole legal regime. The mean overall score was 0.9 out of 2 (44.9 per cent).

Table 3: Doctors' Overall Scores (For Those Participants Who Discussed *both* the Common Law and the Guardianship Scheme)[33]

Overall level of knowledge	**Number of doctors (proportion)**
No knowledge of the law	15 (18.8%)
Knowledge of only the common law	38 (47.5%)
Knowledge of only the guardianship legislation	18 (22.5%)
Knowledge of both the common law and the guardianship legislation	9 (11.3%)
Total	80 (100%)

[33] Those participants who did not give a specific answer (either because they did not answer or were not explicitly asked) were excluded from this table.

B *Attitudes Towards the Law*

The vast majority of doctors had an overall negative, rather than positive, attitude towards the law. The types of negative and positive attitudes that doctors had towards the law are shown in Table 4.

Table 4: Doctors' Overall Attitudes Towards Law[34]

Attitudes towards law	**Number of doctors**
Overall negative attitude	**59**
The law does not support doctors' decisions/puts too much power in the hands of substitute decision-makers	41
The Public Guardian is unhelpful in dealing with withholding or withdrawing life-sustaining treatment	20
Afraid of legal consequences	15
The law is confusing/have not received consistent advice on what the law is	15
Causes defensive medicine	14
The law does not recognise practical considerations	10
The law is illogical	9
Lengthy time for decision-making when law is engaged	8
The law does not let us consider the need to conserve scarce resources	6
Law is irrelevant to medical practice	5
Taking legal action has a negative impact on relationship with patients/families	2
Overall positive attitude	**29**
The law or legal processes support appropriate outcomes	22
The law strikes the right balance between substitute decision-makers and doctors	13
The Public Guardian is helpful/supportive of doctors' decisions to withhold or withdraw life-sustaining treatment	7
I am not afraid of the law	3
The law helps resolve disputes	2

[34] Eight participants of the total sample of 96 either were not asked or did not express any attitudes about the law. Some participants expressed both positive and negative attitudes towards the law; each of these attitudes was coded individually and participants were also given a score of 'overall positive' or 'overall negative' based on their dominant attitude (see Part III(E)).

The most common negative attitude doctors expressed was that the law does not provide them with enough support to make appropriate decisions to withhold or withdraw futile treatment. These doctors questioned the ability of a judge or a substitute decision-maker to make a better decision than they could, as illustrated by these quotes:

> I was angry with the — I thought that the law — obviously, I was wrong, but we all thought that it was actually a given that if there were multiple people agreeing that care was futile, none of us with any vested interest in thinking differently, that we should not and could not be forced to provide treatment against our wishes. No, that sounds awful. What we think is right. … We were all in agreement, so we were all a bit stunned and shocked at the adult guardian's decision [that life-sustaining measures could not be withdrawn without the substitute decision-maker's consent] and angry, because obviously, I think intensive care beds are precious and should be used for people who've got a chance at improving. So after five or six days, she died. It might have been four or five days, I can't remember now, but it was an extraordinary waste, and not a dignified death. Dying in intensive care is not pretty. (Participant 413041 – Internal Medicine)

> I would never intentionally break the law, but I think it's a little bit foolish that the people who have trained for many years and are maybe experts in their chosen field can be overruled by family with the medical treatment and often a large emotional component. … My biggest problem with it is giving the family too much say in how someone is treated. Most of the time it's not going to be an issue. Most people are sensible. Most futile treatment, I mean, if the patient's going to die, they're going to die whether they have treatment or not, so you could argue it doesn't change the outcome very much. But I think the manner of someone's death is quite important, so that bothers me. (Participant 413068 – Internal Medicine)

> I think the law should give some right for doctors to make decisions based on what they think about the best possible outcome the patient should have. If required, maybe having a medical board or a combined decision from a medical board or other to resolve the conflict, rather than totally on the patient's and the family's right. (Participant 413035 – Internal Medicine)

Doctors also often expressed frustration with the perceived lack of clarity in the law, as the following quotes demonstrate:

> Look from my perspective it gets back to the fact where we have a number of people where medically we believe treatment is futile but patients and families demand therapies and there's been a shift in the culture from when I started work. Previously once you'd say look I don't think that is appropriate therapy and on my medical advice we're not going to be offering that to now - except for those extreme sorts of examples we mentioned before — now even if you advise against the therapy and the patients say I want antibiotics, I want this, you're more inclined now to give it than what you were years ago. That's partly because of perhaps the lack of clarity in terms of the law. (Participant 413053 – Respiratory Medicine)

> I think this is the difficult area and I think it's not made easier by the acute resuscitation plan because previously there was a strong feeling that we could make someone not for resuscitation without consultation but we would consult the family out of courtesy of what our decision was. I think the good thing about the advanced health directive is it has made that discussion more formal and it has made us document the discussion but there's mixed messages around well we're not obliged to provide futile treatment but we have to get now consent from the family. I don't think that's ever been satisfactorily explained whether despite a family member or the surrogate

> decision-maker firmly expressing the opinion about what management should be made following discussion about it. It's not — to me it's still uncertain whether you can then go against what they've said. So I'm not actually sure. I feel quite uncertain and particularly in our department there are consultants who disagree quite fervently. (Participant 413081 – Geriatric Medicine)

Other negative attitudes reflected the general theme that the law is a blunt instrument with barriers to access, and is poorly suited to medical decision-making at the end of life. Some doctors said legal mechanisms were too slow and cumbersome to resolve futility disputes, which are by their nature, time sensitive. Some also commented that the legal position does not take into account a practical understanding of medical realities. This attitude is captured in these quotes:

> Clearly laws were drafted by people who have very little understanding of what goes on in the clinical environment. … I think people have no idea what they're signing up for when they — I mean look, doctors cop a lot of flak for the historically perceived paternalistic attitude right. Because we come from this perspective of being experts in what we do. But I have to say in intensive care it's very difficult for lay people and even people who work in other areas of health care, to really understand the burdensome nature of the treatment that we provide. I think it's really difficult for people to comprehend just how tough it is. …It's okay to put you through a short period of intensive suffering if at the end of it there's a positive benefit. But it's really not okay to do that to people if there's not a positive benefit to be achieved. I think that concept is really difficult for the community to grasp just how invasive what we do to people is. People have no concept of that and there's no real way of grasping that concept. I would say the only people who are really able to make an informed choice in that situation are health care professionals. That's what I would say. (Participant 413084 – Intensive Care)

> … when they are writing the law, [they] are thinking about the person in Intensive Care who's in there for a week. Or the person who's got some underlying cognitive impairment, who's being protected by the Guardianship Act. That people aren't making unilateral [decisions] — and so that's what they're thinking about. They're not thinking about that this law actually applies to every person who's elderly who dies, which is what it does. It means that what this law means is that every person presenting to ED [the Emergency Department] in Queensland, needs to have the family's consent to not have CPR. The other thing is that in theory, you need consent to stop CPR. So if the family said no, no, keep going, then to follow the law you'd have to do it for one week, two weeks, three weeks … the intent of the law is one thing. But the practicality of it —and I don't think — the law, I don't think, was ever written to apply to that situation. … Which is why a legal position is one point of view, but the medical position is another. (Participant 413096 – Emergency Medicine)

Doctors also expressed concern that legal mechanisms eroded relationships with patients and families. For example:

> I often say to people I believe if you have to involve a lawyer that's an abject failure of the doctor/patient relationship and you have irretrievably destroyed that relationship, that you will no longer be able to look after the patient and their family again. (Participant 413057 – Intensive Care)

Doctors' attitudes about the level of autonomy granted to doctors under the guardianship legislation were overwhelmingly more negative than positive. While 41 doctors thought that the

law put too much power in the hands of substitute decision-makers, only 13 doctors thought the law struck the right balance between patient autonomy and medical paternalism (see Table 4).

The most frequently expressed positive attitude was that the law or legal processes support appropriate outcomes. A range of sentiments are captured within this heading. Some doctors who had this attitude were simply mistaken about the law, and made positive comments about their belief that the law allowed them to refuse to provide futile treatment. Others, who were aware of the legal requirement to obtain consent to withhold or withdraw futile treatment for patients without capacity, believed that if a dispute over futile treatment escalated, the courts would support the doctors' assessment of futility. For example:

> … if such a matter did progress to court, if a reasonable body of medical opinion, that's the expert opinion felt that this was in keeping with reasonable medical practice, under those circumstances the law would be on your side. That is my understanding in reading of the law, if it went to that extreme. (Participant 413051 – Renal Medicine)

The comments from doctors who felt the law supported their actions appeared to be underpinned by a common underlying belief that the law supports what is appropriate, well-intentioned and medically reasonable. One participant engaged with this concept from a slightly different point of view, commenting that the court plays an important societal role in adjudicating disputes about futile treatment, assessments of which are inherently subjective:

> Well, look, I think doctors are the agents of society and, look, if a family really want to go to court, I'm happy to have society judge what we do. I don't feel as though I'm doing anything malevolent. I can't remember a case where I've been conflicted in the care of a patient. But if society wants to tell me to do something else, then, as long as they understand the facts, then, sure, we'll do that. (Participant 413019 – Intensive Care)

A comparative matrix of doctors' knowledge versus attitudes (Table 5) reveals two interesting trends. Firstly, doctors' attitudes towards the law were negatively associated with their level of knowledge of the guardianship legislation. Those who knew the guardianship legislation tended to have more negative attitudes towards the law in this area, compared to those who knew only the common law or had no knowledge of the law. This is unsurprising, given that 41 doctors (46.6 per cent of those who expressed a view on the law) voiced the opinion that the law detracts from their autonomy and does not adequately support their decisions to withhold or withdraw futile treatment at the end of life (see Table 4). Second, of those doctors who had a positive attitude towards the law, the vast majority (23 doctors, 79.3 per cent) were unaware of their obligations to seek consent to withhold or withdraw life-sustaining treatment under the guardianship regime. These doctors had either no knowledge of the law or thought that the common law principle that they did not have to provide treatment when it was futile.

Table 5: Doctors Overall Attitudes Towards the Law Compared To Their Knowledge Of The Law On Futile Treatment

Level of knowledge of the law	Number of doctors with an overall positive attitude	Number of doctors with an overall negative attitude
No knowledge of the law	9	11
Knowledge of only the common law	14	20

Knowledge of only the guardianship legislation	5	20
Knowledge of both areas of law	1	8
Total	29	59

C *The Impact of Law on Clinical Practice*

The way in which the law governing futile treatment has, or has not, affected doctors' practices was also examined. Some doctors spoke of how the law influenced their practices (ie ways that the law has compelled them to act, or actions or behaviours they take to avoid engagement with the legal system), while others said the law did not affect them. Although the vast majority of doctors held negative attitudes towards the law, about half indicated that the law influenced how they practised medicine (see Table 6).

Table 6: Doctors' Views on the Impact of Law on Their Practice[35]

Impact of law on practice	**Number of doctors**
Law has an impact on practice (overall)	**48**
Caused futile treatment	27
Consulted colleagues for a second opinion on futile treatment for legal protection	17
Consulted other hospital authorities or defence organisation for legal advice	16
Consulted Public Guardian to act as a substitute decision-maker	15
Consulted Public Guardian to resolve futility dispute	14
Provided futile treatment as a result of interaction with the Public Guardian	12
Needed to interpret the content and legal weight of advance care planning documents	8
Escalated to the Queensland Civil and Administrative Tribunal to resolve a futility dispute	4
Advance Health Directives address my worries about future legal risk	2
Law does not have an impact on practice (overall)	**44**
Good medical practice is enough	36
If you communicate well with the family you do not need to worry about law	26
I do not think about the law	16

[35] Four participants of the total sample of 96 did not comment on the impact of the law on their practice. Some participants expressed more than one way that the law had (or did not have) an impact on their practice; each of these impacts was coded individually and participants were also given an overall score based on their main response (see Part III(E)).

The ways in which the law affected doctors' practices varied. The most frequent impact on practice doctors discussed was that the law (or fear of the law) caused futile treatment to be provided. For example:

> We can either go against our best wishes and keep the family happy and do whatever we feel. Or we can go to the Guardian and try and get an overrule around that. Now to go to the Guardian and get an overrule from a legal point of view to refuse to abide by next of kin's wishes is time consuming. So invariably we'll probably be forced to go ahead and do some treatment we don't agree with until we can go through the process of getting a ruling of support. (Participant 413034 – Emergency Medicine)

> I think if someone gave me the opportunity to die of a heart attack suddenly at the age of 85 that would be fantastic. But — so when I get that phone call at three o'clock in the morning that's what I really think should be done and I honestly think that's in the best interests of the patient. The thing that prevents me from saying no I don't want to do anything is that there's no medico-legal construct, as far as I can tell. … There's nothing that protects me. There's not a medico-legal construct that protects me from sanction as a result of that decision. (Participant 413082 – Cardiology)

Several doctors also reported providing futile treatment as a result of interactions with the Public Guardian, either because they were directed to do so, or because the Public Guardian did not make a decision about withholding or withdrawing treatment.

Doctors also reported that the law led them to take steps to protect themselves against legal sanction. Some doctors described ways that they would seek institutional assistance when unsure about the law, by escalating a matter to hospital authorities or lawyers, or to the Public Guardian. A number of doctors said that when they thought treatment was futile, they sought second opinions from colleagues to help discuss their position with the patient or family and such action would provide legal protection.

About half of the participants said that the law did not affect their practice. Most thought that following 'good medical practice' (broadly understood by the participants as doing the right thing for the patient) was the appropriate course of action whether supported by law or not, as described in the following quotes:

> I would not, whether the letter of the law said so or not, if I knew someone should not be resuscitated I wouldn't give them a choice in that. (Participant 413004 – Palliative Medicine)

> Whether or not I had contravened the G & A [Guardianship and Administration] Act by not following through with what had been expressed in the past as the wishes of the family — to me it's only secondary to whether or not I practice outside of the scope of practice which morally, ethically and probably from a societal point of view would have been perceived to be the right thing to do. (Participant 413022 – Intensive Care)

A number of doctors said that as long as the medical teams took enough time to communicate with substitute decision-makers, legal mechanisms do not need to be engaged or even considered. For example:

> With compassion, empathetic communication skills and with talking through what is appropriate practice or not and having doctors uniting in their voice towards these families. Most times, we will get through it without thinking about the law. (Participant 413024 – Palliative Medicine)

Doctors usually characterised these discussions with family as being part of good medical practice, rather than something that the consent requirement in Queensland guardianship law has compelled. However, it may be that the law is playing some part in driving these extensive discussions. For example, an intensivist made the following comment when discussing withdrawing futile treatment from a patient without capacity:

> Participant: I would usually attempt to achieve consensus [with the family], and you get there eventually but it takes time.
>
> Facilitator: But if the law supported you more would you still try and reach a consensus?
>
> Participant: That's a good question. Probably not. I think it would be beneficial to have the support of the law in making the decisions that we make all the time anyway, rather than to be at odds with it. But would it change clinical practice. … It would be helpful in those situations where there is an impasse with the family, you know what I mean. It would be helpful to say, look we have no further requirement to provide this and I can tell you that we should stop and that's all we're going to do. It would be nice to have that as a fall-back position. (Participant 413084 – ICU Consultant)

V DISCUSSION AND CONCLUSIONS

This article presents findings from our analysis of the transcripts of 96 in-depth interviews. The limitations of the research method should be noted. The study is based on the views held by doctors who volunteered to be interviewed and who may have had strong views about the subject matter. The findings therefore may not be generalisable to a broader cohort. Nevertheless, some strong trends emerged from the research, which may provide important information to hospital executives, medical colleges and societies, the medical profession generally, and medical educators, about the need for clinical practice and medical education to take account of the law and the legal context in which treatment decisions are made.

When reporting on doctors' knowledge of the law in this field, it is important to acknowledge that the law is complex, and perhaps more so in Queensland where the law differs depending on whether a person has capacity (common law) or not (guardianship regime). Further, some may regard the law as counter-intuitive, as a doctor is not required to obtain patient consent to withhold or withdraw life-sustaining treatment when he or she has decision-making capacity, yet must obtain consent (generally from a member of the patient's family) when the patient lacks capacity and may well be in a more dire medical condition than a patient who still retains capacity. Indeed, some may suggest the Queensland law should be reviewed.[36] Nevertheless, the findings of this research point to some concerns, in that 89 per cent of the doctors who were specifically asked

[36] Two of the authors have elsewhere considered the appropriate nature of the legal regime in this field. See Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: a Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26(1) *New Zealand Universities Law Review* 24.

about their obligation to seek consent to withhold or withdraw futile treatment did not fully understand the legal position for a patient with and without capacity.[37]

This article also reports on the negative attitudes that doctors have toward the law on this issue. Overall, doctors did not perceive the law in a positive light, with 59 doctors having a negative attitude towards the law and only 29 doctors observing that it could be helpful in end of life decision-making. Of those doctors who had positive attitudes about the law, most were unaware of their obligations under the guardianship legislation. Negative attitudes about the law were associated with increased knowledge of the guardianship legislation; this may reflect the frequently cited view expressed by participants that the law overly fetters their autonomy in this area. Half the participants said that the law affected their practice; the primary perceived impact was that the law causes futile treatment to be provided.

In light of these empirical findings and the current legal framework in Queensland, we make the following recommendations. Firstly, the legal framework needs to be certain and clear (and, ideally, consistent across all Australian jurisdictions). Three of the authors have elsewhere made suggestions in this regard.[38] Further, health departments and hospitals should develop policies that translate legal obligations into accessible language that will guide clinical practice. In addition, position statements and professional guidelines developed by professional bodies and societies should be consistent with those legal obligations and indeed encourage legal compliance. It is not sufficient to suggest that acting according to professional ethics or principles of 'good medical practice' will be sufficient to ensure legal compliance.

Secondly, this research points to the need to educate medical professionals. Doctors need to know when they are required to seek consent from substitute decision-makers to stop treatment that has already commenced, or to withhold other treatment. However, our findings about doctors' attitudes towards the law also point to the need to persuade doctors about the importance of knowing and complying with the law. Unless doctors form the view that it is important to carry out their practice in a legally compliant manner, we are unlikely to see any improvement in doctors' knowledge of the law governing decision-making at the end of life. Greater collaborative educational efforts should occur, involving medical schools, hospitals, specialist colleges and societies, and the Office of the Public Guardian, to clarify Queensland's unique legislative requirements to obtain consent to withhold or withdraw futile treatment from patients without capacity.

[37] For further research into the knowledge of specialists on the law that governs withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity, see White et al, above n 6.
[38] Willmott et al, 'The Legal Role Of Medical Professionals (Victoria)', above n 5.

APPENDIX A - INTERVIEW GUIDE

Note: these questions are to be used as a flexible guide. The interviewer will begin with a general question like those described, and use the other questions as prompts depending on what the participant says. The interview will be conversational, and participants will answer questions in their own words and address issues in the order they wish.

General questions

Initial question: Can you please describe a situation from your experience (one you were responsible for or one from a colleague) when a person got treatment at the end of life you didn't think they should have had?

- Why was this treatment provided?
- How did you feel about this experience?
- What do you think could have been done differently (if anything)?

What about a situation where a patient *didn't* get treatment that you thought they should have had?

Can you describe a situation where treatment at the end of life was appropriately withdrawn?

Describe a situation where a decision was made to withhold or withdraw treatment that resulted in a poor outcome?

Have *you* ever given treatment you knew was futile (ie likely to be ineffective)? Why?

- What factors led to the decision?
- Why was treatment withheld/withdrawn?
- Why did you/others think that treatment was futile/inappropriate?
- Why do you/others think that treatment was appropriate?
- How did you feel?
- What was your colleague's reaction?
- What do you think could have been done differently (if anything?)

Prompts

☐ Family
   a. What role, if any, do you think family members play in the provision of futile treatment?
   b. What role, if any, do you think patients play in the provision of futile treatment?
   c. How often is futile treatment given just because family requests it?

☐ Interpersonal dynamics/communication
   a. Some believe that communication plays a role in futile treatment. What do you think about this? (i.e. communication with other staff, family, patient)
   b. Some believe that expectations play a role in futile treatment. What do you think about this? (i.e. expectations of other staff, family, patient, self)

- ☐ Institutional culture
  a. Why do doctors make varying decisions about when to withhold or withdraw treatment at the end of life?
  b. Is your practice similar to others in your specialty? Why or why not?
  c. What is the impact (if any) of interaction/opinions of nurses, registrars, other staff ?
  d. Some say that this treatment is provided because doctors don't have enough time to have adequate conversations because of workload. What do you think about this?

- ☐ Training
  a. What training (if any) did you receive in relation to how to deal with end of life care? Deciding when to cease active treatment?
  b. Nature, duration, place of training
  c. What, if anything, should be done to change this training?

- ☐ Resources
  a. Some say resources are a factor in assessing whether or not to offer treatment that may be futile. What do you think about this?
  b. Some say that by providing treatment that is futile (even when there is some justification) others miss out on beneficial treatment. What do you think about this?

- ☐ Law
  a. Some believe that if they do not provide treatment when a patient/substitute decision-maker requests it, there may be legal consequences. What do you think about this?
  b. What does the law say on this?
  c. What do you think of the law? Is treatment provided because of it?
  d. Have you ever had a situation escalate to a legal proceeding?
  e. Thoughts on the legal proceeding?
  f. Does the law support your decisions in this area?
  g. Would an increased understanding of the law assist?

- ☐ Policy
  a. Are there any policies/practices/guidelines in your department/hospital/Queensland Health that deal with futile treatment at the end of life?
  b. What do they say?
  c. What do you think of these?
  d. Do you use them in practice?
  e. What about professional/ethics guidelines? Do they address this? What do you think of them?

- ☐ Nature of futile treatment
  a. Can you think of instances in other specialties when this occurs? Which ones?
  b. What is the nature of futile treatment provided (resuscitation/medication/procedures, etc)?
  c. What about your own specialty (discipline, department) – any examples?
  d. How frequently do you perceive futile treatment occurs in your department?
  e. Main reason that futile treatment is provided?

☐ Definition
   a. What do you mean by futile treatment?
   b. Can you define futile treatment?

☐ Improvement
   a. Is it a problem? What troubles you the most about it? (Harm to patient, resource use, doctor's autonomy, etc.)
   b. What do you think needs to happen (if anything) to address the issue of futile treatment?

Case example

The interviewer will use the case study in a flexible way, encouraging the participant to guide the discussion.

Case study

- John is an 84 year old male with advanced dementia and end stage bowel cancer which has metastasised
- He is admitted from the high care unit of an residential aged care facility to hospital with abdominal pain
- It is possible to undertake surgery, but this is expected to have limited, if any, benefit
- John's daughter demands the operation despite the poor prognosis

What to do – listen for cues from participant:

1. Administer treatment? When? Why this point?
2. What information would you want?
3. How would you make this decision? Who would you speak to?
4. Any laws/policies/processes affecting your decision?
5. Cost considerations?
6. What if John did not have dementia and was requesting futile treatment?

Categorise

- Continue even if know is futile?
- Or stop because know is futile?

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LEGALISED PHYSICIAN-ASSISTED DEATH IN OREGON

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In the United States, five states have legalised physician-assisted death ('PAD'), but most information and research comes from the state of Oregon, in which the practice has been legal since 1997. This law allows a physician to prescribe a lethal dosage of medicine to terminally ill, mentally competent residents, for the purposes of self-administration. About 3 in 1000 deaths are now from PAD and the patients most often have cancer or amyotrophic lateral sclerosis. Concerns that legalisation would undermine the development of palliative care and be disproportionately utilised by patients unable to access good end of life care have been unfounded.

