

THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by - DR LINDA SHEAHAN - 2012 Churchill Fellow
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THE DOROTHEA SANDARS AND IRENE LEE CHURCHILL FELLOWSHIP to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia.

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Signed
Linda Sheahan

Dated
13 July 2013



<u>INDEX</u>	Page(s)
<u>1. INTRODUCTION</u>	3
<u>2. EXECUTIVE SUMMARY</u>	4
<u>3. PROGRAMME</u>	5 - 7
<u>4. MAIN BODY</u>	
4.1 Background	8 - 9
4.2 Literature Review and Summary of the Issues	10 - 14
4.3 USA	
4.3.1 Social and Contextual Backdrop	15
4.3.2 Oregon	16 - 21
4.3.3 Washington State	22 - 28
4.3.4 Montana	29
4.3.5 Take Home Messages	30
4.4 The Netherlands	31 - 40
4.4.6 Take Home Messages	41 - 42
4.5 Belgium	43 - 49
4.5.6 Take Home Messages	50
4.6 Luxembourg	51 - 52
4.7 Switzerland	53 - 56
4.7.4 Take Home Messages	57
<u>5. DISCUSSION AND REFLECTIONS</u>	58 - 65
<u>6. CONCLUSIONS AND RECOMMENDATIONS</u>	66 - 69
<u>7. THE WAY FORWARD</u>	70
APPENDIX 1 Semi-Structured Interview Outline	71 - 72



1. INTRODUCTION

In 2012 I was awarded the DOROTHEA SANDARS AND IRENE LEE CHURCHILL FELLOWSHIP to study the interface between Palliative Care and legalized Physician Assisted Dying (Physician Assisted Suicide and Voluntary Euthanasia). The fellowship allowed me to travel around the world to jurisdictions where physician assisted death is practiced, and explore how these practices interfaced with palliative and end-of-life care.

The literature surrounding this issue demonstrates overwhelming community support for legalized PAD (Physician Assisted Death) in the form of Physician Assisted Suicide (PAS) or Voluntary Euthanasia (VE). In the Australian context, community support for legalized assisted death is high, thus legalization continues to be debated at a parliamentary level around the country. The Northern Territory was indeed the first jurisdiction in the world to formally legalize physician-assisted death with the *Rights of the Terminally Ill Act (RTIA)* in 1996, before the Australian federal government intervened and overturned the law. Internationally, there are seven jurisdictions around the world where PAD is legal or decriminalized. These include: The Netherlands, Belgium, Luxembourg, Switzerland, and the US states of Oregon, Portland and Montana.

In the Australian context, palliative care specialists have traditionally largely opposed the legalization of euthanasia, or deliberately distanced themselves from the issue. As caregivers at the end of life, we face this issue frequently in our clinical practice. I began to wonder how we ought to be managing this question, both at the bedside, and at a policy level, and realized that we needed much more information before we could answer this question well.

I would like to sincerely thank the Churchill Trust of Australia for their support of my endeavours, and am eternally grateful for my sponsors Dorothea Sanders and Irene Lee, whose legacy of contribution to the Australian community and the Churchill foundation lives on in this report, and the contributory work that will follow.

2. EXECUTIVE SUMMARY

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Project description: to gather information on the interface between palliative care and legalized physician assisted death (PAD) (physician assisted suicide (PAS) and/or voluntary euthanasia (VE)). The **Dr Dorothea Sandars and Irene Lee Churchill Fellowship** to travel to jurisdictions around the world where PAD is legal or decriminalized, and engage with key palliative care stakeholders regarding how these practices affect communities and healthcare at the end of life. Jurisdictions visited included: USA (Oregon and Washington State), The Netherlands, Belgium, Luxembourg, and Switzerland.

Highlights and key lessons learned:

- I am not currently in favour of legalization of PAD in Australia. I believe we need more accurate data on current perspectives and practices in the context of best practice palliative care, and more rigorous engagement in the values at play as they apply to the Australia community.
- I cannot yet conclude that PAD is a “good” per se, but this does not necessarily mean it should remain illegal in Australia.
- Legalization of PAD would represent a significant shift in our communal values, and the cultural and communal sequelae of this shift can only be understood over time. This makes it a choice we must make as a community, based on what values define us going forward.
- ‘Relief of suffering’ in the context of legalized assisted death is understood to be intricately connected to individual autonomy, self-determination and physical independence rather than unrelieved physical suffering per se.
- Data surrounding this issue currently relies on outdated concepts and knowledge in the context of developments in palliative and end-of-life care, and it is therefore inadequate to inform the debate for Australian legal reform.
- Legalized physician assisted death is not as bad in practice as it is often feared to be in principle. It enables a small number of individuals to control what they can of their own dying, without necessarily resulting in a “slippery slope” effect in terms of abuse of the legal parameters. It also has some strong arguments based on a harm minimization perspective.
- Palliative care currently defines itself in direct opposition to PAS/VE, but they can work synergistically. The question remains as to whether they ought to.

Proposed dissemination of findings:

1. Education plan to disseminate findings and promote discussion within palliative care circles – booked for presentations at St George Cancer Care forum July 15th, Calvary Healthcare Friday Education Forum Friday August 2013. More dates to follow.
2. Presentation of Churchill Fellowship report and preliminary survey data at National/Australasian Palliative Care meetings where accepted – accepted for first presentation at Palliative Care Australia National Conference Canberra September 2013.
3. Formal publication of data gathered from survey of palliative care specialists in Australasia, and commitment to undertake more comprehensive research and academic projects based on lessons learned from the Churchill experience overseas.
4. Dissemination of the key findings through the general media in order to stimulate debate.
5. Ongoing formal contribution to the debate at a governmental policy level where the issue arises.

3. PROGRAMME/ ITINERARY

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			<p>Dr Bregje Onwuteaka- Philipsen b.philipsen@vumc.nl Center of Expertise in Palliative Care VU University Medical Center, PO Box 7057, 1007 MB Amsterdam, the Netherlands -Meeting cancelled due to interviewee absence</p>
			<p>Prof Agnes van der Heide, Department of Public Health, Erasmus Medical Centre, Kamer G4-51, Postbus 5201, 3008 AE Rotterdam +31 (0)10-7041003</p>
			<p>Dr Suzanne van de Vathorst, Ethics Department Kamer G4-51, Postbus 5201, 3008 AE Rotterdam +31 (0)10- 7041003 – interview did not eventuate due to interviewee absence;</p>
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13/5	19/5	Brussels, Belgium	<p>Prof. Dr. Joachim Cohen, Kenneth Chambaere, Tinne Smets Postdoctoral Fellows and of the Research