I INTRODUCTION

As of 2016, five US states have legalised physician-assisted death ('PAD'), through a variety of pathways. In the Northwest states of Oregon and Washington, PAD was legalised through citizens' initiatives, as both states have methods in which constituents can petition to have laws changed by statewide vote. The *Oregon Death with Dignity Act* was passed 20 years ago in 1994, though legal challenges delayed enactment until 1997. In 2008, voters in neighbouring Washington passed an almost identical law.[1] More recently a judge in Montana ruled that physicians cannot be prosecuted for prescribing lethal medications for terminally ill, mentally competent patients.[2] In 2013 and 2015, the legislatures of the state of Vermont and California respectively legalised PAD. The laws in Oregon, Washington, California and Vermont include safeguards that limit the conditions under which lethal prescriptions can be written and methods for publishing statistical data on the use of lethal prescriptions (little information is available from Vermont at this time). In contrast, there is almost no information about PAD from Montana as the pathway through which legalisation occurred did not result in any reporting requirements and, to date, no independent researchers have published any information. No other form of PAD — that is, physician prescription and patient consumption of medications for the sole purpose of causing death — is legal in the US at this time. The focus of this paper is on available information from Oregon, in which many years of published data from the state and independent research have resulted in substantial information on the practice of PAD.

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[1] Elizabeth Trice Loggers et al, 'Implementing a Death with Dignity Program at a Comprehensive Cancer Center' (2013) 368(15) *New England Journal of Medicine* 1417.

[2] *Morris v Brandenberg*, No D-202-CV 2012-02909 (NM 2d Jud Dist Jan 13, 2014); *Baxter v Montana*, 2009 MT 449 (Mont, 2009).

A survey in 1995 reported that before legalisation 7 per cent of Oregon physicians had ever prescribed medications to be used to cause death.[3] Back and co-authors surveyed 828 Washington physicians in 1996.[4] Ninety-nine (12 per cent) of physicians had received a request for physician assisted death in the previous year and 32 had complied. A national survey from 1998 reported that 3.3 per cent of US physicians had ever written a prescription to hasten death.[5] This data suggests that a significant minority of physicians in Oregon and Washington were willing to participate in aid in dying even before legalisation and that physician-assisted death does occur outside the law across the US.

II LEGALISED PHYSICIAN-ASSISTED DEATH IN OREGON AND WASHINGTON

The Oregon and Washington *Death with Dignity Acts* are nearly identical.[6] They allow a competent adult resident of the state to obtain a prescription from a physician for a lethal dose of medication, for the purposes of causing death through self-administration. The laws do not allow lethal injection nor can individuals acquire a lethal prescription through advance directive to be used when mentally incapable in the future. A variety of safeguards limit the conditions under which the prescription can be written. Two physicians, one of whom will write the prescription, must confirm that the patient has a terminal illness (likely to cause death within six months), is competent to make the decision, and is doing so voluntarily. Individuals must be informed of the options of hospice and comfort care. In order to minimise the risk of impulsive decisions, individuals must make one written request and two oral requests over a period of 15 days. The patient must be referred to a psychiatrist or a psychologist if there is concern that the request for a lethal prescription stems from impaired judgment resulting from mental illness such as depression. The physician must request, though may not require, that the patient inform their family of the request. Physicians who do not comply with the laws' requirements may be subject to action from the state licensing board. Several Oregon physicians have been investigated, though for relatively minor problems in documentation.

Prescribing physicians are required to report information to the state on patients who receive prescriptions; they are not required to report any information on requests that do not result in a prescription; therefore, less is known about the reasons why patients are denied prescriptions. Annual statistical reports include the number of prescriptions written, characteristics of patients who have died of PAD, and complications. These reports are comprehensive in including every individual who received a prescription under the law, and allow tracking of changes in practice over time. They contain no information on PAD, including euthanasia that occurs outside the law. Other information about PAD comes from groups of researchers in each state who have used a variety of methods including surveys, interviews and qualitative studies to examine the

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[3] Melinda A Lee et al, 'Legalizing Assisted Suicide: Views of Physicians in Oregon' (1996) 334(5) *New England Journal of Medicine* 310.

[4] Anthony L Back et al, 'Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses' (1996) 275 *Journal of the American Medical Association* 919.

[5] Dianne E Meier et al, 'A National Survey Of Physician-Assisted Suicide and Euthanasia in The United States' (1998) 338 *New England Journal of Medicine* 1193.

[6] Oregon Public Health Division, *Oregon's Death with Dignity Act – 2014* <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>; Washington State Department of Health, *Washington State Department of Health 2014 Death with Dignity Act Report* (2014) <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct>.

practical aspects of the law; its impact on end of life care; and the views and experiences of health care professionals, requesting patients, and their families.

Oregon, with statistical reports from the state extending back to 1999, has the most comprehensive data on legalised PAD, though initial data from Washington is similar on most measures. Up to the end of 2014, under Oregon's law, 859 Oregonians have died by PAD. The rates have increased slowly from 1 in 1000 deaths to, in 2014, 3 in 1000 deaths (an average of 2 in 1000 deaths during the law's operation). Opponents of the law believe this increase is evidence of the anticipated slippery slope, whereas supporters of the law underscore the very low rate overall, even with the slow increase over time. The median age of decedents is 71 years, almost equally divided between men and women. Racially 97 per cent were white, 1 per cent were Asian and 0.7 per cent were Hispanic. The most common terminal diseases were cancer (78 per cent) and amyotrophic lateral sclerosis (8 per cent). Overall, 90 per cent had been enrolled in hospice, 95 per cent died at home, and 1.5 per cent lacked medical insurance. Ninety-three per cent of individuals informed their family of the decision. After taking the medications, most commonly secobarbital or pentobarbital, patients became unconscious on average within five minutes and died within a median of 25 minutes. Complications included regurgitation in 22 patients and regaining of consciousness after ingestion of medication in six patients.[7] The Oregon Department of Human Services compared those who died by PAD to all other Oregon decedents through 2005: those who die by PAD are less likely to be very old, less likely to be married, and more likely to have cancer.[8] In addition PAD deaths occur in persons with much higher levels of education — PAD decedents are 8 times more likely to have completed college education. In Oregon the risk of choosing PAD is comparatively very high in patients with ALS (rate ratio 31, 95 per cent confidence interval 14.4-73.5) and HIV (rate ratio 25.1, 95 per cent confidence interval 6.9-80.4), though the absolute numbers of PAD deaths from these diseases are small because these diseases are relatively rare compared to other causes of death.[9] In 2014, 83 physicians wrote the 155 prescriptions provided.

III PHYSICIAN-ASSISTED DEATH, PALLIATIVE CARE AND HOSPICE

Throughout the United States, individuals become eligible for hospice care at the time they have less than six months expected life and are no longer pursuing life-sustaining treatment. Financially, hospice organisations are paid on a per diem rate, not, as in much of the rest of US medicine, a fee-for-service payment. Within that financial structure, most hospice services are delivered at the patient's home, with visits from hospice nurses, social workers, and other personnel depending on the patient's needs. Oregon has around 60 different hospice organisations, though most offer a similar set of federally mandated services. Even the most rural and sparsely populated areas of Oregon have hospice coverage. Palliative care services, for patients not enrolled in hospice, are delivered in the hospital or in outpatient settings and are mostly supported through medical centers because insurance payments often do not adequately

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[7] Oregon Public Health Division, *Oregon's Death with Dignity Act – 2014* <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>.

[8] Oregon Department of Human Services, Office of Disease Prevention and Epidemiology, *Eighth Annual Report on Oregon's Death with Dignity Act* (9 March 2006) <http://euthanasia.procon.org/sourcefiles/EighthAnnual.pdf>.

[9] Ibid.

cover the costs. At the time of passage of Oregon's *Death with Dignity Act*, there was concern that legalised PAD might undermine support for hospice and palliative care, both of which were early in their development. The costs of expanding and improving the quality of hospice and palliative care against the minimal costs of a lethal prescription provoked fears of subtle pressure for PAD.[10] In fact, PAD became an option within hospice, with 90 per cent of PAD decedents hospice enrolled. Advocates for palliative care were able to effectively use the specter of bad publicity around patients choosing PAD because of denial of care with hospital administrators, insurers and the state. Hospitals added palliative care services and most insurers, including Medicaid, the primary health care insurer for the poor, covered hospice. During the three years of preparation allowed between passage of the law in 1994 and implementation in 1997, Oregon health care leaders came together to develop educational programs and both advocates and opponents of PAD legalisation agreed on the importance of good palliative care. Uptake of interest in hospice and palliative care among Oregon's health care providers was strong. In a survey of over 2600 Oregon physicians soon after the law's enactment, 30 per cent agreed they made higher rates of hospice referrals the previous year compared to five years earlier; only 2 per cent of surveyed physician indicated they had made fewer referrals. Among the over 2000 who had cared for at least one terminally ill patient in the previous year, 76 per cent reported they had made efforts to improve their knowledge of the use of pain medications 'somewhat' or a 'great deal'.[11] Hospice professionals agreed. In a 2001 survey of 237 hospice nurses and social workers, 67 per cent ranked Oregon physicians as more competent in caring for hospice patients than five years earlier, and 4 per cent viewed them as less competent; 77 per cent viewed them as more willing to refer to hospice compared to five years earlier, and only 3 per cent viewed them as less willing.[12] These improvements paralleled increases across the US in palliative care and hospice services, and cannot necessarily be credited to legalisation of PAD. Yet the concern that PAD would undermine end of life care was not supported.

PAD was ultimately rarely chosen by terminally ill patients, with, over the period of the law's operation through to 2014, only 2/1000 deaths in Oregon attributed to this. Only one in ten who make explicit requests die by lethal prescription.[13] In part this may reflect barriers to obtaining the prescription—patients require planning and foresight as many physicians are unwilling to participate in prescribing. Only one third of Oregon physicians are willing to prescribe.[14] Although there is a 15-day waiting period from time of initial request to obtaining the prescription, in fact the median time between first request and death is 47 days. Some patients lose the ability to participate because they succumb to their disease before they complete the process, or develop physical symptoms that make it difficult to ingest the medication. Physicians are very reluctant to prescribe to patients if there are family members with objections.[15]

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[10] Elizabeth R Goy et al, 'Oregon Hospice Nurses And Social Workers' Assessment Of Physician Progress In Palliative Care Over The Past Five Years' (2003) 1 *Palliative and Supportive Care* 215.

[11] Linda Ganzini et al, 'Oregon Physicians' Attitudes About And Experiences With End-Of-Life Care Since Passage Of The Oregon Death With Dignity Act' (2001) 285 *Journal of the American Medical Association* 2363.

[12] Goy et al, above n 10.

[13] Linda Ganzini et al, 'Physicians' Experiences with the Oregon Death with Dignity Act' (2000) 342 *New England Journal of Medicine* 557.

[14] Ibid.

[15] Linda Ganzini et al, 'Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families' (2003) 6 *Journal of Palliative Medicine* 381.

Palliative interventions, particularly referrals to hospice, did result in some patients changing their mind about pursuing PAD.[16]

Another challenge to care providers at the end of life is that individuals who request PAD often are motivated by concerns that are not easily ameliorated by hospice care. Although many of the arguments around legalisation focused on pain, a surprising finding is that most patients at the time of their first request for PAD have minimal pain — though fear of future pain is a more important reason for requests.[17] Because most patients receive the prescription before they actually experience substantial pain, there is less of a role for expert pain management in reducing prescriptions. The reasons individuals give for wanting access to PAD are primarily to maintain independence and control, minimise dependence on others, and die at home. Furthermore the desire for independence and control represent lifelong values and characteristics, not transient, illness-based perspectives.[18] For hospices, PAD patients can present a variety of challenges both for individual practitioners and at a policy level. For individual practitioners, those opposed to PAD may believe they have failed when their patients choose to take the lethal medication.[19] Many believe that a natural death offers opportunity for growth and spiritual transformation for both the patient and family that is missed when the patient chooses PAD. Hospice nurses with discomfort around PAD struggle to maintain boundaries and not be drawn in, for example, being asked to manage a symptom such as nausea to help prepare a patient to take the medication.[20] But overall, in surveys completed in Oregon within five years of legalisation, 48 per cent of hospice nurses, 72 per cent of hospice social workers, and even 40 per cent of hospice chaplains supported the law, and very few hospice workers would decline to care for such a patient.[21] It is possible for patients to obtain prescriptions and take them without ever telling their hospice provider as the prescribing physician-patient relationship may be entirely separate from the hospice.

Among the hospice organisations in Oregon, policies around PAD vary. All hospices share core values of not hastening death, not abandoning patients, and respecting both the patient-physician and the interdisciplinary team relationships but they differ in how they balance these values. Campbell and Cox outline a variety of organisational positions and policies of Oregon hospices around PAD.[22] Oregon hospices will not discharge a patient who entertains the goal of PAD, yet no hospice will provide the patients with the lethal medication or assist in the self-

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[16] Linda Ganzini and Steven K Dobscha, 'Clarifying Distinctions Between Contemplating And Completing Physician-Assisted Suicide' (2004) 15 *Journal of Clinical Ethics* 119.

[17] Linda Ganzini, Elizabeth R Goy and Steven K Dobscha, 'Oregonians' Reasons for Requesting Physician Aid In Dying' (2009) 169 *Archives of Internal Medicine* 489.

[18] Ibid.

[19] Theresa A Harvath et al, 'Dilemmas Encountered by Hospice Workers When Patients Wish to Hasten Death' (2006) 8 *Journal of Hospice and Palliative Nursing* 200.

[20] Ibid.

[21] Linda Ganzini et al, 'Experiences Of Oregon Nurses And Social Workers With Hospice Patients Who Requested Assistance With Suicide' (2002) 347 *New England Journal of Medicine* 582; Bryant Carlson et al, 'Oregon Hospice Chaplains' Experiences With Patients Requesting Physician-Assisted Suicide' (2005) 8 *Journal of Palliative Medicine* 1160.

[22] Courtney S Campbell and Jessica C Cox, 'Hospice And Physician-Assisted Death: Collaboration, Compliance, And Complicity' (2010) 40 *Hastings Center Report* 26; Courtney S Campbell and Jessica C Cox, 'Hospice-assisted Death? A Study of Oregon Hospices on Death with Dignity' (2012) 29 *American Journal of Hospice Palliative Care* 227.

administration. Within these boundaries, hospices vary on the degree to which they allow staff to discuss PAD with the patient, notify the attending physician of the patient's interest in PAD, refer the patient to an advocacy organisation for more information, or allow hospice staff presence before or during ingestion of the medication. For example, hospices range from the minority of mostly religiously-based hospices that view PAD as incompatible with hospice care, will not provide information about patient choices, and ask patients to respect their hospice's position to those that emphasise respect for patient self-determination, allow hospice personal to openly discuss this option, refer the patient to PAD advocacy organisations for more information, or attend the death by PAD.

IV OTHER CONCERNS REGARDING OREGON'S LAW

The laws in Washington and Oregon have been criticised as both inadequate in safeguards and lacking in enforcement in safeguards. For example, unlike the Netherlands, intolerable suffering is not a requirement for legal euthanasia, reflecting the primary role of autonomy and self-determination in support for the law. Neither state requires that the primary or the consulting physician have expertise in palliative care. Patients are evaluated to make sure they have decision making capacity when they receive the prescription, but there are no safeguards to assure they are of sound mind at the time they take the prescription. Although patients become eligible under the law at the time they have less than six months life expectancy, some patients who obtain prescriptions outlive this life estimate, bringing into question the accuracy of physician assessment of prognosis. In 2015 the Oregon legislature is considering a bill to expand eligibility to persons who have a one year life expectancy. This change is opposed by Compassion and Choices, the chief advocacy organisation for persons choosing PAD, as it would leave some patients potentially choosing PAD who were not yet eligible for hospice benefits.[23] Because many physicians decline to participate in the law or work for religious health care systems that contractually preclude them from participating, patients who wish to secure lethal prescriptions often must find a new physician late in the course of their terminal illness if they wish to access a lethal prescription. There are concerns that the physician may not know the patient well enough to prescribe in such cases.

Safeguards are written into the law to make sure that patients are competent and not requesting PAD because of a treatable mental illness. Although mental illness itself does not exclude patients from obtaining lethal prescriptions, the assessment that mental illness impacts the patient's judgment to hasten death does require evaluation by a psychiatrist or psychologist. As stated in the law 'No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment'.[24]

Although 'depression' is not defined in the law, this is accepted to refer to 'clinical depression' or, in psychiatric nomenclature, major depressive disorder. During an episode of major depressive disorder a patient has pervasive low mood; inability to experience pleasure; and has sad, blue or depressed feelings most of the time over weeks, so persistently that everyday functioning is impacted. Other symptoms include hopelessness, a belief of burdening others,

[23] Barbara Coombs Lee, 'Don't Change Eligibility for Death with Dignity Law' *Oregonian* (Oregon), 4 April 2015.
[24] Oregon Public Health Division, above n 7.

guilt, poor self-esteem, and desire to die. This type of depression differs from understandable and normal grief, sadness, and dysphoria experienced by many with a terminal illness. Major depressive disorder can be reliably diagnosed in between 10 per cent and 25 per cent of patients with advanced cancer.[25] Among persons requesting PAD in Oregon, we found that three quarters are confidently diagnosed as not depressed.[26]

There are several important arguments for excluding patients with clinical depression from being eligible for PAD. Depressed persons view their future through a lens of pessimism and hopelessness. Major depressive disorder can render a person unable to enjoy life or experience pleasure, personal worth, or hope for recovery. Depressed persons therefore can make decisions that are inconsistent with their values, life philosophy, or personality, even if the decisions otherwise appear competent and voluntary. In fact, depression may not prevent expression of an articulate and coherent analysis of the benefits and rationale for PAD.[27] Depression and hopelessness are strongly associated with suicide in other contexts but suicidal patients may reembrace life with successful mental health treatment. Treatment of depression effectively reduces hopelessness and suicidal thoughts and ideation among older primary care patients.[28]

There are also arguments for, in some cases, allowing patients with depression to access lethal prescriptions. Depression causes suffering at the end of life. Many patients who request PAD have only weeks of remaining life, yet most antidepressant treatment regimens are not effective until after one or two months of treatment. Successful treatment of major depressive disorder increases interest in life-sustaining treatments in only a minority of patients and only those with the most severe mood symptoms.[29] Understanding whether depression influences the decision for PAD requires knowing an individual over time while both depressed and euthymic. In a survey of Oregon psychiatrists, 95 per cent were 'somewhat' or 'very confident' in the context of a long-term relationship that they could determine whether a mental disorder, such as depression, was influencing the decision for PAD, but only 6 per cent were very confident that they could make this assessment in a single evaluation.[30] Ethical views on PAD may influence these assessments. In a national study of US forensic psychiatrists, those ethically opposed to PAD advocated for higher thresholds for competence — including that the finding of depression should result in automatic finding of incompetence and more extensive reviews of the decision, for example, more than one forensic examiner or judicial review.[31] As such, the determination of whether depression is influencing the decision about PAD may reflect more about the mental health professional's ethical and moral views of PAD than psychiatric expertise. In the US

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[25] M Hotopf et al, 'Depression in Advanced Disease: A Systematic Review Part 1. Prevalence and Case Finding' (2002) 16 *Palliative Medicine* 81.

[26] Linda Ganzini, Elizabeth R Goy and Steven K Dobscha, 'Prevalence of Depression and Anxiety in Patients Requesting Physicians' Aid in Dying: Cross Sectional Survey' (2008) 337 *British Medical Journal* 1682.

[27] Linda Ganzini and Steven K Dobscha, 'If It Isn't Depression' (2003) 6 *Journal of Palliative Medicine* 927.

[28] Martha L Bruce et al, 'Reducing Suicidal Ideation and Depressive Symptoms in Depressed Older Primary Care Patients: A Randomized Controlled Trial.' (2004) 291 *Journal of the American Medical Association* 1081.

[29] Linda Ganzini et al, 'The Effect of Depression Treatment on Elderly Patients' Preferences For Life-Sustaining Medical Therapy' (1994) 151 *American Journal of Psychiatry* 1631.

[30] Linda Ganzini et al, 'Attitudes Of Oregon Psychiatrists Toward Physician-Assisted Suicide' (1996) 153 *American Journal of Psychiatry* 1469.

[31] Linda Ganzini et al, 'Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists' (2000) 157 *American Journal of Psychiatry* 595.

survey of forensic psychiatrists, 42 per cent did not agree that major depressive disorder should automatically exclude a patient from choosing assisted suicide.[32]

The prevalence of depression in individuals in Oregon who actually request PAD does not appear to be markedly higher than the prevalence of depression in terminally ill patients who have not made such requests. In a study of Oregonians who requested PAD and underwent rigorous assessment for depression, 26 per cent met criteria for major depressive disorder.[33] Studies of the prevalence of depression in patients with terminal illness who are not seeking PAD report proportions of 10 per cent to 25 per cent.[34] Hospice social workers and nurses rated depression as a relatively unimportant reason that Oregon hospice patients requested PAD. In fact, among 21 reasons, hospice social workers, who have substantial experience in evaluating the psychosocial state of patients at the end of life, rated depression as mostly unimportant.[35]

Though overall the burden of depression may be lower than anticipated among patients pursuing PAD, some depressed patients may access lethal prescriptions. In our study of 58 Oregonians who requested PAD, 18 received lethal prescriptions, including three patients who had met very rigorous criteria for depression. All three died by lethal ingestion within two months of the research interview, though in one case the depression was successfully treated before death and in the other two cases the patients denied that depression was influencing their decision.[36] This finding supports the need for more active and systematic screening and surveillance for depression to determine which patients should be referred for mental health evaluation. Despite this finding, the proportion of Oregon and Washington PAD decedents referred for mental health evaluation has remained very low and critics have called for mandatory mental health evaluation in all cases.[37] It is unknown how many patients were referred to mental health professionals who found the patient ineligible for a prescription—the health department data of these states only include information on persons who received prescriptions, not those found ineligible. With aforementioned problems with psychiatric evaluation, it remains unclear if mandatory psychiatric assessment would balance the protection of vulnerable persons with advancing patient autonomy, or if it would cast mental health professionals in the role of ethics consultants.[38]

V CONCLUSION

Oregon now has almost 18 years of experience with legalised PAD. In contrast to concerns that this practice would be common, and be chosen by socioeconomically vulnerable patients unable to access palliative care, studies and reports from the Oregon Public Health Division find that the practice is rare, accessed mostly by educated people with health insurance, most of who are receiving comprehensive end of life care through hospice. A small number of persons with depression do access the law, however, supporting the need for improved screening for mental illness.

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[32] Ibid.
[33] Ganzini, Goy and Dobscha, above n 26.
[34] Hotopf et al, above n 25.
[35] Linda Ganzini et al, 'Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide' (2002) 347 *New England Journal of Medicine* 582.
[36] Ganzini, Goy and Dobscha, above n 26.
[37] Oregon Public Health Division, above n 7.
[38] Mark D Sullivan, Linda Ganzini and Stuart J Youngner, 'Should Psychiatrists Serve As Gatekeepers For Physician Assisted Suicide?' (1998) 28 *Hastings Center Report* 14.

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PERMITTING VOLUNTARY EUTHANASIA AND ASSISTED SUICIDE: LAW REFORM PATHWAYS FOR COMMON LAW JURISDICTIONS

JOCELYN DOWNIE*

End-of-life law and policy reform is the subject of much discussion around the world. This paper explores the pathways to permissive legal regimes that have been tried in various common law jurisdictions. These include legislation, prosecutorial charging guidelines, court challenges, jury nullification, the exercise of prosecutorial discretion in the absence of offence-specific charging guidelines, and the exercise of judicial discretion in sentencing. In this paper, I describe these pathways as taken (or attempted) in five common law jurisdictions (USA, UK, Australia, New Zealand, and Canada) and reflect briefly on lessons that can be drawn from the recent experiences with law reform in Canada. Through its bird's eye view, it highlights the remarkable number and variable nature of past attempts at law reform and suggests a shifting tide. It debunks some common myths that have either limited or stymied reform in the past. Finally, it illuminates jurisdictional similarities and differences and lessons learned by those who have gone before so as to inform choices about pathways to pursue for those who will seek to advance a law reform agenda in the future.

I INTRODUCTION

End-of-life law and policy reform is the subject of much discussion around the world. Many jurisdictions, including Canada, have been actively exploring the issue of whether to move to more permissive regimes with respect to voluntary euthanasia and assisted suicide. However, this is not a paper on that well-travelled terrain. Rather, it explores the pathways to permissive legal regimes that have been tried in various common law jurisdictions.

There are, of course, a number of pathways to permissive legal regimes with respect to voluntary euthanasia and assisted suicide. These include legislation, prosecutorial charging guidelines, court challenges, jury nullification, the exercise of prosecutorial discretion in the absence of offence-specific charging guidelines, and the exercise of judicial discretion in sentencing. In this paper, I describe these pathways as taken (or attempted) in five common law jurisdictions (USA, UK,

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Australia, New Zealand, and Canada) and reflect briefly on lessons that can be drawn from the recent experiences with law reform in Canada.

I seek to gather into one place descriptions of law reform initiatives across a significant set of jurisdictions. This consolidation provides a useful resource for those simply seeking a record of past activities in order to do further comparative work across jurisdictions or across spans of time. Through its bird's eye view, it highlights the remarkable number and variable nature of past attempts at law reform and suggests a shifting tide. It debunks some common myths that have either limited or stymied reform in the past. Finally, it illuminates jurisdictional similarities and differences and lessons learned by those who have gone before so as to inform choices about pathways to pursue for those who will seek to advance a law reform agenda in the future.

II LOOKING BACKWARD

First, looking backward – what have the five subject common law jurisdictions tried with respect to permitting voluntary euthanasia and assisted suicide?

A *Legislation*

Canada has a long history of failed attempts at legislative reform at the federal level. There have been a host of bills and motions introduced in the Federal Parliament over more than two decades, none of which have been successful (see Table 1 below). In 2010, the most recent completed attempt at introducing a new Bill was defeated 59 – 228.[1]

Table 1: Unsuccessful Legislative Attempts in Canada

Date	Bill/Motion	Sponsor
March 1991	Bill C-351[2]	Robert Wenman
16 May 1991	Bill C-203[3]	Robert Wenman
19 June 1991	Bill C-261[4]	Chris Axworthy
December 1992	Bill C-385[5]	Svend Robinson
March 1993	Motion in house	Ian Waddell
November 1996	Bill S-13[6]	Sharon Carstairs
November 1997	Motion in house	Svend Robinson
April 1999	Bill S-29[7]	Thérèse Lavoie-Roux

[1] Bill C-384, *An Act To Amend The Criminal Code (Right To Die With Dignity)*, 2nd Sess, 40th Parl, 2009.
[2] Bill C-351, *An Act To Amend The Criminal Code (Terminally Ill Persons)*, 2nd Sess, 34th Parl, 1989-90-91.
[3] Bill C-203, *An Act To Amend The Criminal Code (Terminally Ill Persons)*, 3rd Sess, 34th Parl, 1991-92-93.
[4] Bill C-261, *An Act To Legalize The Administration Of Euthanasia Under Certain Conditions*, 3rd sess, 34th Parl, 1991-92-93.
[5] Bill C-385, *An Act To Amend The Criminal Code (Aiding Suicide*), 3rd Sess, 34th Parl, 1992.
[6] Bill S-13, *An Act To Amend The Criminal Code (Protection Of Health Care Providers)*, 2nd Sess, 35th Parl, 1996-97.
[7] Bill S-29, *An Act To Amend The Criminal Code (Protection Of Health Care Providers)*, 1st Sess, 36th Parl, 1997-98-99.

Date	Bill/Motion	Sponsor
February 2004	Bill C-215[8]	Svend Robinson
15 June 2005	Bill C-407[9]	Francine Lalonde
12 June 2008	Bill C-562[10]	Francine Lalonde
12 May 2009	Bill C-384[11]	Francine Lalonde

Other common law countries similarly have many occupants in their graveyards of unsuccessful bills (see Table 2 below). Attempts have been made, without success, in the United Kingdom, Australia[12], and New Zealand. That said, the defeats are becoming narrower over time. For example, in the United Kingdom, the most recent attempt was defeated in 2006 by a margin of 148 to 100, receiving the most support of any proposed end-of-life bill in the UK.[13] In Tasmania, the most recent attempt was defeated in 2013 by just two votes.[14]

Table 2: Unsuccessful Legislative Attempts in England and Wales, Scotland, Australia, New Zealand

Country	Date	Jurisdiction	Bill
England and Wales	2003		Patient (Assisted Dying) Bill[15]
	2004 2005		Assisted Dying for the Terminally Ill Bill[16]
	2009		Coroners and Justice Bill – Amendment Bill[17]
Scotland	2010		End of Life Assistance (Scotland) Bill[18]
Australia	2000 2003 2005	South Australia	Dignity in Dying Bill[19]

[8] Bill C-215, *An Act To Amend The Criminal Code (Consecutive Sentence For Use Of Firearm In Commission Of Offence)*, 1st Sess, 38th Parl, 2004.
[9] Bill C-407, An Act to amend the Criminal Code (right to die with dignity), 1st Sess, 38th Parl, 2005.
[10] Bill C-562, An Act To Amend The Criminal Code (Right To Die With Dignity), 2nd Sess, 39th Parl, 2008.
[11] Bill C-384, An Act To Amend The Criminal Code (Right To Die With Dignity), 2nd Sess, 40th Parl, 2009.
[12] For a thorough review of legislative attempts to reform the law in Australia, see Lindy Wilmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' *University of New South Wales Law Review* (forthcoming).
[13] Julia Shaw, 'Recent Developments in the Reform of English Law on Assisted Suicide' (2009) 16 *European Journal of Health Law* 333, 340.
[14] Voluntary Assisted Dying Bill 2013 (Tas); David Beniuk, 'Tasmania's Euthanasia Bill Fails Narrowly' News.com.au (online), 17 October 2013 <http://www.news.com.au/national/breaking-news/tasmanias-euthanasia-bill-fails-narrowly/story-e6frfku9-1226741999723>.
[15] Patient (Assisted Dying) Bill 2003 (UK).
[16] Assisted Dying for the Terminally Ill Bill 2004 (UK); Assisted Dying for the Terminally Ill Bill 2005 (UK).
[17] Coroners and Justice Bill – Amendment Bill 2009 (UK).
[18] End of Life Assistance (Scotland) Bill 2010 (Scot).
[19] Dignity in Dying Bill 2000 (SA); Dignity in Dying Bill 2003 (SA); Dignity in Dying Bill 2005 (SA).

Country	Date	Jurisdiction	Bill
Australia	1995 1996 2006 2007 2008 2010 2012	South Australia	Voluntary Euthanasia Bill[20]
	2008	South Australia	Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill[21]
	2008 2010	South Australia	Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill[22]
	2011	South Australia	Criminal Law Consolidation (Medical Defences - End of Life) Arrangements Amendment Bill[23]
	2013	South Australia	Ending Life with Dignity Bill[24] Ending Life with Dignity (No 2) Bill[25]
	2008	Victoria	Medical Treatment (Physician Assisted Dying) Bill[26]
	2009	Tasmania	Dying with Dignity Bill[27]
	2013		Voluntary Assisted Dying Bill[28]
	1993	Australian Capital Territory	Voluntary and Natural Death Bill[29]
	1995 1997		Medical Treatment (Amendment) Bill[30]
	1997		Euthanasia Referendum Bill[31]
	1997		Crimes (Assisted Suicide) Bill[32]
	1995 1997	Northern Territory	Rights of the Terminally Ill Bill[33] Criminal Code (Euthanasia) Amendment Bill[34]
	1997	NSW	Voluntary Euthanasia Referendum Bill[35]

[20] Voluntary Euthanasia Bill 1995 (SA); Voluntary Euthanasia Bill 1996 (SA); Voluntary Euthanasia Bill 2006 (SA); Voluntary Euthanasia Bill 2007 (SA); Voluntary Euthanasia Bill 2008 (SA); Voluntary Euthanasia Bill 2010 (SA); Voluntary Euthanasia Bill 2012 (SA).
[21] Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill 2008 (SA).
[22] Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2008 (SA); Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010 (SA).
[23] Criminal Law Consolidation (Medical Defences - End of Life) Arrangements Amendment Bill 2011 (SA).
[24] Ending Life with Dignity Bill 2013 (SA).
[25] Ending Life with Dignity (No 2) Bill 2013 (SA).
[26] Medical Treatment (Physician Assisted Dying) Bill 2008 (Vic).
[27] Dying with Dignity Bill 2009 (Tas).
[28] Voluntary Assisted Dying Bill 2013 (Tas).
[29] Voluntary and Natural Death Bill 1993 (ACT).
[30] Medical Treatment (Amendment) Bill 1995 (ACT); Medical Treatment (Amendment) Bill 1997 (ACT).
[31] Euthanasia Referendum Bill 1997 (ACT).
[32] Crimes (Assisted Suicide) Bill 1997 (ACT).
[33] Rights of the Terminally Ill Bill 1995 (NT). [Included here because subsequently repealed].
[34] Criminal Code (Euthanasia) Amendment Bill 1997 (NT).
[35] Voluntary Euthanasia Referendum Bill 1997 (NSW).

Country	Date	Jurisdiction	Bill
	2002 2003	New South Wales	Voluntary Euthanasia Trial (Referendum) Bill[36]
	2001 2003 2010 2013		Rights of the Terminally Ill Bill[37]
	2007	Commonwealth of Australia	Australian Territories Rights of the Terminally Ill Bill[38]
	2008		Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill[39]
	2010 2012		Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill[40]
New Zealand	1995 2003		Death With Dignity Bill[41]
	2013		End of Life Choice Bill[42]

In the United States, attempts have been unsuccessful in Washington (although it eventually succeeded there), California, Michigan, Massachusetts, and Maine.

Table 3: Unsuccessful Legislative Attempts in the United States

State	Date	Legislative Attempt
Washington	1991	Aid-in-Dying Initiative 119[43]
California	1992	Aid-in-Dying Act Proposition 161[44]
	1995	Bills AB 1080 and 1310[45]
	1999	Bill AB 1592[46]
	2005	Bill AB 654[47]

[36] Voluntary Euthanasia Trial (Referendum) Bill 2002 (NSW); Voluntary Euthanasia Trial (Referendum) Bill 2003 (NSW).

[37] Rights of the Terminally Ill Bill 2001 (NSW); Rights of the Terminally Ill Bill 2003 (NSW); Rights of the Terminally Ill Bill 2010 (NSW); Rights of the Terminally Ill Bill 2013 (NSW).

[38] Australian Territories Rights of the Terminally Ill Bill 2007 (Cth).

[39] Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 (Cth).

[40] Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2010 (Cth); Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2012 (Cth).

[41] Death With Dignity Bill 1995 (NZ). Vote recorded: Parliamentary Conscience Votes Database, *Death with Dignity 1995 Bill* (16 August 1995) <votes.wotfun.com/bill/33>; Death With Dignity Bill 2003 (NZ).

[42] End of Life Choice Bill 2012 (NZ) <http://www.parliament.nz/resource/0000197305>.

[43] Ballotpedia.org, *Washington Aid-in-Dying Initiative 119* (1991) <http://ballotpedia.org/Washington_Aid-in-Dying,_Initiative_119_(1991)>.

[44] Ballotpedia.org, *California Aid-in-Dying Act proposition 161* (1992) <http://ballotpedia.org/California_Proposition_161,_the_Aid-in-Dying_Act_(1992)>.

[45] US, AB 1080, AB 1310 *An Act To Add Chapter 3.95 (Commencing With Section 7195) To Part 1 Of Division 7 Of The Health And Safety Code, Relating To The Death With Dignity Act,* 1995-96, Reg Sess, Cal, 1995.

[46] US, AB 1592, *An Act To Add Chapter 3.95 (Commencing With Section 7195) To Part 1 Of Division 7 Of The Health And Safety Code, Relating To The Death With Dignity Act,* 1999-2000, Reg Sess, Cal, 1999.

[47] US, AB 654, *An Act To Add Chapter 3.95 (Commencing With Section 7195) To Part 1 Of Division 7 Of The Health And Safety Code, Relating To Death,* 2005-06, Reg Sess, Cal, 2005.

State	Date	Legislative Attempt
	2006	Bill AB 651[48]
Michigan	1998	Legalization of Lethal Medication to Terminally Ill, proposal B[49]
Massachusetts	2012	Death with Dignity initiative, question 2[50]
Maine	2000	Physician-assisted Deaths for Terminally Ill Adults, question 1[51]
	2013	An Act Regarding Patient-directed Care at the End of Life[52]

There have, however, also been some successes in moving toward permissive regimes through legislation.

On June 5, 2014, *An Act Respecting End-of-Life Care*, was passed by the National Assembly in Quebec by a vote of 94-22.[53] This Act establishes the right to end-of-life care and regulates 'continuous palliative sedation'[54] and 'medical aid in dying.'[55] More specifically, it legalises medical aid in dying in cases where an individual: 1) is at the end of life; 2) has an incurable disease; 3) is in an advanced state of irreversible decline; and 4) is experiencing unbearable and intolerable suffering.[56] The Act also establishes a Commission on end-of-life care to examine all matters relating to end-of-life care and to oversee the specific requirements relating to medical aid in dying.[57] This legislation was introduced at a provincial level because, in Canada, the criminal law falls within federal jurisdiction while the administration of health falls within provincial jurisdiction. The Bills listed in Table 1 were all introduced at the federal level and sought to change the *Criminal Code*. The Quebec legislation, in contrast, was cast as ensuring proper health care for individuals at the end of their lives.[58]

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[48] US, AB 651, *An Act To Amend Sections 14132.27 And 14132.100 Of The Welfare And Institutions Code, Relating To Medi-Cal*, 2005-06, Reg Sess, Cal, 2005.

[49] Ballotpedia.org, *Michigan Legalization of Lethal Medication to Terminally Ill, Proposal B* (1998) <http://ballotpedia.org/Michigan_Legalization_of_Lethal_Medication_to_Terminally_Ill,_Proposal_B_%281998%29>.

[50] Ballotpedia.org, *Massachusetts "Death with Dignity" Initiative, Question 2* (2012) <http://ballotpedia.org/Massachusetts_%22Death_with_Dignity%22_Initiative,_Question_2_%282012%29>.

[51] Ballotpedia.org, *Maine Physician-Assisted Deaths for Terminally Ill Adults, Question* 1 (2000) <http://ballotpedia.org/Maine_Physician-Assisted_Deaths_for_Terminally_Ill_Adults,_Question_1_%282000%29>.

[52] US, LD 1065, *An Act Regarding Patient-directed Care at the End of Life*, 126th Maine Legislature, Reg Sess, Me, 2013.

[53] Bill 52, An Act Respecting End-of-Life, 1st Sess, 41st Leg, 2014.

[54] Ibid 3(5) "continuous palliative sedation" means care that is offered as part of palliative care and consists in administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues.

[55] Ibid 3(6) "medical aid in dying" means care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death.

[56] Ibid 26.

[57] Ibid 35.

[58] The question of whether Quebec has jurisdiction to legislate in this way was before the Supreme Court of Canada in *Carter v Canada (Attorney General),* 2015 SCC 5: 'Are the impugned laws constitutionally inapplicable to PAD [physician-assisted death] by reason of the doctrine of interjurisdictional immunity?', Supreme Court of Canada, *Case Information 35591* <http://www.scc-csc.gc.ca/case-dossier/info/sum-som-eng.aspx?cas=35591> and see arguments as presented by parties and intervenors: Supreme Court of Canada, *Factums 35591* (17 March 2015) <http://www.scc-csc.gc.ca/case-dossier/info/fac-mem-eng.aspx?cas=35591>. The Supreme Court of Canada concluded that

There have also been some successes outside Canada. Voluntary euthanasia was briefly legal in the Northern Territory in Australia by virtue of the *Rights of the Terminally Ill Act* of 1995.[59] However, this success was only temporary as it was rendered of no force and effect by the *Euthanasia Laws Act* of the federal parliament in 1997.[60]

More long-lasting success has been enjoyed in the United States. Successful legislative reform started in Oregon in 1997, followed by Washington State in 2008, and Vermont in 2013. Law reform in both Oregon and Washington was initiated by ballot initiatives and in Vermont it was initiated by the legislature. All of these states now have statutes that establish a permissive (circumscribed and regulated) regime for assisted suicide for terminally ill competent adults.

Table 4: Successful Legislative Attempts in the United States

State	Date	Legislation
Oregon	1994	Measure 16, 'Allows Terminally ill adults to obtain prescription for lethal drugs'[61]
	1997	*Death with Dignity Act*[62]
Washington	2008	Initiative 1000, 'Assisted Death Initiative'[63]
	2008	*Death with Dignity Act*[64]
Vermont	2013	*An Act Relating to Patient Choice and Control at End of Life*[65]

In sum, there have, to date, been more failures than successes in efforts to establish more permissive regimes with respect to voluntary euthanasia and assisted suicide through legislation. That said, there have been some significant successes in Canada and the United States, close votes in other jurisdictions, and it appears that the pace of change along this pathway may be picking up (see below, 'Looking Forward').

> [i]n our view, the appellants have not established that the prohibition on physician-assisted dying impairs the core of the provincial jurisdiction. Health is an area of concurrent jurisdiction; both Parliament and the provinces may validly legislate on the topic: *RJR-MacDonald Inc. v Canada (Attorney General)*, [1995] 3 SCR 199, [32]; *Schneider v The Queen*, [1982] 2 SCR 112, 142. This suggests that aspects of physician-assisted dying may be the subject of valid legislation by both levels of government, depending on the circumstances and focus of the legislation. We are not satisfied on the record before us that the provincial power over health excludes the power of the federal Parliament to legislate on physician-assisted dying. It follows that the interjurisdictional immunity claim cannot succeed. [53].

[59] *Rights of the Terminally Ill Act 1995* (NT) held to be valid in *Wake v Northern Territory* (1996) 109 NTR 1; rendered of no force and effect by *Euthanasia Laws Act 1997* (Cth).

[60] *Euthanasia Laws Act 1997* (Cth).

[61] Ballotpedia.org, *Oregon Death with Dignity Measure 16* (1994) <http://ballotpedia.org/Oregon_%22Death_with_Dignity%22,_Measure_16_%281994%29>.

[62] *Death with Dignity Act* ORS 127.800-995 (1997).

[63] Ballotpedia.org, 'Washington "Death with Dignity Act" Initiative 1000' (2008) <http://ballotpedia.org/Washington_%22Death_with_Dignity_Act%22,_Initiative_1000_%282008%29>.

[64] *Death with Dignity Act* RCW 70.245 (2008).

[65] *An Act Relating to Patient Choice and Control at End of Life* 18 VSA 113 (2013).

B *Guidelines for the Exercise of Prosecutorial Discretion*

Offence-specific guidelines for how prosecutorial discretion should be exercised in cases of assisted suicide and voluntary euthanasia may also be a pathway to a more permissive legal regime. In Canada, many people point to the British Columbia 'Crown Counsel Policy Manual: Euthanasia and Assisted Suicide'[66] as evidence of some euthanasia or assisted suicide being permitted through guidelines for the exercise of prosecutorial discretion. However, these guidelines do not in fact perform that function. The Guidelines are useful in clarifying the difference between conduct that will not be prosecuted (palliative care and withholding or withdrawal of treatment) and conduct that will be prosecuted (all cases of euthanasia and assisted suicide, and those cases of palliative care and withholding or withdrawal that were not provided or administered according to accepted ethical medical standards). However, they do not expand the circumstances in which voluntary euthanasia or assisted suicide will not be prosecuted.[67]

In England and Wales, however, there are charging guidelines that explicitly address assisted suicide and arguably render the system more permissive. The first attempt at compelling the creation of these prosecutorial charging guidelines was the case of Ms Diane Pretty.[68] Ms Pretty suffered from advanced motor neuron disease and hoped that her husband could assist her to end her life. She sought immunity from prosecution for her husband from the Director of Public Prosecutions ('DPP') but this was denied by the courts. The court held that the DPP had no power to undertake that a crime yet to be committed and should be immune from prosecution because this power required Parliamentary consent.[69] Ms Pretty was also unsuccessful in her challenge to the European Court of Human Rights under the *European Convention for the Protection of Human Rights and Fundamental Freedoms*.[70]

The second attempt at compelling the creation of prosecutorial charging guidelines was successful. Ms Debbie Purdy, a woman with primary progressive multiple sclerosis, wanted to travel with her husband's assistance to a jurisdiction where assisted suicide was lawful. Ms Purdy was concerned that her husband might be prosecuted for assisting in her suicide. She requested information from the DPP about the factors that would be considered when deciding whether to prosecute someone for assisted suicide.[71] When the DPP declined to provide such information, Ms Purdy challenged that decision. The House of Lords held that Ms Purdy, under her right to 'respect for private life' in Article 8 of the *European Convention for the Protection of Human Rights and Fundamental Freedoms*, had a right to know what factors the DPP used to decide whether or not to prosecute someone for assisted suicide. The court concluded there was a disparity between the prohibition and practice and directed the DPP to release an offence-specific policy to address this disparity.[72]

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[66] British Columbia, Ministry of Attorney General, 'Crown Counsel Policy Manual: Euthanasia and Assisted Suicide', Criminal Justice Branch (BC: AG 200) <http://www.ag.gov.bc.ca/prosecution-service/policy-man/pdf/EUT1-EuthanasiaAndAssistedSuicide-15Mar2004.pdf>.

[67] For a proposal for permissive prosecutorial charging guidelines in Canada, see Jocelyn Downie and Ben White, 'Prosecutorial Discretion in Assisted Dying in Canada: A Proposal for Charging Guidelines' (2012) 6(2) *McGill Journal of Law and Health* 113.

[68] *R (on the application of Pretty) v Director of Public Prosecutions* [2001] UKHL 61.

[69] Ibid para 39.

[70] *Pretty v the United Kingdom* [2002] ECHR 427, ECHR 2346/02.

[71] *R (on the application of Purdy) v Director of Public Prosecutions* [2010] 1 AC 345.

[72] Ibid.

In response, the DPP issued the 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide'[73] which establishes 16 factors that favour prosecution and six factors that tend against it.

The Policy faced a subsequent challenge in *R (Nicklinson & Lamb) v Ministry of Justice*.[74] In this case, a man using the pseudonym Martin had suffered a brain stem stroke which left him very severely disabled and, eventually, with a wish to end his life but a need for assistance in doing so.[75] Without a family member willing to assist him to die, he wanted the assistance of a health care worker, a member of the public, or a solicitor. However, he was unsure whether they would be prosecuted if they helped him. Martin challenged the lack of clarity in the DPP prosecutorial charging guidelines with respect to health care providers. On July 31, 2013, the Court of Appeal held that the Policy was not sufficiently clear and urged the DPP to clarify the prosecution criteria with respect to health care workers. The Supreme Court, in turn, unanimously allowed the DPP's appeal and found that 'the Court should [not] involve itself with the terms of the DPP's policy on assisted suicide.'[76]

It should be noted here, however, that during the trial, counsel for the DPP stated on instructions from the DPP, that it was the view of the DPP that a professional care-worker, who does not have previous influence or authority over the person wishing to die and provides services, would not be more likely to be prosecuted than a family member for providing assistance with death. The Supreme Court majority noted the confusion over the content and interpretation of the Policy and the appearance that the Policy 'does not appear to reflect what the DPP intends'[77] and indicated that the DPP has an obligation to clarify any confusion about the meaning of the Policy.[78] If the DPP does not meet that obligation, Lord Neuberger stated 'the court's powers could be properly invoked to require appropriate action.'[79] Until the Policy is clarified, it seems unlikely that a professional care-worker will be prosecuted for providing assistance with death.

There is no evidence that definitively demonstrates that the legal regime in the UK is more permissive with respect to assisted suicide than it was before the introduction of the Policy and it is true that the criminal law has not changed. However, there are some indicators of an increase in permissibility. It is clear from the official reports that conduct that clearly constitutes assisted

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[73] England and Wales, Director of Public Prosecutions, *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide* (DPP, 2010) <www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf>. Following the *Purdy* case, the Director of the Public Prosecution Service for Northern Ireland issued a policy to similar effect: Public Prosecution Service for Northern Island, *Policy on Prosecuting the Offence of Assisted Suicide* (2010) <http://www.ppsni.gov.uk/SiteDocuments/PPS%20Press%20Office/Policy%20on%20Prosecuting%20the%20Offence%20of%20Assisted%20Suicide.pdf>. The Scottish Lord Advocate Elish Angiolini stated that the DPP's policy would apply only to England and Wales and that she believed that any changes in law in Scotland rested with the Scottish Parliament. See Hector L MacQueen and Scott Wortley, 'Lord Advocate's Statement on Assisted Suicide' *Scots Law News* (Scotland), 23 September 2009 <http://www.sln.law.ed.ac.uk/2009/09/23/lord-advocates-statement-on-assisted-suicide/>.

[74] *R (Nicklinson & Lamb) v Ministry of Justice* [2013] EWCA Civ 961.

[75] Ibid [9].

[76] *R (Nicklinson & Lamb) v Ministry of Justice*; *R (AM) v Director of Public Prosecutions* [2014] UKSC 38, 148.

[77] Ibid 146.

[78] Ibid 142-143.

[79] Ibid 146.

suicide is not being prosecuted (as prosecution is seen as not being in the public interest) and that only a small number of cases of assisted suicide are still being prosecuted. The DPP reports every six months on the 'Latest Assisted Suicide Figures.' From April 1, 2009 to February 13, 2014,

> there have been 91 cases referred to the CPS by the police that have been recorded as assisted suicide or euthanasia. Of these 91 cases, 65 were not proceeded with by the CPS, 13 cases were withdrawn by the police. There are currently 8 ongoing cases, 1 case of assisted attempted suicide was successfully prosecuted in October 2013 and 4 cases were referred onwards for prosecution for murder or serious assault.[80]

There is also evidence of an increase in the number of individuals from Great Britain dying as a result of assisted suicide in Switzerland following the publication of the DPP Policy.[81]

In sum it can be seen that prosecutorial charging guidelines may be a path to a somewhat permissive legal regime with respect to voluntary euthanasia or assisted suicide in some circumstances.[82] Use of this path, however, has been exceedingly rare.

C *Court Challenges to Prohibitive Regimes*

1 *Unsuccessful*

In Canada, there have been two unsuccessful court cases.[83] The first, and most famous, was the case of Sue Rodriguez in 1993.[84] Ms Rodriguez, a woman with ALS, argued that the Criminal Code prohibitions on assisted suicide violated her rights with respect to equality (section 15)[85] and the right not to be deprived of life, liberty, or security of the person except in accordance with the principles of fundamental justice (section 7)[86] and that these violations were not demonstrably

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[80] Crown Prosecution Service, *Assisted Suicide: Latest Assisted Suicide Figures* (2014) <http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html>.

[81] Sasika Gauthier et al, 'Suicide Tourism: A Pilot Study on the Swiss Phenomenon' (2014) *Journal of Medical Ethics* (online) <http://jme.bmj.com/content/early/2014/07/03/medethics-2014-102091.abstract>.

[82] On the release of the Policy, the Director of Public Prosecutions said 'The policy does not change the law on assisted suicide. It does not open the door for euthanasia. It does not override the will of Parliament. What it does is to provide a clear framework for prosecutors to decide which cases should proceed to court and which should not.' By 'permissive' I therefore mean 'not subject to prosecution' as opposed to 'expressly allowed by statute.' Crown Prosecution Service, *Assisted Suicide* (2010) <http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html>.

[83] The LeBlanc case will not be discussed here because, while Ginette LeBlanc challenged the Criminal Code provisions that serve to prohibit assisted dying, she died before her case could be heard. *Ginette LeBlanc v Canada (Attorney General) and Quebec (Attorney General)*, October 31, 2011 (Notice of Claim) <http://choiceisanillusion.files.wordpress.com/2012/01/ leblanc_ncc_001.pdf>.

[84] *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519.

[85] *Canadian Charter of Rights and Freedoms*, s 15, *Constitution Act 1982,* Part I, being Schedule B to the *Canada Act 1982* (UK) c 11 provides that '(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.'

[86] Section 7 of the *Charter* provides that 'Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.' The principles of fundamental justice are not a closed set but include, for example, arbitrariness, vagueness, overbreadth, and gross disproportionality.

justified in a free and democratic society (section 1).[87] She was unsuccessful at the Supreme Court of Canada by a margin of one vote. The case, in large part, hinged on the view that it was reasonable to fear the slippery slope. Justice Sopinka, for the majority, relied on concerns that exceptions to the blanket prohibition could not be relied upon to prevent abuses and effectively protect the vulnerable. The majority 'assumed without deciding' a violation of equality rights but found that was saved by section 1 and found that the limits on the right to life, liberty, and security of the person were in accordance with the principles of fundamental justice and so there was no violation of section 7. The later case of *Wakeford* in 2001 was another challenge to the same provisions.[88] It failed to progress on the grounds that the matter had already been determined by the Supreme Court of Canada in *Rodriguez*. The plaintiff conceded that the adjudicative facts had not changed since *Rodriguez* and he had not demonstrated that the legislative facts had changed sufficiently.

2 *Other Common Law Jurisdictions Have Also Seen Unsuccessful Cases*

The US Supreme Court has ruled unanimously that there is no constitutional right to assisted suicide. In *Washington v Glucksberg*, in a challenge by a group of physicians and Compassion in Dying to Washington State's prohibition of assisted suicide, the US Supreme Court concluded that assistance in suicide is not a fundamental liberty interest protected by the due process clause of the US Constitution.[89] In *Vacco v Quill*, a group of physicians challenged the New York State prohibition of assisted suicide as violating patients' equal protection rights under the US Constitution.[90] The District Court ruled against them, the Court of Appeals reversed the decision, but the US Supreme Court ultimately also ruled against them – finding the legislation did not infringe a fundamental right. However, it is worth noting here that this case and *Glucksberg* have been taken by many as an invitation for states to legislate in this arena – they do not have to under the US Constitution (it is not a federal constitutional violation to prohibit assisted death) but they are free to (criminal law is a state matter).

In *Kirsher v McIver*, a patient and his physician argued that Florida's prohibition of assisted suicide violated the privacy clause of the Florida Constitution and the due process and equal protection clauses of the US Constitution.[91] The trial judge agreed with the privacy and equal protection arguments but not the due process argument. However, the Florida Supreme Court overturned the decision (following *Vacco* and *Glucksberg* on the US Constitution arguments and concluding that the privacy amendment of the Florida Constitution does not include a right to assisted suicide). It too, though, issued an invitation for permissive legislation: 'We do not hold that a carefully crafted

[87] Section 1 of the *Charter* provides that 'The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society. Under the *Charter*, the plaintiff must first demonstrate a violation of one or more of their *Charter* rights. If successful in persuading the court of the violation, the burden shifts to the government who must demonstrate that the limits on the right are 'demonstrably justified in a free and democratic society.' That is, the limits must serve a pressing and substantial objective, there must be a rational connection between the ends and the means, the limits must minimally impair the rights, and there must be proportionality between the ends and means as well as between the salutary and deleterious effects of the challenged law.

[88] *Wakeford v Canada* (2001), 81 CRR (2d) 342, upheld in *Wakeford v Canada* 91 CRR (2d) 213, leave to appeal denied SCC 2002.

[89] *Washington v Glucksberg* 521 US 702 (1997) USSC.

[90] *Vacco v Quill* 521 US 793 (1997) USSC.

[91] *Krischer v McIver* 697 So.2d 97, 100, 104 (Fla 1997).

statute authorizing assisted suicide would be unconstitutional.'[92] In *Sampson v Alaska* in 1998, two terminally ill patients challenged the prohibition of assisted suicide as violating their constitutional rights to privacy and liberty but were unsuccessful.[93] The Superior Court ruled that the prohibition did not violate the state's constitution and that decision was affirmed by the State Supreme Court.

In the United Kingdom, Tony Nicklinson and Paul Lamb argued for the recognition of the defence of necessity for individuals who assist in suicide and challenged the prohibition of assisted suicide in section 2 of the *Suicide Act* [94] under Article 8 of the *European Convention on Human Rights* (the right to respect for private and family life).[95] Both of these claims were unsuccessful at the Court of Appeal.[96] A further appeal was heard by the Supreme Court of the United Kingdom in December 2013. On June 25, 2014, the Supreme Court, by a majority of seven to two, dismissed the appeals.[97] In response to the first argument, Lord Neuberger concluded that applying the defence of necessity to a charge of assisted suicide would be 'wholly inconsistent with both recent judicial dicta of high authority, and the legislature's intentions.'[98] In response to the second argument, a slim majority, five Justices, concluded that the court has constitutional authority to make a declaration that the general prohibition on assisted suicide in section 2 is incompatible with Article 8 of the *ECHR*. However, the Justices declined to do so in this case; instead they urged Parliament to take the opportunity to address the issue through legislation in the near future. Lord Neuberger, writing for the majority, held that 'Parliament now has the opportunity to address the issue of whether section 2 [of the *Suicide Act*] should be relaxed or modified, and if so how, in the knowledge that, if it is not satisfactorily addressed there is a real prospect that a further, and successful, application for a declaration of incompatibility may be made.'[99] Though the Supreme Court did not make a declaration of incompatibility in this case, they did send a strong message to Parliament to address the issue in the near future and hinted that if another challenge reached the court in the future, it would likely be successful.

3 *Successful*

In the United States, there has been success in the more recent cases. Courts have held that the criminal law does not prohibit assisted suicide in some circumstances (*Baxter v Montana*)[100] or that state constitutional rights protect assisted suicide in some circumstances (*Morris v Brandenberg*).[101]

In *Baxter v Montana*, the Supreme Court of Montana held that physicians who provide 'aid in dying' (so termed and limited to assisted suicide by the court) to terminally ill, mentally competent adult patients are shielded from criminal liability by the patient's consent. The court did not address

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[92] Ibid 104.
[93] *Sampson and Doe v State of Alaska* 31 P 3d 88 (Alaska Supreme Court 2001).
[94] *Suicide Act 1961* (UK).
[95] *Nicklinson v Ministry of Justice; R (AM) v Director of Public Prosecutions* [2012] EWHC 2381.
[96] *R (Nicklinson & Lamb) v Ministry of Justice* [2013] EWCA Civ 961.
[97] *R (Nicklinson & Lamb) v Ministry of Justice*; *R (AM) v Director of Public Prosecutions* [2014] UKSC 38, 148.
[98] Ibid 130.
[99] Ibid 118.
[100] *Baxter v Montana* 2009 WL 5155363.
[101] *Morris v Brandenberg* No. D-202-CV 2012-02909 (NM 2d Jud Dist Jan 13, 2014).

the constitutional rights arguments and instead decided the case based on state criminal law.[102] Montana criminal law provides that consent to a criminal act is a defense unless it is against public policy. The Supreme Court held that a patient's end-of-life autonomy and a physician's duty to comply with patient's wishes are reflected in state law and therefore are not against public policy. As a result, a patient's consent to the prescription of lethal drugs is an adequate defense to the crime of homicide in situations when a competent, terminally ill patient makes the decision whether or not to take the prescribed medication.[103]

In *Morris v Brandenberg*,[104] the Second Judicial District Court of New Mexico held that the liberty, safety and happiness interest of a competent, terminally ill patient to choose 'aid in dying' (again so termed and limited to assisted suicide by the court) is a fundamental right under the Constitution of the State of New Mexico. In deciding that the due process clause of the New Mexico Constitution contains a right to choose aid in dying, the court recognised that the US Supreme Court had denied the existence of this right under the US Constitution, but found that the New Mexico Constitution provides more rights than the federal constitution.

There has also been a dramatic success in a recent case in Canada. Kay Carter and Gloria Taylor, two women dying from degenerative conditions, believed that the Canadian Criminal Code prohibitions on assisted death violated their Charter rights – their section 15 equality rights and their section 7 right not to be deprived of life, liberty, and security of the person except in accordance with the principles of fundamental justice. After consideration of a truly extraordinary volume of evidence, Justice Lynn Smith of the British Columbia Supreme Court, struck down the Criminal Code prohibitions on assisted death – finding they violate section 7 and section 15 and are not demonstrably justified in a free and democratic society.[105] She rejected the slippery slope arguments and found that palliative care would not suffer and that the vulnerable could be protected from abuse if assisted death was made available only to individuals who met certain conditions. Not surprisingly, the Government appealed to the British Columbia Court of Appeal. Justice Smith's decision was overturned but it is very important to understand the basis of the court's decision.[106] By a 2:1 margin, the Court of Appeal allowed the appeal on the grounds of stare decisis – concluding that the issue had been decided by the Supreme Court of Canada in the 1993 case of Sue Rodriguez and so it was not for a trial judge to oust the Supreme Court's ruling – only the Supreme Court of Canada can overturn Supreme Court of Canada judgments. It is important to emphasise that the Court of Appeal did not reject Justice Smith's arguments with respect to equality, life, liberty, and security of the person, and the principles of fundamental justice. The Court of Appeal did not (nor could it) dislodge the findings of fact made by Justice Smith regarding palliative care and slippery slopes. The case proceeded to the Supreme Court of

[102] *Baxter v Montana* 2009 WL 5155363, 10.
[103] Ibid 38.
[104] No. D-202-CV 2012-02909 (NM 2d Jud Dist Jan 13, 2014).
[105] *Carter v Canada (Attorney General)* 2012 BCSC 886. Justice Smith described the evidentiary record as follows, at [114]: 36 binders of affidavits, transcripts and documents entered through admission. There were 116 affidavits filed. Some of these run to hundreds of pages in length and attach as exhibits many secondary sources. In addition, 18 witnesses were cross-examined on their affidavits, including 11 witnesses who were cross-examined on their affidavits before the Court.
[106] *Carter v Canada (Attorney General)* 2013 BCCA 435.

Canada (who obviously did not have their hands tied by the principle of vertical stare decisis).[107] The arguments were heard in mid-October 2014 and the decision was released on 6 February, 2015.[108] The Supreme Court of Canada, in a unanimous decision authored by 'The Court', held that: the prohibitions on physician-assisted death violate the section 7 rights to life, liberty, and security of the person; they are overbroad and therefore not in accordance with the principles of fundamental justice (catching more people in the prohibitive net than required to serve the objective of protecting the vulnerable); the prohibitions do not minimally impair the rights (a regime less restrictive of life, liberty, and security of the person could address the risks associated with physician-assisted death); and therefore the legislation is not demonstrably justified in a free and democratic society and so cannot be saved under section 1.

The trial judge made a series of factual findings that were critical to her decision, were endorsed or relied upon by the Supreme Court of Canada, and are relevant to other jurisdictions contemplating law reform.

- 'vulnerability can be assessed on an individual basis using the procedures physicians apply in their assessment of informed consent and decision capacity in the context of medical decision-making more generally.'[109]
- 'no evidence from permissive regimes that people with disabilities are at heightened risk of accessing physician-assisted dying.'[110]
- 'no evidence of inordinate impact on socially vulnerable populations in permissive jurisdictions'[111]
- 'in some cases palliative care actually improved post-legalisation'[112]
- 'physicians were better able to provide overall end-of-life treatment once assisted death legalised.'[113]
- 'The trial judge, after an exhaustive review of the evidence, rejected the argument that adoption of a regulatory regime would initiate a descent down a slippery slope into homicide.'[114]

The Supreme Court of Canada issued the following declaration:

> [t]hat s. 241 (b) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability)

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[107] See for example: *Canada v Craig* [2012] SCC 43 which overturned *Moldowan* to allow a more generous interpretation of farming under the *Income Tax Act*; *United States of America v Burns* [2001] 195 DLR 1 which overturned *Kindler v Canada* in finding that the extradition of individuals to places where they may face the death penalty breached section 7 of the Charter; *R v Robinson* [1996] 1 SCR 683 which overturned *MacAskill v The King* on admissibility of intoxication evidence; *R v B(KG)* [1993] 1 SCR 740 which overturned *Deacon v The King* on admissibility of prior inconsistent statements; *Brooks v Safeway Canada* [1989] 1 SCR 1219 which over turned *Bliss v Canada* to find that pregnancy policies are considered discrimination on the basis of sex.

[108] *Carter v Canada (Attorney General)* 2015 SCC 5.

[109] *Carter v Canada (Attorney General)* 2015 SCC 5, 115.

[110] Ibid 107.

[111] Ibid.

[112] Ibid.

[113] Ibid.

[114] Ibid 120.

> that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. 'Irremediable,' it should be added, does not require the patient to undertake treatments that are not acceptable to the individual.[115]

The Supreme Court of Canada then suspended the declaration of invalidity for 12 months to give federal/provincial/territorial governments time to develop and implement a regulatory framework for physician-assisted death.

As a consequence of these cases, assisted death can, in some circumstances in parts of the US and all of Canada (as of February 2016) proceed without (or with less) fear of prosecution. Again, there have been fewer successes than failures but, with the recent successes, the tide may have turned on this pathway to law reform.

4 *Jury Nullification*

Jury nullification occurs when a jury acquits because its members disagree with the application of the law in a particular instance (the offence and/or the sentence attached to the offence), because they believe that the law is simply unjust or that the application of the law in the specific case would be unjust.

Canada has a dramatic history with respect to jury nullification in the context of contentious moral issues. Dr Henry Morgentaler publicly operated an abortion clinic for several years before being charged under s 251 of the Criminal Code for intending to procure the miscarriage of a female person. At his first jury trial, Morgentaler admitted to performing over 5000 abortions but he argued the defence of necessity and was acquitted by the jury. Between 1973 and 1975, Morgentaler was tried three more times by the Quebec Crown. He was acquitted by the jury each time and in the third trial, the jury only deliberated for one hour before returning their verdict.[116] It became clear to the Quebec Crown that even if Morgentaler admitted to performing abortions, Quebec juries would not convict him. This became known as the Morgentaler phenomenon.[117]

In a 1976 trial, Morgentaler's defence counsel, Morris Manning, told the jury that 'it is up to you and you alone to apply the law to this evidence and you have a right to say it shouldn't be applied.'[118] On appeal, the Supreme Court of Canada held that, while the jury has the power to disregard the law, Manning was wrong to tell the jury members that if they did not like the law they need not enforce it.[119] This decision has been interpreted to mean that jury nullification is still a valid component of the Canadian justice system but lawyers are not allowed to tell the jury that jury nullification is an option.

In 1976, the newly appointed Justice Minister in Quebec, Marc-Andre Bedard, dropped all charges against Morgentaler and announced that the Crown would not lay any more charges against doctors

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[115] Ibid 127.
[116] Wayne Sumner, 'The Morgentaler Effect', *The Walrus Magazine* (2011) <http://thewalrus.ca/the-morgentaler-effect>.
[117] Ibid.
[118] *R v Morgentaler* [1988] 1 SCR 30, 77.
[119] Ibid.

performing clinic abortions in Quebec.[120] Morgentaler then began operating abortion clinics in Winnipeg and Toronto where he was predictably charged under s 251 of the Criminal Code. He went to trial, argued the defence of necessity, and was acquitted by juries every time.[121]

While there have been no reported cases of jury nullification in the context of voluntary euthanasia or assisted suicide in Canada, the issue has surfaced in two ways. First, in testimony before the Special Senate Committee on Euthanasia and Assisted Suicide on 12 December, 1994, David Thomas, a Crown prosecutor, explained his decision to charge Dr de la Rocha with administering a noxious substance with intent to cause bodily harm instead of murder as follows: 'if we went to trial, we would see 12 common folk from Timmins kind of chart the course for euthanasia at this point in time.'[122] It is possible that a number of the decisions with respect to the exercise of prosecutorial discretion discussed below can be traced to a similar fear of jury nullification and a repeat of the Morgentaler phenomenon.

Second, in the Robert Latimer case, the prospect of jury nullification was certainly viable (given the differing opinions on euthanasia among the Canadian public).[123] Robert Latimer was charged with murder in the death of his severely disabled daughter Tracy in circumstances that might well have been conducive to jury nullification (constant pain and repeated surgeries). However, Mr Latimer's lawyer was precluded from alluding to jury nullification as a result of the Supreme Court of Canada decision in *Morgentaler*. Furthermore, despite Latimer's lawyer requesting that the jury be told of the mandatory minimum sentence for murder and the jury having asked the judge a specific question about the sentence that would attach to a conviction,[124] the jury was not informed about the sentence that would or could attach. After the fact, and very unusually as Canadian jurors are prohibited from disclosing jury discussions,[125] some jurors indicated that had they known that there would be a mandatory sentence of life imprisonment with no possibility of parole for 25 or 10 years (for first and second degree murder respectively), they would not have convicted Latimer of murder in the death of his daughter.[126]

Jury nullification has also played a significant role in assisted suicide cases in the United States. In Michigan, Dr Jack Kevorkian was charged with assisting the suicide of Thomas Hyde, a 30-

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[120] Dave Thomas, 'Quebec Drops Case Against Morgentaler' *The Montreal Gazette* (Montreal) 11 December 1976 <http://news.google.com/newspapers?nid=1946&dat=19761211&id=2R4uAAAAIBAJ&sjid=eqEFAAAAIBAJ&pg=4579,2551456>.

[121] *R v Morgentaler, Smoling and Scott* [1985] ONCA 116.

[122] Mr David Thomas, Crown Attorney's Office, Timmins, Ontario, testimony before the Special Senate Committee on Euthanasia and Assisted Suicide. Senate Special Cttee No 29 (12 Dec 1994) 42-3.

[123] In 1994, at the time of the Latimer trial, 69 per cent of Canadians believed that assisting suicide should not be charged as a crime. The Environics Institute, 'Canadian Public Opinion on Assisted Suicide' (Toronto) October 11 2013 <http://www.environicsinstitute.org/news-events/news-events/canadian-public-opinion-on-assisted-suicide>.

[124] The jury requested more information about sentencing, including 'Is there any possible way we can have input into a recommendation for sentencing?' Justice Noble declined to give them information about sentencing and emphasised that it was the jury's role to focus on the issue of guilt and innocence, not on the penalty. Michael Stingl, *The Price of Compassion: Assisted Suicide and Euthanasia* (Broadview Press, 2010) 78.

[125] Criminal Code, RS 1985 c C-46, s 469. Pursuant to section 649 of the Criminal Code, 'any jury member…who discloses any information relating to the proceedings of the jury when it was absent from the courtroom that was not subsequently disclosed in open court is guilty of an offence.'

[126] The Canadian Press, 'Robert Latimer Deserves Parole: Jury Member' *CTV News* (online) 23 December 2007 <http://www.ctvnews.ca/robert-latimer-deserves-parole-jury-member-1.268689>.

year-old with Lou Gehrig's disease. Before his jury trial, Kevorkian's lawyer, Geoffrey Fieger, told media outlets that he would urge the jury to disregard the law.[127] At a pre-trial motion, Fieger was banned from communicating with the media but his comments had already been extensively reported across the United States.[128] At trial, Kevorkian admitted to placing a mask connected to a canister of carbon monoxide on Hyde's face and placing a string to release the gas in Hyde's hand. Despite this evidence, the jury acquitted him. Between 1994 and 1997, Kevorkian was tried four more times for assisting suicides and was acquitted three times by juries (the fourth ended in a mistrial).[129] It is possible that some or all of these acquittals were cases of jury nullification. By 1998, Dr Kevorkian had assisted in 100 suicides and had yet to be found guilty. Eventually, Kevorkian was found guilty of second-degree murder after he released a video of himself giving a lethal injection to Thomas Youk.[130]

Thus it can be concluded that jury nullification might but has not yet had a transformative effect on the application of any prohibitive criminal law regime.

5 *Exercise of Prosecutorial Discretion in the Absence of Offence-Specific Charging Guidelines/Judicial Discretion in Sentencing*

While murder carries mandatory minimum sentences in Canada, cases of assisted death often end in charges and convictions for lesser offences (eg, administration of a noxious substance or manslaughter), which do not. Many cases of assisted death begin with a murder charge (first or second degree) but result in a guilty plea for a lesser offence such as administering a noxious substance. Prosecutors are using their discretion in plea bargaining to reduce the seriousness of the state's response to the conduct. Furthermore, unlike murder, the lesser offences noted above do not carry a mandatory minimum sentence. Therefore, judges often have the opportunity to exercise discretion in sentencing in assisted death cases. The results of prosecutions given in reported cases to date are set out in the table below:

Table 5: Results in Reported Canadian Prosecutions

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Mataya, 1992 CarswellOnt 5214, Ont Ct J (August 24, 1992)	First-degree murder	Pled guilty to administering a noxious substance	Life	3 year suspended sentence
R v de la Rocha, 1993WL1447201 (2 April 1993), Timmins (Ont Ct (Gen Div))	Second-degree murder	Pled guilty to administering a noxious substance to endanger life	Life	3 year suspended sentence

[127] Ralph Slovenko, 'Jury Nullification' (1994) *The Journal of Psychiatry and Law* 22, 165.
[128] Ibid 165.
[129] Fred Charatan, 'Dr Kevorkian Found Guilty Of Second Degree Murder' (1999) 318 *British Medical Journal* 7189.
[130] Ibid.

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Myers, [1994] NJ No 688 (23 Dec 1994), Halifax (NSSC)	Second-degree murder	Pled guilty to manslaughter	Life	3 years probation
R v Brush, [1995] OJ No 656 (2 March 1995) Toronto (Ont Ct J (Prov Div))	First-degree murder	Pled guilty to manslaughter	Life	18 months probation
R v Morrison, [1998] NSJ No 75, Case No 720188	First degree murder	Trial judge declined to commit Dr. Morrison to stand trial Appeal to NSSC was dismissed	Life	No trial
R v Genereux, [1999] OJ No 1387 (ONCA)	Aiding and abetting suicide	Pled guilty	14 years	2 years less one day and 3 years probation
R v Latimer, 2001 SCC 1	Second degree murder	Guilty verdict	Life	Life (no possibility of parole for 10 years)
R v Zsiros, 2004 BCCA 530	Aiding and abetting suicide	Guilty verdict	14 years	Suspended sentence
R v Martens, 2004 BCSC 1450	Aiding and abetting suicide	Acquittal	14 years	Acquitted by jury
R c Houle, 2006 QCCS 319	Aiding and abetting suicide	Pled guilty	14 years	3 years probation with conditions
R c Bergeron [2005] QCCS 5634	Attempted murder	Guilty verdict	Attempted murder = Life Aggravated assault = 14 years	3 years probation for aggravated assault
R v Kirk, 2006 ONCJ 509	Aiding and abetting suicide	Pled guilty	14 years	3 years probation
Ramesh Kumar Sharma (June 2007)	Aiding and abetting suicide	Pled guilty	14 years	Conditional sentence of 2 years less a day to be served in the community

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R c Dufour, 2010 QCCA 2413	Aiding and abetting suicide	Acquittal	14 years	Acquitted due to limited mental capacity Appeal dismissed by Quebec Court of Appeal
R v Fonteece, 2010 ONSC 2075	Assisted suicide and criminal negligence causing death	Pled guilty to criminal negligence causing death Not guilty verdict of assisting suicide	Aiding and abetting suicide = 14 years Criminal negligence causing death = Life	Time served and 12 months probation
R v Jeanvenne, 2010 ONCA 706	First degree murder in 1983 shooting	Pled guilty to mercy killing New trial ordered, hung jury at new trial in 2012	Life	Crown stayed charges in 2012

The same phenomena with respect to exercises of prosecutorial discretion with respect to plea bargains and judicial discretion with respect to sentencing have been seen in other countries as well. Consider, for example, New Zealand.

Table 6: Results In Reported New Zealand Prosecutions

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Ruscoe (1992) 8 CRNZ 68, 20 March 1992	Aiding and abetting suicide	Guilty		12 months supervision
R v Karnon (HC Auckland, S14/99, 29 April 1999)		Guilty		2 years supervision
R v Law (HC Hamilton T 021094, 19 August 2002)	Murder	Guilty		18 months imprisonment, leave granted to apply for home detention

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Martin [2005] NZCA 3	Attempted murder	Guilty	14 years	15 months imprisonment with leave to apply for home detention
R v Crutchley HC Hamilton CRI-2007-069-000083, 9 July 2008	Attempted murder	Guilty	14 years	Six months community detention, 150 hours community work
R v Davison HC Dunedin CRI-2010-012-004876 24 Nov 2011	Attempted murder	Guilty to inciting and procuring suicide	14 years	Five months home detention
R. v Mott [2012] NZHC 2366 (13 September 2012)	Assisted suicide	Guilty		Discharge without conviction

Similarly, in Australia, sentences tend to be much lower than the maximum and often do not include a prison sentence.[131]

Table 7: Results in Reported Australian Prosecutions

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Hood [2003] [2002] VSC 123	aiding or abetting suicide	Guilty	five years imprisonment	18-month prison sentence that was suspended in entirety
R v Maxwell [2003] VSC 278	aiding or abetting suicide	Guilty	five years imprisonment	18-month prison sentence that was suspended in entirety
DPP v Karaca [2007] VSC 190	Attempted murder	Guilty	25 years imprisonment	3 years imprisonment wholly suspended for 3 years
DPP v Nestorowycz [2008] VSC 385	Attempted murder	Guilty	25 years imprisonment	2 years and 9 months imprisonment but the sentence was wholly suspended
DPP v Rolfe [2008] VSC 528	Manslaughter by suicide pact	Guilty	10 years imprisonment	Wholly suspended sentence of imprisonment for two years

[131] Lorana Bartels and Margaret Otlowski, 'A Right to Die? Euthanasia and the Law in Australia' (2010) 17 *Journal of Law and Medicine* 532.

Case	Charge	Plea or Verdict	Maximum Sentence for Charge	Actual Sentence
R v Justins [2011] NSWSC 568	aiding and abetting suicide	Guilty	10 years imprisonment	22 months of jail time to be served on the weekends
R v Mathers [2011] NSWSC 339	Murder	Guilty to manslaughter	25 years imprisonment	2 years imprisonment
R v Nielsen [2012] QSC 29 [Note: the deceased was not terminally ill and Mr. Nielsen was the sole beneficiary under the deceased's will]	Aiding and abetting suicide	Guilty	5 years imprisonment	3 years imprisonment
R v Klinkermann [2013] VSC 65	Attempted murder	Guilty	25 years imprisonment	Community corrections order of 18 months with conditions of medical and mental health treatment and rehabilitation
Walmsley v R [2014] ACTCA 24 (1 Aug 2014) [Note: the far less compelling facts may account for the severity of sentence]	Aiding and abetting suicide	Guilty	5 years imprisonment	2 years and 9 months imprisonment, non parole period of 1 year and 8 months is fixed. (sentence backdated to account of time spent in custody)

Similarly, in the United Kingdom, the rare convictions in cases of assisted suicide or euthanasia result in lenient sentences. For example, in *R v Webb*, the Court of Appeal gave a man a twelve months suspended sentence for 'manslaughter committed as a mercy killing intended by the appellant to help his wife achieve her settled intention to end her own life.'[132] In *R v March*,[133] David March was charged with murder but pled guilty to aiding and abetting the suicide of his wife. Despite the maximum sentence of 14 years imprisonment, he was given a nine month suspended sentence.[134] According to Julia Shaw in 'Recent Developments in the Reform of English Law on Assisted Suicide',

> [a]lthough assisting suicide is a criminal offence in the UK, no health professional has been convicted in spite of anecdotal evidence and voluntary disclosures … [and] Law Lord Baroness

[132] *R v Webb* [2011] EWCA Crim 152 [24].
[133] *R v March* (Unreported, Central Criminal Court, Barker J, 19 October 2006).
[134] Maxine Frith, 'Freedom for Husband Who Helped Disabled Wife to Die' (20 October 2006) *The Independent* <http://www.independent.co.uk/news/uk/crime/freedom-for-husband-who-helped-disabled-wife-to-die-420869.html>.

> Murphy recently observed, 'In more than 15 years, not one mercy-killing case has resulted in a sentence for murder.' Juries are similarly reluctant to convict in cases which involve close relatives claiming to have acted in good faith to alleviate suffering.[135]

It can be concluded that the exercise of discretion by prosecutors (re: plea bargains) and judges (re: sentences) could have a transformative effect on the application of a prohibitive criminal law regime. Indeed, looking at the cases noted above, one could reasonably conclude that, in a number of jurisdictions, the law de facto is not nearly as prohibitive as the law de jure.

D *Looking Backwards Conclusion*

In sum, law reform has come about (and failed to come about) in various common law jurisdictions through legislative reform, prosecutorial charging guidelines, court decisions, jury nullification, the exercise of prosecutorial discretion in the absence of offence-specific charging guidelines, and the exercise of judicial discretion in sentencing.

III LOOKING FORWARD

Before turning to lessons learned, it is worth briefly reviewing the voluntary euthanasia and/or assisted suicide law reform initiatives that are currently active in the five countries under consideration.

A *Canada*

In February 2014, the National Liberal Party (the Official Opposition in the Federal Parliament), passed a resolution that calls for voluntary medically-assisted death to be decriminalised. The resolution calls for a public consultation process to make recommendations to Parliament with respect to criteria for access to, and appropriate oversight of, medically-assisted end-of-life.[136] According to the National Liberal Party's website, 'Policy resolutions adopted by convention delegates officially become "Party policies" and inspire [but do not direct] the next electoral platform.'[137] Ultimately, however, the decision to include a policy resolution in the electoral platform rests with the party leadership. Following the release of the Supreme Court of Canada decision in *Carter*[138], the leader of the Liberal Party expressed support for the decision and made a motion in the House of Commons to appoint a special committee to 'consider the ruling of the Supreme Court; that the committee consult with experts and with Canadians, and make recommendations for a legislative framework that will respect the Constitution, the Charter of Rights and Freedoms, and the priorities of Canadians.'[139] The motion failed with 132 in favour 146 against.[140] If the Liberal Party forms the Government after the 2015 election, it seems

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[135] Julia Shaw, 'Recent Developments in the Reform of English Law on Assisted Suicide' (2009) 16(4) *European Journal of Health Law* 333, 336-337.

[136] Liberal Party resolution 165, *Death with Dignity: Legalizing Medically-Assisted Death* (2014) <http://www.liberal.ca/165-death-dignity-legalizing-medicallyassisted-death/>.

[137] National Liberal Party, *Policy Process FAQ* (2015) <http://convention.liberal.ca/policy-faq/>.

[138] *Carter v Canada (Attorney General)* 2012 BCSC 886.

[139] iPolitics, *Daily Watch: Liberals Push Motion on Assisted Suicide* (2015) <http://www.ipolitics.ca/2015/02/24/daily-watch-liberals-push-motion-on-assisted-suicide/>.

[140] OpenParliament, *Vote #340 on February 24th, 2015* (2015) <https://openparliament.ca/votes/41-2/340/>.

reasonable to assume that the goal of the policy resolution and the Supreme Court of Canada decision will be reflected in legislative action by the Government.

On March 27, 2014, Conservative MP Steven Fletcher and NDP MP Manon Perreault introduced Bill C-581 to decriminalise physician-assisted death[141] and Bill C-582 to establish an oversight commission on physician-assisted death.[142] To the same end and in much the same form, Bill S-225 was subsequently introduced into the Senate by Senators Larry Campbell and Nancy Ruth.[143] However, even when introduced it was clear that, barring some extraordinary parliamentary maneuvering, none of these bills would ever proceed to a vote. Nonetheless, they reopened the conversation at the federal legislative level and may be taken as a foundation upon which to build legislation if Parliament decides to legislate in response to the Supreme Court of Canada decision in *Carter*.

Outside Canada, there is also considerable law reform activity in progress.

B *United Kingdom*

In the United Kingdom, the *Assisted Dying Bill* was introduced in front of the House of Lords on 15 May, 2013.[144] It passed second reading and moved to Committee on 18 July, 2014. It was considered by the Committee on 7 November, 2014 and 16 January, 2015.[145] The Bill provides for a person over the age of 18 who is terminally ill and has six months or less to live to seek and lawfully be provided with assistance to end their own life. Health care professionals can prescribe the lethal medication and prepare it for administration. However, the individual would need to take the final act that ended their own life by self-administering the medication.[146]

In Scotland, the Assisted Suicide Bill was introduced in the Scottish Parliament on 13 November, 2013.[147] The Bill is working its way through various Committees and may reach Parliament in the Spring of 2015.[148] The Bill enables people with terminal or life-shortening illnesses or progressive conditions which are terminal or life-shortening and who wish to end their own lives to obtain assistance in doing so. It does this by removing criminal and civil liability from those who provide such assistance provided that the procedure set out in the Bill is followed. The individual must be over the age of 16 and must have an illness which, in his or her case, is terminal or life-shortening or a condition which, in his or her case, is progressive and either terminal or life-shortening.[149]

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[141] Bill C-581, *An Act To Amend The Criminal Code (Physician-Assisted Death)*, 2nd Sess, 41st Parl, 2014.

[142] Bill C-582, *An Act To Establish The Canadian Commission On Physician-Assisted Death*, 2nd Sess, 41st Parl, 2014.

[143] Bill S-225. *An Act To Amend The Criminal Code (Physician-Assisted Death) 2014* <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=6811259&File=27&utm_source=Euthanasia+Prevention+Coalition+Newsletter&utm_campaign=66625d55e8Canadian_Senate_to_debate_euthanasia+bill&utm_medium=email&utm_term=0_105a5cdd2d-66625d55e8-157171481#1>.

[144] Assisted Dying Bill 2013-2014 (UK).

[145] UK Parliament, *Assisted Dying Bill [HL] 2014-15* <http://services.parliament.uk/bills/2014-15/assisteddying.html>.

[146] Explanatory Notes, Assisted Dying Bill 2013-2014 (UK) <http://www.publications.parliament.uk/pa/bills/lbill/2013-2014/0024/en/2014024en.pdf>.

[147] Assisted Suicide (Scotland) Bill 2013 (Scot).

[148] The Scottish Parliament, *Assisted Suicide (Scotland) Bill* (2015) <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/69604.aspx>.

[149] Explanatory Notes, Assisted Suicide (Scotland) Bill 2013 (Scot).

C *United States*

In the United States, successful legislative reform in Oregon, Vermont, and Washington has encouraged other states to consider passing permissive assisted suicide legislation. Legislation is being considered in 27 states and the District of Columbia.[150]

D *Australia*

In South Australia, the Ending Life with Dignity (No 2) Bill 2013 provides for the administration of medical procedures to assist death for those who are terminally ill, suffering unbearably and who have expressed a desire for the procedures.[151] It was introduced in October 2013, but the Bill lapsed when Parliament was prorogued. At the federal level, on June 24, 2014, Senator Richard Di Natale released an Exposure Draft of a bill - *Bill for an Act relating to the provision of medical services to assist terminally ill people to die with dignity, and for related purposes* (*Medical Services (Dying with Dignity) Bill 2014*).[152] The Exposure Draft of the Bill was considered by the Legal and Constitutional Affairs Legislation Committee which issued its report in November 2014.[153] The Committee made two key recommendations:

> (1) That Senator Di Natale should address the technical and other issues raised in evidence to the committee, and seek the advice of relevant experts before drafting the final Bill.
> (2) That if the Bill is introduced in the Senate, Party Leaders should allow Senators a conscience vote.[154]

This Bill seeks:

> (a) to recognise the right of a mentally competent adult who is suffering intolerably from a terminal illness to request a medical practitioner to provide medical services that allows the person to end his or her life peacefully, humanely and with dignity; and
>
> (b) to grant a medical practitioner who provides such services immunity from liability in civil, criminal and disciplinary proceedings.[155]

E *New Zealand*

On March 20 2015, Lecretia Seales filed a claim in the New Zealand High Court claiming that the prohibition on physician-assisted death violates her right not to be deprived of life or subjected to cruel treatment under the *Bill of Rights Act* and seeking a ruling on whether her physician can provide her with physician-assisted death without fear of criminal liability.[156]

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[150] For details on current legislative initiatives, see Compassion & Choices, *In Your State* (2015) <https://www.compassionandchoices.org/what-you-can-do/in-your-state/>.
[151] Ending Life with Dignity (No 2) Bill 2013 (SA).
[152] Medical Services (Dying with Dignity) Bill 2014 (Cth) <http://richard-di-natale.greensmps.org.au/sites/default/files/dying_with_dignity_medical_services_draft.pdf>.
[153] Medical Services (Dying with Dignity) Exposure Draft Bill 2014 <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Dying_with_Dignity/~/media/Committees/legcon_ctte/Dying_with_Dignity/report/report.pdf>.
[154] Ibid
[155] Ibid.
[156] Jared Savage, 'Lecretia Seales Story' *The New Zealand Herald* (online) 21 March 2015 <http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11420767>.

F *Looking Forward Conclusions*

Here it can be concluded that there is a significant amount of law reform activity aimed at moving toward more permissive regimes with respect to voluntary euthanasia and assisted suicide taking place right now in Canada and in other common law jurisdictions. Whether we will see significant increases in the number of permissive regimes of course remains to be seen.

IV LESSONS FROM LOOKING BACKWARD AND FORWARD

Given recent developments in Canada (in particular the Quebec legislation and the Supreme Court of Canada decision in *Carter*[157] there are lessons from Canada for those seeking law reform in common law jurisdictions.

First, reform is possible. There are now 13 jurisdictions which have, in one way or another, permitted voluntary euthanasia and/or assisted suicide in some circumstances. As Canada has recently demonstrated, it may take years, but with persistence it can come.

Second, legislators and judges can be persuaded of the fact that slippery slopes do not materialise after decriminalisation. First, permissive regimes do not slide from voluntary euthanasia to non-voluntary or involuntary euthanasia (either in relation to the criteria for access or in practice).[158] Second, palliative care and, more generally, end of life care, is benefitted rather than harmed by the decriminalisation of assisted death. [159]

Third, there is wisdom in linking palliative care to assisted death in the reform process. The decriminalisation of voluntary euthanasia and/or assisted suicide can be used to benefit access to and quality of palliative care – this has been seen, for example, in Oregon.[160] This lesson was clearly learned by the Quebec legislators as *An Act Respecting End of Life Care* explicitly addresses and strengthens palliative care in Quebec (including, for example, the establishment of a right to palliative care). [161]

Fourth, it is important to prepare in advance for the (legislative or judicial) window of opportunity to open. Academics had been developing the legal and philosophical arguments for a number of years in anticipation of there being the political will for legislative reform or an appropriate case upon which to build a court challenge. For example, I published my first paper advocating for the decriminalisation of voluntary euthanasia in 1993,[162] and a book on the same topic in 2004.[163]

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[157] *Carter v Canada (Attorney General)* 2015 SCC 5.

[158] The Royal Society of Canada Expert Panel, *End-of-Life Decision Making* (RSC, 2011) <http://rscsrc.ca/sites/default/files/pdf/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf> 12; *Carter v Canada (Attorney General)*, 2012 BCSC 886, [1241]; Quebec Select Committee on Dying with Dignity (Report of the National Assembly of Quebec, 2012) <www.assnat.qc.ca/en/actualites-sallepresse/nouvelle/Actualite-25939.html> 37.

[159] Ibid.

[160] 98 per cent have health care insurance and most are enrolled in hospice before death. See Ronald Lindsay, 'Oregon's Experience: Evaluating the Record' (2009) 9(3) *American Journal of Bioethics* 19-27.

[161] Bill 52, *An Act Respecting End-of-Life Care*, 1st Sess, 41st Leg, 2014, Quebec, section 5.

[162] Jocelyn Downie, 'Voluntary Euthanasia in Canada' (1993) 14(1) *Health Law in Canada* 13-30.

[163] Jocelyn Downie, *Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada* (University of Toronto Press, 2004).

When the facts about the impact of decriminalisation became known over a significant period of time (particularly in the Netherlands and Oregon) and the legal principles driving the analysis in section 7 of the *Charter* changed, I published a paper arguing that the time had come to launch another *Charter* challenge to the prohibitions on assisted death under section 7 in 2008.[164] So when the right plaintiffs and counsel came along ready to launch a challenge in *Carter v Canada*[165], the foundation for the case had been laid (by these pieces as well as essential scholarship produced by others in Canada and abroad) and the academic analysis was ready for the litigation strategy (both to shape, support, and be used by it). By way of an example from the political arena, in the same paper in which the argument for a *Charter* challenge was laid out, my co-author and I included a draft federal statute. When Stephen Fletcher indicated that he was going to introduce a private members bill into the Federal Parliament, a collection of key documents laying out the core arguments and evidence was ready along with draft legislation and so the window of opportunity for such an initiative could be capitalised upon.[166]

Fifth, evidence and the law itself changes over time. The evidence in front of the court in Rodriguez in 1993 and in front of the Senate Special Committee on Euthanasia and Assisted Suicide in June 1995, was taken to demonstrate that: medical associations around the world were opposed to decriminalising assisted suicide[167]; palliative care was threatened by decriminalisation[168]; and descents down the slippery slope from voluntary to non-voluntary and even involuntary euthanasia follow decriminalisation.[169] The evidence in front of the court in Carter and presented to the Special Committee on Dying with Dignity in Quebec and the Quebec National Assembly, by contrast, was taken to demonstrate that: some medical associations now support or have taken a position of 'studied neutrality' on decriminalisation[170]; palliative care is not harmed (and may be helped) by decriminalisation[171]; and the slippery slopes have not materialised.[172] These facts certainly made a difference in the results in these various venues. The law had changed as between

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[164] Jocelyn Downie and Simone Bern, 'Rodriguez Redux' (2008) 16 *Health Law Journal* 27. Recall, section 7 is the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

[165] *Carter v Canada (Attorney General)* 2012 BCSC 886.

[166] See Bill C-581, *An Act To Amend The Criminal Code (Physician-Assisted Death)*, 2nd Sess, 41st Parl, 2014 and Bill C-582, *An Act To Establish The Canadian Commission On Physician-Assisted Death*, 2nd Sess, 41st Parl, 2014.

[167] Justice Sopinka concluded that 'I also place some significance in the fact that the official position of various medical associations is against decriminalizing assisted suicide (Canadian Medical Association, British Medical Association, Council of Ethical and Judicial Affairs of the American Medical Association, World Medical Association and the American Nurses Association).' *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519, 613.

[168] Canada, Special Senate Committee on Euthanasia and Assisted Suicide, 'Of Life and Death: Final Report' Chapter VII Assisted Suicide (Ottawa: Special Committee on Euthanasia and Assisted Suicide, June 1995) <www.parl.gc.ca/Content/SEN/Committee/351/euth/rep/lad-e.htm>.

[169] *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519.

[170] *Carter v Canada (Attorney General)* [2012] BCSC 886, [276]. Even the Canadian Medical Association recently modified its stance with the adoption of the following resolution at the 2014 Annual Meeting '6. The Canadian Medical Association (CMA) supports the right of all physicians, within the bounds of existing legislation, to follow their conscience when deciding whether to provide medical aid in dying as defined in CMA's policy on euthanasia and assisted suicide. (DM 5-6) (Confirmed by the Board of Directors on August 21, 2014)' <https://www.cma.ca/Assets/assets-library/document/en/GC/Final-Resolutions-GC-2014-unconfirmed-e.pdf>.

[171] Justice Smith found that 'Legislation of assisted death has not undermined palliative care; on the contrary, palliative care provision has improved since legalization by some measures.' *Carter v Canada (Attorney General)* [2012] BCSC 886, [731].

[172] Ibid [1241].

Rodriguez and Carter with respect to the principles of fundamental justice (neither overbreadth nor gross disproportionality were recognised as principles of fundamental justice in Rodriguez and yet played important roles in Carter)[173] and the role of administrative facts in section 1 analysis.[174] These changes made a difference in terms of the case even being heard (affecting the stare decisis analysis) and the result (affecting the sections 7 and 1 analyses).

Sixth, empirical evidence matters, so it is important to build good evidence-gathering processes into any permissive regime. The results in the Quebec National Assembly and in Justice Smith and the Supreme Court of Canada's decisions in Carter turned in large part on the availability of reliable and reassuring evidence from other permissive regimes, in particular with respect to the impact of decriminalisation on vulnerable people. It is therefore important for all permissive regimes to maintain accurate, comprehensive, and transparent oversight systems to continue to provide the empirical foundation for law reform initiatives elsewhere.

Seventh, it is not necessary to restrict permissible assisted death to assisted suicide or terminal illness in order to appropriately circumscribe access. The Supreme Court of Canada's decision in *Carter* applies to both voluntary euthanasia and assisted suicide. The Quebec legislation permits voluntary euthanasia (termed 'medical aid in dying'). The criteria for access to voluntary euthanasia and assisted suicide in Justice Smith's decision in *Carter* and in Quebec's *An Act Respecting End-of-Life Care* do not include 'terminal illness'. This term has been rightly criticised in the literature[175], and the Supreme Court of Canada and the Quebec legislators wisely used other terminology and concepts to limit access to assisted death.

Eighth, some strategies that worked elsewhere could not be used in Canada (but might be workable elsewhere and so should not be forgotten). In Canada, we do not have the *European Convention for the Protection of Human Rights and Fundamental Freedoms* that provoked the prosecutorial charging guidelines in England and Wales so we could not motivate or launch any actions under that.[176] Except in British Columbia,[177] we also do not have the people's ballot initiatives process, unlike Oregon and Washington State, so we could not translate the 70-80+ per cent support among Canadians for decriminalising assisted death into statutory reform through that form of direct

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[173] Ibid [983]. Justice Smith concluded that 'additional principles of fundamental justice [overbreadth and gross disproportionality] have been recognized and defined since Rodriguez was decided.' The Supreme Court of Canada agreed with respect to overbreadth and did not opine on gross disproportionality (as not necessary to do so given their conclusion that the prohibitions are overbroad) [90].

[174] Ibid [994]. Justice Smith found that 'in my view Hutterian Brethren marks a substantive change [to section 1 analysis]…Courts are to widen their perspective at the final stage to take full account of the deleterious effects of the infringement on individuals or groups, and determine whether the benefits of the legislation are worth that cost.'

[175] See, for example, the RSC: end-of life decision making panel, 'The Panel recommends against using 'terminal illness' as a prerequisite for requesting assistance. The term is too vague…there is no precise science to providing a prognosis of a terminal illness in terms of a specific length of time…there are many individuals whose lives are no longer worth living to them who have not been diagnosed with a terminal illness…There is no principled basis for excluding them from assisted suicide of voluntary euthanasia.' The Royal Society of Canada Expert Panel, 'End-of-Life Decision Making' (Ottawa: RSC, 2011) 102-103 <http://rsc-src.ca/sites/default/files/pdf/RSCEndofLife Report2011_EN_Formatted_FINAL.pdf >.

[176] See earlier discussion under 'Guidelines for the exercise of prosecutorial discretion'.

[177] Elections BC, *Initiative* <http://www.elections.bc.ca/index.php/referendum-plebiscite-recall-initiative/initiative/>

democracy.[178] Furthermore, criminal law is federal in Canada (unlike in the United States where jurisdiction rests with the state) so we did not have the option of situating the criminal law reform theatre at the state (ie provincial/territorial) level. Others, however, may be able to pursue these pathways.

Finally, not only is a consultative, rigourous, evidence-based, non-partisan process of legislative reform possible (albeit hard work), it may even increase the chances of successful legislative reform. Quebec provides powerful evidence for this claim. In Quebec, the process of passing Bill 52, *An Act Respecting End-of-Life Care*, required over five years of cross-party work. It began in 2009 when the National Assembly responded to a discussion paper from the Collège Des Médecins Du Québec well as polls showing support for decriminalizing assisted death among general practitioners[179], specialist physicians[180], and the general public.[181] The National Assembly unanimously passed a motion to create the Select Committee on Dying with Dignity to study the issue of dying with dignity.[182] The all-party committee was chaired by Liberal MNA Geoff Kelley with opposition Parti Quebecois MNA Veronique Hivon as co-chair. The Select Committee engaged in extensive consultation across the province with a first stage focused on experts and a second phase on members of the public. They heard from 32 experts and received over 16 000 comments online.[183] The Committee made a trip to France to learn about the on-going debate there and to the Netherlands and Belgium to learn from those countries' experiences with assisted death legislation. The final March 2012 report, *Dying with Dignity*, made 24 recommendations, including that Quebec allow medically assisted death and increase accessibility to palliative care.

On June 12, 2013, Bill 52 was introduced to the National Assembly by then Minister Veronique Hivon and subsequently went through consideration by the Health and Social Services Committee which studied the Bill and made 57 amendments.[184] This amended Bill 52 was introduced to the National Assembly on February 11, 2014 but its progress stalled when a provincial election was called. After the election, though, on 22 May 2014, Bill 52 was reintroduced into the National Assembly in a motion adopted unanimously by all four provincial parties.[185] Remarkably, Veronique Hivon was included as a co-author of the Bill, along with Gaetan Barrette, the current minister of Health and Social Services, even though her political party, the Parti Quebecois, was

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[178] Dying With Dignity Canada, *Ipsos-Reid Survey 2014* (2014) <http://www.dyingwithdignity.ca/resources/first-release-poll-results>.

[179] Fédération des Médecins Omnipraticiens du Québec, *Press release 'The FMOQ Reveals the Results of its Consultation on Euthanasia* (29 October 2009), Quebec, 'Select Committee on Dying with Dignity Report' (Quebec City: National Assembly of Quebec, 2012) 11.

[180] Ibid.

[181] Catherine Handfield, *Les Québécois Favorables à l'euthanasie* (11 August 2009) <http://www.cyberpresse.ca/actualites/quebec-canada/sante/200908/10/01-891423-les-quebecois-favorables-a-leuthanasie.php>.

[182] Quebec, 'Select Committee on Dying with Dignity Report' (Quebec City: National Assembly of Quebec, 2012) 90 <www.assnat.qc.ca/en/actualites-sallepresse/nouvelle/Actualite-25939.html>

[183] Ibid 11.

[184] National Assembly of Quebec, *Commission De La Sante Et Des Services Sociaux: Etude Detaillee Du Projet De Loi No 52 – Loi Concernant Les Soins De Fin De Vie* (11 February 2014) <http://www.assnat.qc.ca/en/travaux-parlementaires/projets-loi/projet-loi-52-40-1.html>.

[185] Jeff Heinrich, 'Bill 52: A Timeline', *The Montreal Gazette* (Montreal), 14 February 2014 <http://www.montrealgazette.com/health/Bill+timeline/9510618/story.html>.

no longer in power. On 5 June 2014, the Quebec National Assembly passed Bill 52 by a vote of 94 to 22.

V CONCLUSION

As the discussions of end of life law and policy reform continue around the world, the pathways followed by those who have already moved to permissive regimes lie before those who have not. Those who seek permissive law reform can, and should, take notice of what has (and has not) worked elsewhere as described above. In common law countries, change is possible. In fact, if the lessons are learned and advocates engaged, it may even be likely.

VI ADDENDUM

There have, of course, been significant developments in a number of the jurisdictions discussed in this paper since the paper was submitted. For example:

1) The Canadian Conservative government was defeated and the Liberal Party was elected. This new government sought a six-month extension on the suspension of the declaration of invalidity that had been issued by the Supreme Court of Canada in *Carter v Canada (Attorney General)* and was granted a four-month extension (equivalent to the suspension of activity caused by the election process). The Supreme Court of Canada also allowed for constitutional exemptions during the period of the extension to enable individuals who meet the *Carter* criteria to apply to a superior court for authorisation of physician-assisted death.[186]
2) California Governor Jerry Brown signed into law the *End of Life Option Act* to permit physician-assisted suicide.[187]
3) In New Zealand, Lecretia Seales was unsuccessful in her effort to challenge the prohibitions on assisted dying.[188] However, the New Zealand Health Select Committee is now holding an inquiry on the issue of assisted dying.[189]
4) The Assisted Suicide (Scotland) Bill was defeated.[190]
5) The United Kingdom Assisted Dying Bill was defeated.[191]

While these examples represent mixed results, the paper's conclusions remain sound: there are important lessons to be learned from efforts at law reform in jurisdictions around the world; and change is possible.

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[186] *Carter v Canada* (Attorney General) 2016 SCC 4 <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/15696/index.do>. Federal legislation is expected to be in force by 6 June 2016.

[187] An Act to Add and Repeal Part 1.85 (commencing with Section 443) of Division 1 of the Health and Safety Code, Relating To End Of Life, AB-15, 2015 <https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15>.

[188] *Seales v Attorney-General* [2015] NZHC 1239.

[189] House of Representatives, *Petition of Hon Maryan Street and 8974 Others* (1 February 2016) New Zealand Parliament <http://www.parliament.nz/en-nz/pb/sc/make-submission/0SCHE_SCF_51DBHOH_PET63268_1/petition-of-hon-maryan-street-and-8974-others>.

[190] Assisted Suicide (Scotland) Bill 2013 (UK) <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/69604.aspx>.

[191] Assisted Dying (No 2) Bill 2015-16 (UK) <http://services.parliament.uk/bills/2015-16/assisteddyingno2.html>.

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TERMINAL SEDATION – GOOD MEDICINE? GOOD ETHICS? GOOD LAW?

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The use of sedation at the end of life is becoming increasingly common, yet its ethics and lawfulness have not been as widely discussed as might have been expected. In this article, the primary focus is on what is known as 'terminal sedation', with particular reference to the use of sedation without the provision of assisted nutrition and hydration ('ANH'). It is argued that, where ANH is not contraindicated by patient wellbeing itself, close scrutiny of the practice is required. There are both ethical and legal reasons why a move towards appropriate regulation is appropriate. The urgency of doing this is evidenced by the variety in practices throughout the world, with some commentators suggesting that the decision whether or not to instigate terminal sedation may be influenced by more than clinical indications for its use (in which case, it may be perilously close to a form of euthanasia). Indeed, it may be argued that there is little that differentiates terminal sedation from a form of euthanasia. Moreover, the relatively common exclusion of existential suffering as an indication for terminal sedation is questioned. Were this also to be accepted as a valid indicator for terminal sedation (without the provision of ANH) it becomes even more urgent that an adequate regulatory framework is developed and that the ethics of the practice are appropriately explored and clarified.

I INTRODUCTION

The purpose of this article is to address the implications – medical, legal and ethical – of the use of terminal sedation, particularly where it is combined with the removal or withholding of assisted nutrition and hydration ('ANH'). My aim is to both evaluate the status of this increasingly common practice against principles that inform other end of life decisions, and to robustly analyse it for consistency and clarity.

The first task of any lawyer is to define her terms. In the case of terminal sedation however this can prove to be extremely difficult. As De Graeff and Dean note:

> Sedation in palliative care has been named in various ways, for example, 'sedation,' 'terminal sedation,' 'sedation for intractable distress in the imminently dying,' 'end-of-life sedation,' 'total sedation,' 'sedation in the terminal or final stages of life,' 'controlled sedation,' 'palliative sedation,' and 'palliative sedation therapy.'[1]

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[1] Alexander De Graeff and Mervyn Dean, 'Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards' (2007) 10(1) *Journal of Palliative Medicine* 67, 69.

Van Delden argues for the use of 'terminal' sedation, 'because it conveys the message that an end-of-life decision is involved, implying that the timing of death may be influenced.'[2] He makes the further point that:

> One of the characteristics of this debate [about terminal sedation] is that it is a very confused one: people disagree about the meaning of the term, the appropriateness of it and, of course, about the conditions under which it (what?) would be morally justified….: as is often the case, a discussion about terms is a discussion about norms in disguise.[3]

Throughout this paper I will use the term 'terminal sedation' unless I am directly quoting from someone else. As Papavasiliou and colleagues note, while palliative sedation is also a commonly used term, terminal sedation 'despite being heavily criticized, persevered in the literature probably because, once used, the concept of terminal was associated with the patient's situation, that is, terminal cancer, not the objective of the treatment.'[4] Whether this assertion represents fact or fancy will be considered further; in particular the desire to separate the outcome or objective from the use of the word 'terminal' requires further analysis.

According to Dean et al:

> Palliative sedation therapy was first described in the early 1990s as an existing practice but little is known about its development. Many definitions have been put forward for various types of sedation used in palliative practice, but at the core they share the ideas that palliative sedation is: (1) the use of (a) pharmacological agent(s) to reduce consciousness; (2) reserved for treatment of intolerable and refractory symptoms; and (3) only considered in a patient who has been diagnosed with an advanced progressive illness.[5]

It is obviously the case that some medical decisions at the end of life – while overtly designed to treat or palliate – can 'shorten survival'.[6] For example, it has been claimed that in the Netherlands in 2010 'an end of life decision was taken in 57.8 per cent of all deaths.'[7] It is plausible that such figures may be mirrored (perhaps even exceeded) in those jurisdictions where medicine is advanced and life expectancy increasing, particularly where assisted dying has been legalised. It is more difficult to estimate what proportion of deaths result from an actual decision in those jurisdictions where assisted dying remains illegal and no reporting criteria exist.

Terminal sedation becomes an option when the patient's symptoms are refractory.[8] According to De Graeff and Dean:

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[2] Johannes J M van Delden, 'Terminal Sedation: Source of a Restless Ethical Debate' (2007) 33 *Journal of Medical Ethics* 187, 187.
[3] Ibid.
[4] Evangelia S Papavasiliou et al, 'From Sedation to Continuous Sedation Until Death: How Has the Conceptual Basis of Sedation in End-of-Life Care Changed Over Time?' (2013) 46 *Journal of Pain and Symptom Management* 691, 695-696.
[5] Mervyn M Dean et al, 'Framework for Continuous Palliative Sedation Therapy in Canada' (2012) 15(8) *Journal of Palliative Medicine* 870, 870.
[6] Sigrid Sterckx, Kasper Raus and Freddy Mortier, 'Introduction' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 1, 4.
[7] Ibid.
[8] For discussion see, Clive Seale, 'Continuous Deep Sedation in Medical Practice: A Descriptive Study' (2010) 39 *Journal of Pain and Symptom Management* 44.

> A symptom is regarded as being refractory (as opposed to difficult to treat) when the clinician perceives that further invasive or non-invasive interventions are (1) incapable of providing adequate relief, (2) associated with excessive and intolerable acute or chronic morbidity, and/or (3) unlikely to provide relief within a tolerable time frame. This implies a rigorous diagnostic approach, paying attention to the physical, psychological, social, and emotional dimensions of the symptom. It also implies that all available symptom-targeted medications, procedures, or interventions attempted have been ineffective or produced unacceptable side effects, or, if considered, were ruled out as too burdensome or risky for the patient, or have been refused by the patient.[9]

As Lanuke and colleagues remind us however, '[t]he incidence of refractory symptoms in palliative care patients is controversial and it is important to distinguish between difficult and refractory symptoms when addressing the needs of palliative care patients.'[10] Careful medical decisions are, therefore required, subject of course, to ethical and legal analysis – of which more later. For the moment, it is interesting to note that the use of terminal sedation seems to be increasing. Indeed as Sterckx, Raus and Mortier write, 'dying after having been continuously sedated for some time is fast becoming one of the standard ways of dying.'[11]

II SUMMARY OF USE

Seale notes that the use in the Netherlands of what he calls continuous deep sedation ('CDS') rose from 5.6 per cent of deaths in 2001 to 7.1 per cent in 2005. In Belgium the rates rose from 8.2 per cent of deaths in 2002 to 14.5 per cent in 2007.[12] According to his findings, 'CDS in the United Kingdom is more common in patients who are younger or dying of cancer.'[13] Further research by Anquinet and colleagues[14] found that '[i]n Flanders, BE [Belgium] in 2007, its incidence was estimated to be 15% of all deaths. In NL [the Netherlands] in 2005, this was 8%. In the U.K. in 2008, its prevalence was 17% of all deaths.'[15] They also found that it lasted 'in most cases, for one week or less in all countries [Flanders (Belgium), Netherlands, UK] and both settings (hospital: 90% -93%; home: 91%-96%).'[16] Noting the variations in rates of use, the authors speculate that this may be a result of the difference in the laws regarding voluntary euthanasia and assisted suicide. Where assisted dying is legally permissible, they suggest that 'physicians and patients can "choose" between euthanasia and continuous deep sedation until death.'[17] In the United Kingdom however, where no legalised assisted dying exists, 'the high rate may be a result of the fact that such sedation is perceived to be the only legal "last resort" option for a physician treating a terminal patient with refractory symptoms.'[18]

As in so many end of life predicaments, the Dutch have played a leading role and this is no less true in the case of terminal sedation. Dean et al report that national guidelines on its use were first drawn up in 2005 (these were amended in 2009). The medical profession was encouraged by the government to develop these guidelines, which require both the existence of refractory

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[9] De Graeff and Dean, above n 1, 70.
[10] Kathryn Lanuke et al, 'Two Remarkable Dyspneic Men: When Should Terminal Sedation be Administered?' (2003) 6(2) *Journal of Palliative Medicine* 277, 279.
[11] Sterckx, Raus and Mortier, above n 6.
[12] Seale, above n 8, 45.
[13] Ibid 51.
[14] Livia Anquinet et al, 'The Practice of Continuous Deep Sedation until Death in Flanders (Belgium), The Netherlands, and the UK: A Comparative Study' (2012) 44 *Journal of Pain and Symptom Management* 33.
[15] Ibid 35.
[16] Ibid 38
[17] Ibid 41.
[18] Ibid 40.

symptoms and a life expectancy of less than two weeks.[19] Guidelines developed by the European Association for Palliative Care also endorse the use of terminal sedation, noting that it requires 'due caution and good clinical practice'.[20] In the United States the American Medical Association adopted guidelines which state that 'palliative sedation should remain an option of last resort for patients with far advanced terminal disease whose suffering has proven refractory to all other usually effective palliative measures.'[21]

While some guidelines do exist, it is perhaps a worrying feature of the use of terminal sedation that significant differences emerge on a comparative analysis both as to its administration and indications for use. For example, while it would seem that terminal sedation is increasingly seen as responsible management in some European countries, in the United States this is less so, and even within the US there are differences of approach and variations in its use. Orentlicher, for example, claims that 'patient access to palliative sedation may turn on the physician's field of practice or other personal attributes.'[22] He notes that '[p]hysicians often develop their practice patterns for idiosyncratic reasons, and that reality will influence the use of palliative sedation.'[23] Seale suggests that terminal sedation is 'more likely to be reported by doctors who support the legalization of euthanasia or PAS and who are nonreligious. This suggests that the decision to provide CDS may be influenced by having attitudes that permit medical actions that shorten life.'[24] He also claims that '[t]he association between providing CDS and doctors' attitudes toward assisted dying and religious beliefs…requires a better understanding of the ethical reasoning of doctors who decide to provide CDS in particular cases.'[25] Sadly, it is possible to conclude from these studies that while terminal sedation decisions should be about the needs of the patient, all too often they 'depend to a large extent on the preferences of the patients' physicians.'[26]

At this point, it is worth further refining our terms. While terminal sedation may occur in a variety of forms, it is with continuous sedation without assisted nutrition and hydration ('ANH') that this paper is concerned. Unarguably, this is likely to be the most controversial form of terminal sedation since the deprivation of hydration in particular seems a different decision from the choice to remove consciousness. Seale reports that terminal sedation without the provision of ANH occurs in '39% of CDS cases in Belgium, and 56%-80% of CDS cases in the Netherlands. In the Netherlands, CDS is believed to have shortened life by more than a week in 27% of cases.'[27] It should be noted that the Dutch guidelines referred to above state that in the case of continuous sedation to death, no assisted hydration should be provided where the patient is unable or unwilling to take fluids. However, since *ex hypothesi* sedated patients will be unable to take fluids naturally, and their willingness to do so can no longer be

[19] For discussion, see Dean et al, above n 5, 870.
[20] Nathan I Cherny, Lukas Radbruch and the Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care' (2009) 23(7) *Palliative Medicine* 581, 581.
[21] Ben A Rich, 'Terminal Suffering and the Ethics of Palliative Sedation (2012) 21 *Cambridge Quarterly of Healthcare Ethics* 30, 32.
[22] David Orentlicher, 'Principle and Practice for Palliative Sedation: Gaps Between the Two' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 116, 122.
[23] Ibid 125.
[24] Seale, above n 8, 51.
[25] Ibid 52.
[26] Orentlicher, above n 22, 122.
[27] Seale, above n 8, 45.

ascertained, a general rule such as this is arguably unhelpful. Of course, should the provision of ANH in itself harm the patient, then good medical practice would mandate it being withheld.

It is also the case that the decision to sedate the patient and withhold ANH can be – and is – viewed differently by different commentators. While some argue that this practice amounts to one single decision (that is, the sedation and withholding of ANH are part of the same spectrum), for others they represent two separate decisions; the first designed to alleviate suffering, the second potentially to shorten life. Williams, for example, argues that '[w]hereas the goal of administering barbiturates to induce sleep to relieve suffering is good and beneficial to the patient, on no interpretation can the additional step of withdrawing artificial nutrition and hydration be considered a necessary condition of relieving pain.'[28] While it has been argued that there is little reason to assume that deprivation of ANH actually *does* shorten life, it must be conceded (a) that there is no evidence against this conclusion and that (b) if it is true, it is likely only to be true when terminal sedation is restricted to those situations where death is imminent.

Indeed, the withholding (or removal) of ANH is clearly implicated in the cause of death in the case, for example, of patients in a permanent vegetative state. Indeed, in the House of Lords (now the UK Supreme Court) case of *Airedale NHS Trust v Bland*,[29] this was explicitly accepted by at least two of the Law Lords. That withholding ANH *can* result in death therefore is equally true in the case of terminal sedation. As for the second point, while this may seem to be answered by guidelines that require a foreseeable, very limited, life expectancy, it remains to be asked why terminal sedation should be restricted to cases of imminent death? If it is indeed designed to alleviate refractory symptoms, then surely it should be available irrespective of the – presumed, but not provable – expectation of length of life?[30] Equally, on what basis can third parties – in this case, doctors – differentiate between kinds of suffering, each of which may be just as dreadful for the patient? However some guidelines, such as the US ones already referred to, specifically do not apply to cases of what has been called 'existential suffering', which is described as 'the experience of agony or distress that results from living in an unbearable state of existence including, for example, death anxiety, isolation, and loss of control.'[31] Further, the requirement that death is imminent may leave patients with refractory symptoms to suffer because their death is not deemed likely to occur within the usually very limited time period. Delbeke agrees, asserting that '[e]very patient has a right to adequate pain and symptom management and it should not be restricted to those with a limited life expectation.'[32] In Belgium, for example, access to palliative care is a legal right of all patients – not just those whose death is imminent. Of course, there may be less than honourable reasons to maintain this position; the earlier that terminal sedation is initiated the more it resembles other actions that bring about the death of a patient, such as voluntary euthanasia.

The exclusion of 'existential suffering' can and should be questioned. As Sterckx, Raus and Mortier assert:

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[28] Glenys Williams, 'The Principle of Double Effect and Terminal Sedation' (2001) 9(1) *Medical Law Review* 41, 51.
[29] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.
[30] For further discussion, see Victor Cellarius, 'Terminal Sedation and the "Imminence Condition"' (2008) 34 *Journal of Medical Ethics* 69.
[31] Rich, above n 21.
[32] Evelien Delbeke, 'The Legal Permissibility of Continuous Deep Sedation at the End of Life: A Comparison of Laws and a Proposal' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 132, 139.

> allowing a patient to die a good death may require bringing existential suffering within the reach of medical action. The extension of permissible indications for continuous sedation to existential suffering, however, is highly controversial. Existing professional guidelines contradict each other in this respect, in that some include existential suffering as an indication for continuous sedation at the end of life, while others do not.[33]

Delbeke further argues that '[t]here is no reason why patients with refractory psychological suffering should be excluded from a right to adequate pain management.'[34] If this pain management results in an earlier death, with the patient's agreement, surely this would amount to good medical practice? The notion that medicine's sole or most noble aim is the preservation or prolongation of life, irrespective of quality, is surely one that has been discredited in certain situations. Of course, accepting the inclusion of existential suffering, or conceding that symptoms may be refractory even when life expectancy is not limited to a couple of weeks, means that the use of terminal sedation would more closely resemble other end of life decisions – a form of assisted dying – and this may sit uncomfortably with clinicians, politicians and some members of the public.

Here, we begin to see most clearly the ethical concerns that underpin the use of terminal sedation without ANH. In the next section, the ethical bases that are argued to support this practice, and the rationales given to present it as ethical practice, will be evaluated.

III ETHICAL CONSIDERATIONS

Hauser and Walsh claim that '[t]he ethical justification of palliative sedation is based upon the principles of double effect, autonomy and proportionality.'[35] If we accept Williams' point referred to earlier, then it would seem that in cases of terminal sedation without ANH, the proportionality issue can be resolved by concluding that removing or withholding ANH is disproportionate to the stated aims of terminal sedation. If the aim is *only* to avoid suffering, then the sedation itself is likely to be sufficient; it may be unnecessary to take the further step of withholding ANH.

The question of autonomy will be left until we deal with legal issues. This leaves for consideration here the principle of double effect. De Graeff and Dean explain the principle in this way:

> The Principle of Double Effect is sometimes used as an ethical justification for the use of PST [palliative sedation therapy]. Briefly, this principle states that when a contemplated action (in this case sedation) has a good (relief of suffering) and a bad (possible foreshortening of life) effect it is permissible if (1) the action is either morally good or is morally neutral, (2) the foreseen yet undesired untoward result is not directly intended, (3) the good effect is not a direct result of the foreseen untoward effect, (4) the good effect is 'proportionate to' the untoward effect, and (5) there is no other way to achieve the desired ends without the untoward effect.[36]

This principle, then, is broadly concerned with intention and causation, and is generally used to distinguish between legitimate and illegitimate practices; namely, the alleged difference

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[33] Sterckx, Raus and Mortier, above n 6, 15.
[34] Delbeke, above n 32, 138.
[35] Katherine Hauser and Declan Walsh, 'Palliative Sedation: Welcome Guidance on a Controversial Issue' (2009) 23(7) *Palliative Medicine* 577, 577.
[36] De Graeff and Dean, above n 1, 77.

between terminal sedation and assisted dying. Taylor and McCann, for example, distinguish the two on the basis of intention, saying:

> Unlike euthanasia or physician-assisted suicide, where the stated objective is the death of the patient (to relieve intractable symptoms), controlled sedation for refractory suffering has been accepted among hospice and palliative care physicians because its stated goal is the relief of suffering, not the death of the patient.[37]

However, even a cursory consideration will suffice to show that inferring or identifying intention from declared motives is highly problematic. Indeed, some studies have demonstrated that mixed motives can and do arise in the practice of terminal sedation. De Graeff and Dean, for example, state that '[t]he use of sedation for the relief of symptoms at the end of life is open to abuse. There are data from several countries indicating that administration of sedating medication, ostensibly to relieve distress, but with the manifest intent of hastening death, is commonplace.'[38] The use of double effect, then, is inappropriate in such cases since the intention is as much to cause death as it is to alleviate suffering. Even where the intention is purely the alleviation of suffering, it can still be questioned whether or not double effect is appropriate where terminal sedation is combined with the failure to provide ANH. For Williams, the principle of double effect is 'wholly inapplicable' in this situation because

> [w]hile it can be argued that 'sedation' eases the patient's pain and can be justified under the principle of double effect, withdrawing artificial nutrition and hydration 'does nothing to relieve the patient's suffering', and the inevitability of death following its withdrawal means that it does not satisfy all the conditions of the principle of double effect.[39]

In fact, in such cases, as Holm argues, this:

> [l]ooks very much like a slow form of euthanasia. The patient is put into a state where she is unable to take water and food, hydration and nutrition is not provided, and she will eventually die from dehydration, if the underlying disease does not kill her first. This means that in patients with very short and certain life expectancy, even continuous TS [terminal sedation] without continued hydration and nutrition may not count as euthanasia, because it is known that the patient will die from her underlying disease. It is, however, rare that we can predict life expectancy with certainty, and there will therefore almost always be the possibility that this kind of TS [terminal sedation] will turn out to be equivalent to euthanasia.[40]

Holm concludes that however much clinicians may wish to separate the two, 'terminal sedation with withdrawal of hydration and nutrition has many ethically relevant similarities with [voluntary] euthanasia, and very few dissimilarities.'[41] Further, Taylor and McCann argue that:

> As in euthanasia, even if the patient were healthy, sedation would end the life of the patient if fluids and nutrients were not provided. This practice differs from voluntarily stopping eating

[37] Brigit R Taylor and Robert M McCann, 'Controlled Sedation for Physical and Existential Suffering?' (2005) 8(1) *Journal of Palliative Medicine* 144, 145.
[38] De Graeff and Dean, above n 1, 77.
[39] Williams, above n 28, 53.
[40] Søren Holm, 'Terminal Sedation and Euthanasia: The Virtue in Calling a Spade What It Is' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal perspectives* (Cambridge University Press, 2013) 228, 231.
[41] Ibid 239.

> and drinking, because the patient is sedated and therefore does not have the chance to continuously reflect on or to change his/her decision.[42]

Van Delden, on the other hand, reaches an apparently different conclusion, namely that 'although in some cases terminal sedation and euthanasia are two morally equivalent ways of hastening death, in most cases they represent essentially different clinical situations.'[43] It may be surmised, however, that the situations where he finds congruence between the two may well be those under consideration here – the use of terminal sedation with no ANH. As Rich argues, 'all current practice guidelines and policies provide that the decision on total sedation and the decision about nutrition and hydration must be separate and distinct, and the latter may not properly be a condition precedent for the former.'[44] Whether this is actually what occurs in practice, however, may be disputed.

It would seem then that the principle of double effect may not in fact provide sufficient justification to render ethically acceptable the practice of terminal sedation without the provision of ANH. For this reason, and while recognising that in some cases the principle may be appropriate, Billings and Churchill propose that 'considering a variety of approaches will deepen our moral perceptions and provide greater wisdom than uncritical reliance on a single rule, however useful that rule may be.'[45] Developing alternative, convincing and broadly applicable approaches is, however, a major challenge. Nonetheless, the apparent convenience of the appeal to the principle of double effect needs to be re-evaluated. As Rich argues, 'the almost reflexive manner in which the double effect finds its way into the ethics of end-of-life care belies its confusing origins and the persistent controversy over whether the doctrine can ever, and if so, under what circumstances, be consistently and coherently applied.'[46]

IV LEGAL CONSIDERATIONS

It is generally accepted that any intervention, whether or not medically supported and clinically indicated, requires that the patient provides a valid consent. Without this, allegations of assault – or worse – might attach to the act in question. Consent, it is said, is the legal means that supports autonomy – the principle referred to above. While some have disputed the efficacy of consent in achieving actual protection of autonomy,[47] it remains the best tool available to the law to offer such protection, however limited it may be. Where terminal sedation *and* the removal or withholding of ANH are proposed, and given the foreseen, if not intended, outcome, obtaining a valid consent is arguably of even greater importance than in less serious decisions. Perhaps surprisingly, however, the Dutch guidelines already referred to seem equivocal as to the value of patient consent. Swart et al, for example note that '[w]hereas being aware of the preferences and wishes of the patient and the family can arguably facilitate the decision to start CPS, this may sometimes also complicate decision making'.[48] Rather, the guidelines are clear that this is a medical decision, where '[t]he preferences of patients and families and the patient's

[42] Taylor and McCann, above n 37, 145.
[43] van Delden, above n 2, 188.
[44] Rich, above n 21, 36.
[45] J Andrew Billings and Larry R Churchill, 'Monolithic Moral Frameworks: How Are the Ethics of Palliative Sedation Discussed in the Clinical Literature?' (2012) 15(6) *Journal of Palliative Medicine* 709, 712.
[46] Ben A Rich, 'Causation and Intent: Persistent Conundrums in End-of-Life Care' (2007) 16 *Cambridge Quarterly of Healthcare Ethics* 63, 69.
[47] See, for example, Sheila AM McLean, *Autonomy, Consent and the Law* (Routledge, 2010).
[48] Siebe J Swart et al, 'Continuous Palliative Sedation: Not Only a Response to Physical Suffering' (2014) 17(1) *Journal of Palliative Medicine* 27, 32.

life expectancy are weighed against the severity of refractory symptoms...'[49] Just who would be better at making such a calculation than the patient him- or herself seems a relevant, albeit overlooked, question here. Orentlicher claims that, apart from the Netherlands where consent was sought in 96 per cent of cases, studies from other countries show that consent from patients was not sought in significant percentages of cases.[50] As consent can amount to a defence against a criminal charge in medical cases – for example, it is already accepted that physicians can engage in consented-to behaviour like surgery which would otherwise amount to an assault – it might be thought strange that consent was not sought.

It may, of course, be asked whether or not a patient may be so incapacitated by their suffering as to make it difficult, if not impossible, for them to make a valid decision. In such cases, proxy decision-makers may be sought, although the extent to which we can be sure that their choice would in fact be that of the patient may be questionable. Ideally, therefore, and where feasible, this would suggest that discussions about the future possibility of terminal sedation should be undertaken early with the patient, as should the separate question of whether or not ANH should be provided. While these are undoubtedly difficult conversations, if the patient is to be truly involved in decisions about their own life or death, and the way in which they die, then they must occur. As De Graeff and Dean note, '[s]uffering and distress are subjective criteria, so only the patients can determine the suffering to be intolerable.'[51] In an echo of the point just made about the patient who is unable to offer a valid consent, they also caution that where a proxy decision-maker is involved '[t]he health care team should be confident that the proxy expresses the (presumed) wishes of the patient and not his or her own.'[52]

From the physician's perspective, a further legal question will relate to the possibility that their actions (or omissions in the case of ANH) might amount to criminal behaviour. This will very much depend on what is seen as the cause of death. In the US Supreme Court judgement in *Vacco v Quill*,[53] the court's view was that the cause of death was the medication 'but that the purpose of the sedation [was] twofold, to ease suffering and to comply with the patient's wishes.'[54] In another Supreme Court decision – *Washington v Glucksberg*[55] — terminal sedation was described as 'one of three situations where "physicians are already involved in making decisions that hasten the death of terminally ill patients."'[56]

If so, then it is tempting to ask in what ways terminal sedation without ANH differs legally from other forms of assisted dying. This question has already been raised from an ethical point of view; what would the legal response be? Leaving aside the question of intention, which has already been discussed, the law's response when clinical decisions and practices are under question is often – in addition to the question of consent – first to address 'standard or reasonable medical practice' and then – sometimes at least – to consider whether the behaviour can be categorised as an act or an omission. Additionally, the concept or defence of necessity may be relevant.

Where doctors are able to argue that their behaviour was in accord with – in the UK at least – a responsible body of medical opinion, then no civil liability will follow. In the UK case of *R*

[49] Ibid 33.
[50] Orentlicher, above n 22.
[51] De Graeff and Dean, above n 1.
[52] Ibid.
[53] *Vacco v Quill*, 521 US 793 (1997).
[54] Williams, above n 28, 48.
[55] *Washington v Glucksberg* 521 US 702 (1997).
[56] Williams, above n 28, 48.

v Arthur[57] accepted medical practice was taken as evidence that no criminal act had been committed. However this case is of dubious precedential value.[58] It does however show the extent to which courts have been prepared to excuse decisions of considerable gravity, essentially by categorising the issues as clinical, rather than criminal. The mistake of categorising events in this way led to the dubious decision in the *Arthur* case and displays a lack of insight. In any case, as Battin has written '[d]istinguishing between different sorts of intentions on the basis of observed practice is not only impossible but morally indefensible.' [59] Delbeke notes that terminal sedation is regarded as 'normal medical practice' in the Netherlands, but argues that:

> ….[i]t is the task of the legislator (and not of a professional medical association or a multidisciplinary commission) to determine the basic framework, the conditions under which an act as far-reaching as CDS [continuous deep sedation] is permitted, especially since there is the underlying risk that it may be found to be a criminal act.[60]

As to the question of the alleged distinction between acts and omissions, while this is widely referred to and often utilised in law, it has been argued to be a 'distinction without a difference' in some cases.[61] While it is clear that in some situations my omissions will be at worst neutral but my acts would be culpable, it is debateable whether or not this applies to omissions that directly bring about death and where there is an existing duty of care, such as that owed by clinicians to patients. While courts in the UK (and elsewhere) have been content to justify the removal of ANH in patients in a permanent vegetative state, categorising it as either a solely medical decision or as an omission rather than an act – this conclusion can be – and has been – challenged, given that at the very least the death (a) results from the dehydration and (b) is at least foreseeable, which is sometimes legally sufficient to infer intent.[62]

One further possible avenue for evaluating terminal sedation without ANH has been raised; namely, the use of the doctrine of necessity. Delbeke argues:

> [t]he concept of necessity implies a conflict between two goods, one of which is considered more important and thus given priority. In the context of palliative care, the conflict exists between maintaining the patient's life on the one hand, and alleviating the patient's severe suffering on the other hand. In the case of CDS, the alleviation of the patient's severe suffering is considered more important.[63]

However, the author does not believe that necessity would work as a defence for two reasons. First, it is meant for use in exceptional cases and pain relief is not exceptional. Second, it would not provide caregivers with certainty since it is a question of interpretation for the courts. It can also be argued that the failure to provide ANH is directly contributory to the death, yet it is not obvious that this can easily – if at all – be covered by the necessity doctrine which refers rather

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[57] *R v Arthur* (1981) 12 BMLR 1.
[58] Not least because this was a decision of one of the lower courts. For discussion, see JK Mason and GT Laurie, *Mason and McCall Smith's Law and Medical Ethics* (Oxford University Press, 9th ed, 2013) particularly at 506-508.
[59] Margaret P Battin, 'Terminal Sedation: Recasting a Metaphor as the *Ars Moriendi* Changes' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds) *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 240, 245.
[60] Delbeke, above n 32, 136.
[61] See McLean, above n 47, particularly chapter 4.
[62] *R v Woollin* [1999] 1 AC 82.
[63] Delbeke, above n 32, 134-135.

to *actions* taken in the face of competing interests, rather than the *choice* not to do something which would otherwise be effectively mandatory.

V CONCLUSION

It can reasonably be concluded from what has gone before that terminal sedation, particularly where it involves the withholding of ANH, is controversial. Not only that, its practice arguably rests on shaky ethical and legal premises. While initially it might have seemed that the dilemmas raised were mostly about the appropriate terminology to use and the normative values reflected in the language applied (and there is no doubt that this remains problematic), the real difficulties concern finding adequate ethical and legal justifications for its practice. On the one hand, questions about causation and intention are vitally important; on the other, they are highly problematic. As Rich says, neither 'can be ascertained with sufficient certainty so as to provide an adequate foundation for the critical moral distinctions involving dying and death in the clinical setting that have often been based upon them.'[64]

Further, the fact that the use of terminal sedation itself seems to be dependent on considerations that are as much – if not more – about the preferences, prejudices and values of doctors rather than patients, predictably entails uneven availability, despite the existence of guidelines. Thus even if we wish to maintain a bright line between terminal sedation without ANH and other assistance in dying, as Holm argues '[i]f we are right in believing that euthanasia should be (strictly) regulated, because there are risks of misuse that need to be guarded against, then we should also think about regulating TS [terminal sedation] with withdrawal of hydration and nutrition.'[65]

But can we really maintain this distinction in any case? Where the patient dies following terminal sedation without ANH, arguably it is the medical act that has brought about the death, even where patients are imminently dying. In these cases, at best, medicine facilitates the death even if there is no real way of knowing precisely what the cause of the death actually is. Justification may be found in the patient's consent, so that the sedation and accompanying deprivation of nutrition and hydration can be evaluated 'by the extent to which it accommodates the patient's authentic wishes and circumstances, and by a more expansive view of the role and responsibility of the physician in the care of such patients than that of merely prolonging life.'[66] However, as we have seen, consent is not always sought or obtained. Additionally, guidelines seem more concerned with limiting the availability of terminal sedation to situations which arguably avoid a direct comparison with assisted dying, rather than good management of symptoms – whether or not physical; and the relief of suffering – irrespective of life expectancy.

The conclusion that the cause, effect and intention in terminal sedation without ANH and voluntary euthanasia are sometimes indistinguishable may be uncomfortable, but for the meantime in many countries it appears that this discomfort is acceptable, at least to some members of the community, and most notably the sensibilities of the medical profession. Failure to call a spade what it is – to use Søren Holm's analogy – may well be the result of perceived community values which 'can result in frustration of the preferences of patients who do not share the values of their communities' majorities.'[67] That this may result in unnecessary

[64] Rich, above n 46, 64.
[65] Holm, above n 40, 231.
[66] Rich, above n 46, 70.
[67] Orentlicher, above n 22, 118.

suffering seems to run counter to the stated desire to alleviate suffering, even if it does result in an earlier death.

In the long run, and as unpopular as this may be in some circles, the variations in practice between and within countries, the arguable lack of suitability of the widely used ethical justifications and the uncertain application of legal rules all seem to mandate that there is a primary – even critical – imperative for the law to take responsibility for establishing parameters for the use of terminal sedation, especially where ANH is not provided. However to do this it may – in some cases at least – mean a reconsideration of attitudes to all end of life decisions. Legal oversight and clearly established legal rules (as opposed to professional guidelines) may provide the kind of certainty that both patients and physicians should surely be able to expect and would most likely welcome.

In conclusion, it can be said that terminal sedation (even without ANH) can be good medicine. However, a 'good' act requires appropriate justification beyond 'this is what doctors do', or 'this is a medical decision'. For this justification we need to look to ethics and from there to a law that reflects agreed, robust and sustainable ethical values. At present, the ethical principles commonly used to justify the provision of terminal sedation without ANH seem inadequate. Given this, it is scarcely surprising if legal contortions are sometimes necessary to justify a given practice. This is surely unacceptable, and the need to expose practice and analyse its appropriateness becomes ever more urgent as the use of terminal sedation continues to grow, reinforcing the need for clarification, consistency, transparency and accountability in this most sensitive of areas.

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HOW THE UK OVERCAME THE ETHICAL, LEGAL AND PROFESSIONAL CHALLENGES IN DONATION AFTER CIRCULATORY DEATH

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Long transplant lists and a shortage of organ donors has led to an international resurgence in the donation of organs after circulatory death ('DCD'). Despite being almost entirely absent for nearly 25 years, DCD now accounts for 40 per cent of deceased organ donation in the UK. This rise is in part due to attempts to resolve the ethical, legal and professional challenges inherent to this type of donation. Since 2008 in the UK, seven major ethical, legal and professional guidances have been published relating to deceased donation and DCD in particular. It is now this author's opinion that the professional framework that underpins the DCD programme in the UK is the strongest in the world. This paper outlines the seven UK publications that justify this bold claim.

I INTRODUCTION

The World Health Organization has called for national self-sufficiency in transplantation to protect the vulnerable from exploitation.[1] While we await a transforming breakthrough in xenotransplantation or the technology for laboratory-grown organs, patients die: three per day in the UK. It is only through the generosity of donors and their families, that the *gift of life* has been given to so many.

There are four types of donation that are possible from a human body:

1) Living (eg blood, bone marrow, single kidney, liver lobe)
2) Tissue (eg corneas, heart valves, skin and bone)
3) Donation of organs after the neurological determination of death, also known as donation after brain death ('DBD') (organs that can be donated: kidneys, liver, pancreas, intestine, lungs and heart)
4) Donation of organs after the circulatory determination of death (DCD) (organs that can be donated: kidneys and lungs (long-term outcomes equal to DBD), livers and pancreas (long-term outcomes inferior to DBD) and heart (single centre experiences: USA, Australia and UK)).

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[1] Francia L Delmonico et al, 'A Call for Government Accountability to Achieve National Self-Sufficiency in Organ Donation and Transplantation' (2011) 378 *Lancet* 1414.

In the UK, the number of potential organ donors each year is around 5000 from an estimated 500 000 deaths. The vast majority of these potential donors will die in an intensive care unit. Organ donation is effectively limited to intensive care units because only in intensive care can the circulation be maintained after a confirmation of death using neurological criteria (DBD) or the withdrawal of life-sustaining treatment, which will result in circulatory cessation, be delayed until transplant teams are in readiness for the donation (DCD).

It was only with the advent of mechanical ventilation that the simultaneous physiological consequences of lethal brain injury, apnoea and circulatory arrest, could be interrupted. The diagnosis of 'brain death' was a discovery made in the intensive care unit. Prior to the acceptance of neurological criteria for human death that allowed DBD, DCD was the original type of deceased organ donation. After the acceptance of neurological criteria, DCD was effectively abandoned in most countries. In DCD, warm ischaemia begins as the circulation fails; organ viability for transplantation likewise rapidly falls (within 20 minutes for example in the liver), and this form of donation was almost entirely absent in the UK for 25 years. It was because of the unmet need on the transplant waiting list and because families in intensive care were advocating organ donation for their relatives who were not brain dead that programmes of donation after circulatory death recommenced. An international resurgence in DCD has occurred over the last decade.

There are a number of types of DCD:

Modified Maastricht Classification[2] (International nomenclature)

- Category I Dead on arrival
- Category II Unsuccessful resuscitation (French and Spanish predominant type)
- **Category III Awaiting cardiac arrest (UK, USA, Netherlands and Australian predominant type)**
- Category IV Cardiac arrest in a brain dead donor.
- Category V Unexpected cardiac arrest in a critically ill patient
- (Categories I, II, and V are uncontrolled whilst Categories III and IV are controlled in the sense that the cardiac arrest is expected.)

In the UK, the predominant type of DCD is Category III or controlled DCD. This type of DCD usually involves a mechanically ventilated patient with overwhelming single organ failure, usually the brain, where a prior decision has been made to withdraw life-sustaining treatment because this is to the patient's overall benefit. If there is a clinical expectation that the circulation will cease imminently upon the withdrawal of life-sustaining treatment (within 3 hours in the UK), DCD may be possible. If consent for organ donation is obtained during discussion with the family by the specialist nurse for organ donation ('SNOD'), a surgical retrieval team is mobilised. Withdrawal only commences once the surgical team is prepared in theatre and recipients for the organs have been identified. The SNOD supports the family throughout this process. The time from family consent to withdrawal can be greater than 12 hours, and this can occasionally lead some families to revoke their consent.

Donation after circulatory death accounts for 40 per cent of all deceased organ donation in the UK, which along with the Netherlands, makes the UK a world leader in this type of donation.

[2] For further discussion on Modified Maastricht Classification, please see eg, Ana I Sanchez-Fructuosa et al 'Renal Transplantation from Non-Heart Beating Donors: A Promising Alternative to Enlarge the Donor Pool' (2000) 11(2) *Journal of the American Society of Nephrology* 350.

This rise has not occurred because more families are proportionally consenting to donation - there has been little change in the family consent rate in the UK over the last decade - but because more families are being approached by intensive care staff and being offered the end of life choice of donation for their loved one. The number of families approached regarding donation from 2007 until 2012 increased by 7 per cent for DBD but increased by a staggering 311 per cent for DCD resulting in a 170 per cent increase in the number of DCD donors (200 to 539 donors over the same five years).[3] Since 2010, more families in the UK consent to DCD each year than DBD, though fewer overall patients progress ultimately to donation.

Such an increase is a direct result of a cultural shift in intensive care attitude and behaviours toward DCD against a background of negativity.[4] While the reasons for this shift are multi-factorial, the attempts to resolve the ethical, legal and professional challenges inherent to DCD has been a major contributor to the rise of DCD in the UK. A number of intensive care clinicians in the UK, including this author, once challenged the professional framework in which DCD was operating.[5] In 2008 the Organ Donation Taskforce made 14 recommendations with the anticipation of a 50 per cent increase in donation over five years (successfully met in 2013).[6] Recommendation 3 of the Taskforce report was

> Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established.[7]

The ambition of the Taskforce was to make organ donation a usual, not an unusual event in hospitals and that discussion about donation would become a normal part of all end of life care when appropriate.

Since 2008 in the UK, seven major ethical, legal and professional guidances have been published relating to deceased donation and DCD in particular. It is now this author's opinion that the professional framework that underpins the DCD programme in the UK is the strongest in the world. This paper outlines the seven UK publications that justify this bold claim.

II THE TWO KEY ETHICAL PRINCIPLES IN DECEASED ORGAN DONATION

Before outlining the seven UK publications, it is worth stating what challenge they were written to answer. In no jurisdiction is there an organ donation and transplantation programme that does not attempt to address (perhaps not always successfully) two key ethical, legal and professional principles. These two principles are the *Dead Donor Rule* and what can be understood as the *Consenting Donor Rule*.

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[3] NHSBT Statistics available at, National Health Service, 'Blood and Transplant Statistics' (2015) <http://www.organdonation.nhs.uk/statistics>.

[4] Helen Fenner, Charmaine Buss and Dale Gardiner, 'Intensive Care Staff Attitudes to Deceased Organ Donation' (2014) 15(1) *Journal of the Intensive Care Society* 53.

[5] Dale Gardiner and Bernard Riley 'Non-Heart-Beating Organ Donation - Solution or a Step Too Far?' (2007) 62(5) *Anaesthesia* 431; Dominic Bell, 'Non-Heart Beating Organ Donation: In Urgent Need of Intensive Care' (2008) 100(6) *British Journal of Anaesthesia* 738.

[6] Department of Health (UK), *Organs for Transplants: A Report from the Organ Donation Taskforce* (2008).

[7] Ibid 9.

Within nine months of Christiaan Barnard performing the world's first heart transplantation in Cape Town, South Africa 1967, the *Journal of the American Medical Association* published two landmark papers, which provided the ethical framework necessary for the future of the emerging transplantation programme. The first paper was the report of the Ad Hoc Committee of the Harvard Medical School, which argued that irreversible coma, as met by their criteria, should be defined as a new criterion for death.[8] The accompanying, but lesser cited paper, was a Judicial Council ethical guidance by the American Medical Association to its members and the wider public regarding the emerging technology of solid organ transplantation.[9] Two ethical principles remained self-evident to the Judicial Council and have been fundamental in transplantation policy and debate ever since. Firstly the principle that would become the *Dead Donor Rule*, 'When a vital, single organ is to be transplanted, the death of the donor shall have been determined by at least one physician other than the recipient's physician'.[10] Secondly, 'A prospective organ transplant offers no justification for relaxation of the usual standards of medical care',[11] and 'full discussion of the proposed procedure with the donor and the recipient or their responsible relatives or representatives is mandatory.'[12] This combined second principle can be understood as the *Consenting Donor Rule*.

The term, *Dead Donor Rule* ('DDR'), was labelled as such by John Robertson in 1988. He described the DDR as the principle that 'organs be removed only from dead patients,'[13] but its origin in the Judicial Council guidance is clear. Over the years, a number of alternative interpretations of the Dead Donor Rule have emerged. The first is a narrow reading, often endorsed in subsequent publications by John Robertson, where the DDR is interpreted to be a prohibition on killing the patient for organ donation. This interpretation would prohibit interventions that bring about the death of the patient in order to retrieve a vital organ and, in particular, those interventions that might bring about the death of the patient by removing a vital organ. From such a reading a proposal was recently published whereby dying but not deceased patients on an intensive care unit might be taken to theatre for kidney removal (analogous to DBD or living donation and therefore not requiring DCD), then returned to the ICU without their kidneys, for withdrawal of life sustaining treatment.[14] Given that death following total kidney failure is likely to take a few days to occur, the death of the patient would follow the withdrawal of life sustaining treatment rather than the donation of the kidneys, and thus the DDR would still be satisfied. The author of this proposal identified that such a program is only suitable for kidneys as the removal of a heart, lungs or liver would rapidly lead to death in the donor.

A broad reading of the DDR would be that procedures for organ donation should not be initiated while the patient is still alive.[15] Arthur Caplan in a *New England Journal of Medicine* Perspective Roundtable on Organ Donation after Cardiac Death, answered the question 'What

[8] Ad Hoc Committee of the Harvard Medical School, 'A Definition of Irreversible Coma' (1968) 205(6) *The Journal of the American Medical Association* 337.
[9] Judicial Council of the American Medical Association, 'Ethical Guidelines for Organ Transplantation' (1968) 205(6) *The Journal of the American Medical Association* 341.
[10] Ibid 342.
[11] Ibid.
[12] Ibid.
[13] John Robertson, 'Relaxing the Death Standard for Organ Donation in Pediatric Situations' in Deborah Mathieu (ed), *Organ Substitution Technology: Ethical, Legal, and Public Policy Issues* (Westview Press, 1988) 69.
[14] Paul Morrissey, 'The Case for Kidney Donation Before End-of-Life Care' (2012) 12(6) *The American Journal of Bioethics* 1.
[15] Dale Gardiner and Robert Sparrow, 'Not Dead Yet: Controlled Non-Heart-Beating Organ Donation, Consent, and the Dead Donor Rule' (2010) 19(1) *Cambridge Quarterly Healthcare Ethics* 1.

is the dead donor rule?' by saying '[t]he dead donor rule says we take organs, vital organs, only from those who've been clearly, unequivocally pronounced dead. So nothing will happen in terms of procurement, requests, anything, until you've got a team that establishes death.'[16] In practice, controlled DCD, but not DBD, will always violate a broad interpretation of the DDR. Even at a minimum, the premortem interventions for a successful DCD must include referral to an organ procurement organisation, blood tests for tissue typing and virology, consent from families for the donation, delay in time and/or change of location of life-sustaining treatment withdrawal.

From these three readings of the DDR (standard - vital organs can only be removed from dead patients; narrow - prohibition against killing a patient in order to retrieve a vital organ; and broad - procedures for organ donation should not be initiated while the patient is still alive) it is easy to see the challenges inherent to DCD compared to DBD. In DBD, though still some debate persists about whether the donors are truly dead,[17] there is legal acceptance in the UK that brain death is human death, satisfying a standard reading of the DDR. Likewise, nothing the clinicians do in DBD can be said to cause the death of the donor, satisfying a narrow DDR reading and there is no necessity to commence organ donation related activities until after the death has been declared, satisfying a broad DDR reading. In contrast in DCD, prior to 2008 there was no guidance on diagnosing death after cardio-respiratory arrest in the UK so that there was uncertainty over how long a clinician must wait before declaring death in DCD. If interventions such as the administration of the blood thinner heparin, as commonly used in the USA to prevent clots in donor organs, resulted in bleeding in a dying brain-injured patient and thereby hasten death, a narrow DDR interpretation, preventing the killing of patients, would also be breached. As explained above, DCD by practical necessity will never satisfy a broad DDR reading, as actions to plan and facilitate donation are required for many hours before death, and it was unknown if such actions pre-mortem were even legal in the UK.[18]

While not explicitly stated as such, the *Consenting Donor Rule* is none-the-less addressed in every jurisdiction as to what legal standard is required for consent to donation. Even in systems of hard-presumed consent or where executed prisoners donate organs, the consent issue will have been addressed by a societal or governmental decision rather than at an individual or family level. In the UK, the *Human Transplantation (Wales) Act 2013* came into force in December 2015 and will apply only in Wales for Welsh residents over 18 years of age. This change in law introduces the concept of *deemed consent*, a soft form of presumed consent. Unless a Welsh resident has opted out on the UK Organ Donor Register their consent for donation will be deemed but their families will still be approached, to ascertain if they knew of any expressed objection by the individual to donation. This emphasises that even legal changes to donation policy are referenced with respect to the need to address the Consenting Donor Rule. The impact deemed consent has on Welsh organ donation rates will be reported in September 2017.

All of the following seven guidances below and published in the UK after the Taskforce call in 2008 for resolution of the outstanding legal, ethical and professional issues in organ donation, can be seen as a response to the challenges raised by these two key principles to a lesser or greater degree.

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[16] New England Journal of Medicine, *Perspective Roundtable on Organ Donation After Cardiac Death* (2008) <http://www.nejm.org/doi/full/10.1056/NEJMp0804161>.

[17] Seema Shah, Robert Truog and Franklin Miller, 'Death and Legal Fictions' (2011) 37 *Journal of Medical Ethics* 719.

[18] Gardiner and Riley, above n 5.

III THE SEVEN MAJOR UK ETHICAL, LEGAL AND PROFESSIONAL PUBLICATIONS ON DECEASED ORGAN DONATION SINCE 2008

A *Academy of Medical Royal Colleges, Code of Practice for the Diagnosis and Confirmation of Death (2008)*[19]

This Code of Practice was the successor to previous versions and updated the Codes of Practice published in 1976, 1979, 1983 and 1998 for the diagnosis of death using neurological criteria. It was notable for being the first Code of Practice to provide guidance on the diagnosis of death following cardiorespiratory arrest (circulatory criteria) and the first code of practice to remove organ donation considerations from the guidance. The guidance is intended to be applicable to all deaths, not just the diagnosis of death for the purposes of organ donation – in contrast to guidance in the USA, Australia and most other countries with a DCD programme. The 2008 Code of Practice gave reassurance to intensive care doctors involved in DCD that by following national guidance on when to diagnose and confirm death after cardio-respiratory arrest, they were acting in accordance to the standard reading of the DDR, that deceased organ donors were dead.

B *Legal Guidance from All Four UK Jurisdictions on DCD (2009-2011)*[20]

All four UK governments have published legal guidance to guide clinical staff involved with DCD. Importantly the legal guidance recognised an important difference in DCD compared to DBD, namely, that the decision and interventions involved in DCD occur on living patients not deceased patients. As such the deceased donation legislation in the UK, the *Human Tissue Act 2004* covering England, Wales and Northern Ireland,[21] and the *Human Tissue (Scotland) Act 2006*,[22] which set out the legislative requirements for seeking consent and authorisation to donation for both living donation (where the donors have capacity) and deceased donation, were not applicable as guides for clinicians making decisions about organ donation for living but lacking capacity patients in the hours before death and potential DCD.

Instead, the legal guidance justified procedures to facilitate DCD by referring to other non-donation legislation, which is used to guide clinicians in caring for patients without the capacity to make decisions for themselves: *Adults with Incapacity (Scotland) Act 2000*,[23] and the *Mental Capacity Act 2005*.[24] These Acts, their associated codes of practice and previous case law make it very clear in the UK that the present and past wishes and feelings of the adult with incapacity should be accounted for, including seeking the views of the nearest relative and the primary

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[19] Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (2008) <http://www.bts.org.uk/Documents/A%20CODE%20OF%20PRACTICE%20FOR%20THE%20DIAGNOSIS%20AND%20CONFIRMATION%20OF%20DEATH.pdf>.

[20] Department of Health (UK), *Legal Issues Relevant to Non-Heartbeating Organ Donation* (2009) <https://www.gov.uk/government/publications/non-heartbeating-organ-donation-legal-issues>; Chief Medical Officer and Public Health Directorate (Scotland), *Guidance on Legal Issues Relevant to Donation Following Cardiac Death* (2010) <www.sehd.scot.nhs.uk/cmo/CMO(2010)11.pdf>; Department of Health, Social Services and Public Safety (Northern Ireland), *Legal Issues Relevant to Donation After Circulatory Death (Non-Heart-Beating Organ Donation) in Northern Ireland* (2011) < http://www.clodlog.com/resources/Documents/NI-Legal-DCD-2011.pdf>.

[21] *Human Tissue Act 2004*.

[22] *Human Tissue (Scotland) Act 2006*.

[23] *Adults with Incapacity (Scotland) Act 2000*.

[24] *Mental Capacity Act 2005*. Applicable in England, Wales and Northern Ireland.

carer of the adult, when deciding if an intervention is of benefit. As stated by the UK's Department of Health:

> Once it has been established that a person wanted to donate, either through direct knowledge of their wishes or as a result of discussions about what the person would have wanted, successful donation may be seen to be in the person's wider best interests in a number of ways:
> (a) by maximising the chance of fulfilling the donor's wishes about what happens to them after death;
> (b) by enhancing the donor's chances of performing an altruistic act of donation; and
> (c) by promoting the prospects of positive memories of the donor after death.[25]

The following steps were outlined as permissible to facilitate DCD:

1) Delaying withdrawal of life-sustaining treatment.
2) Changing the patient's location.
3) Maintaining physiological stability.[26]

In addition, 'anything that places the person at risk of serious harm (such as systemic heparinisation) or distress (such as resuscitation) is unlikely ever to be in the person's best interests in this situation.'[27]

In reference to the DDR, what this legal guidance offered clinicians was the assurance that, by not giving heparin, the narrow reading of the DDR (not killing patients) was fully satisfied. While the broad reading (procedures for organ donation should not be initiated while the patient is still alive) can never be satisfied in a controlled DCD programme, the legal guidance effectively sidestepped this issue by advancing the legal view that it was the *Consenting Donor Rule* that was the pre-eminent consideration in a living patient in the hours before their death. While the legal guidance has not been tested in court, subsequent publications in the UK have reinforced this conclusion. With the introduction of deemed consent in Wales from December 2015, the justification for activities to facilitate donation prior to death (if there has been no registration of an objection to donation) may have been legally strengthened in Wales.

C *General Medical Council Guidance: 'Treatment and Care towards the End of Life' (2010)*[28]

The General Medical Council ('GMC'), which regulates medical practitioners in the UK, included the following statement in their 2010 end of life guidance: [29]

> If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility; and
> you should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator [specialist nurse - organ donation].[30]

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[25] Department of Health, above n 20, 8.
[26] Ibid.
[27] Ibid 11.
[28] General Medical Council (UK), *Treatment and Care towards the End of Life* (2010) <http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp>.
[29] Ibid.
[30] Ibid 42.

This guidance, by the regulatory body of doctors, effectively established a duty on UK doctors to explore donation at the end of life, where clinically appropriate, and to follow national professional guidance. The impact of this duty would be most felt by intensive care doctors who were the medical practitioners most likely to care for potential deceased organ donors. Again, the emphasis on patient wishes, or those wishes as interpreted by those close to the dying patient, are emphasised.

D *Joint Professional Statement from the Intensive Care Society and the British Transplantation Society (2010)*[31]

This document stated unambiguous professional support from the UK Intensive Care Society for DCD and importantly gave professional support for admission to ICU purely for organ donation. This latter point was important in addressing ethical concerns with respect to the admission of dying patients into a scarce intensive care bed and the opinion that a dying patient's interests were not advanced by ICU admission. This document provided guidance for intensive care clinicians before and after the patient's death. After an experience in Australia was reported where the heart restarted during a lung DCD,[32] this guidance was able to establish a safer practice for lung DCD, which has allowed lung DCD to rise to 16 per cent of all lung transplants in the UK, with outcomes comparable to DBD lungs.[33]

E *Joint Professional Statement from the College of Emergency Medicine and the British Transplantation Society (2011)*[34]

Up to 15 per cent of UK potential deceased organ donors are identified in the Emergency Department [35] As such, Emergency Department health professionals have a vital role in identifying and referring to specialist nurses dying patients where it might be appropriate to explore the option of organ donation with their families. This joint statement provided professional support for the robust identification of potential donors in the Emergency Department and support for managing organ donation from the Emergency Department if admission to ICU is not possible (a common occurrence in the UK).

F *Independent UK Donation Ethics Committee Guidance on DCD (2011)*[36]

Recommendation 3 of the Taskforce report included the need to establish an independent UK-wide Donation Ethics Group. The UK Donation Ethics Committee ('UK DEC') was established in January 2010, with support from all four UK governments and is hosted by the Academy of Medical Royal Colleges. The purpose of UK DEC is to provide independent advice and resolution on ethical aspects of organ donation and transplantation (but not to

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[31] Intensive Care Society and British Transplantation Society, *Report of a Donation after Circulatory Death Consensus meeting held in June 2010* (2010).

[32] Dale Gardiner, 'Report on the 4th International Meeting on Transplantation from Non-Heart Beating Donors: London 15-16 May 2008' (2008) 9(2) *Journal of the Intensive Care Society* 206.

[33] NHSBT Statistics available at, National Health Service, 'Blood and Transplant Statistics' (2015) <http://www.organdonation.nhs.uk/statistics>.

[34] College of Emergency Medicine and British Transplantation Society, *Report of a Workshop on The Role of Emergency Medicine in Organ Donation* (2011) <http://www.odt.nhs.uk/pdf/role_of_emergency_medicine_in_organ_donation.pdf>.

[35] Accessed by the author from NHSBT statistics.

[36] UK Donation Ethics Committee, *An Ethical Framework for Controlled Donation After Circulatory Death* (2011).

increase organ donation per se). Sir Peter Simpson was the inaugural chair of UK DEC and as well as having been a Past President of the Royal College of Anaesthetists, he had been the Chair of the Working Group that had authored the 2008 Academy of Medical Royal Colleges' Code of Practice for the Diagnosis and Confirmation of Death. The first major publication by UK DEC was ethical guidance for DCD.

UK DEC identified two guiding principles to their work:

> **Principle 1:** where donation is likely to be a possibility, full consideration should be given to the matter when caring for a dying patient; and
> **Principle 2:** if it has been established that further life-sustaining treatment is not of overall benefit to the patient, and it has been further established that donation would be consistent with the patient's wishes, values and beliefs, consideration of donation should become an integral part of that patient's care plan in their last days and hours.[37]

Its DCD guidance, published in 2011,[38] provided procedural and process ethical guidance for clinicians. Other ethics groups, like the British Medical Association,[39] and the Nuffield Council on Bioethics[40] have historically focused on big issues of public policy such as presumed consent and paying for the funeral expenses of donors, which were not directly applicable to a dying patient in an intensive care unit. UK DECs focus was on roles, responsibilities, and conflicts of interest. Key statements by UK DEC in their DCD guidance were that:[41]

- Contact between the clinical team treating the potential donor and the SNOD before the decision has been made to withdraw life-sustaining treatment is ethically acceptable.
- SNODs should not provide medical care to the potential donor whilst they are still alive.
- Two senior doctors, who should both have been registered for at least five years, and at least one of whom should be a consultant, should verify that further active treatment is no longer of overall benefit to the patient. It would be preferable for this to be the case for all patients, not only for those where organ donation is a possibility (although the UK DEC remit extends only to organ donation).
- Care should be in an appropriate environment and provided by staff with the appropriate skills and experience to deliver the end of life care plan.
- After death, it is acceptable for the treating clinician to take actions necessary to facilitate donation, e.g. tracheal re-intubation for lung DCD.

G *NICE Guidance on Organ Donation (2011)*[42]

The National Institute for Health and Clinical Excellence ('NICE') will in some topic areas set the expected standard of practice applicable in England, Wales and Northern Ireland, based on

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[37] Ibid 6.
[38] Ibid.
[39] British Medical Association, *Building on Progress: Where Next for Organ Donation Policy in the UK?* (2012) <http://bma.org.uk/-/media/files/pdfs/working%20for%20change/improving%20health/organdonation_buildingonprogressfebruary2012.pdf>.
[40] Nuffield Council on Bioethics, *Human Bodies: Donation for Medicine and Research* (2011) <http://nuffieldbioethics.org/project/donation/>.
[41] UK Donation Ethics Committee, above n 36.
[42] National Institute for Health and Clinical Excellence, *Organ Donation for Transplantation: Improving Donor Identification and Consent Rates for Deceased Organ Donation* (2011) <https://www.nice.org.uk/guidance/cg135>.

a review of the international published medical evidence. Compliance to NICE guidance is auditable and reportable within hospitals.

The 2011 NICE, *Organ Donation for Transplantation: Improving Donor Identification and Consent Rates for Deceased Organ Donation*[43] guidance recommended:

- A triggered referral to a SNOD if there is a:
  - Plan to withdraw life-sustaining treatment.
  - Plan to perform brain stem testing.
  - Catastrophic brain injury (early referral), defined as the absence of one or more cranial nerve reflexes, e.g. one fixed pupil, and a Glasgow Coma Scale score of 4 or less that is not explained by sedation.
- That while assessing the patient's best interests, the patient be clinically stabilised in an appropriate critical care setting while the assessment for donation is performed – for example, an adult intensive care unit or in discussion with a regional paediatric intensive care unit.[44]
- A collaborative approach to the family for organ donation involving:
  - A specialist nurse for organ donation.
  - A local faith representative if appropriate.

III CONCLUSION

When Joseph Murray carried out the world's first kidney transplant in 1954, it looked like the world was going to change, and it has — but only by one donor at a time. In the UK, it may be a case of one ethical, legal and professional framework at a time. These seven publications outlined in this paper were an answer to the 2008 Recommendation of the Taskforce report to urgently resolve outstanding legal, ethical and professional issues in deceased donation in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. A clear focus of the publications was on resolving uncertainties in DCD. At their heart, they are professional guidance designed to answer how the UK satisfies the *Dead Donor Rule* and the *Consenting Donor Rule*. Whether they were successful in this endeavour will only be known in time but little else in intensive care medicine has received such robust attention, by such a wide body of experts, in such a short period.

[43] Ibid.
[44] Ibid 8.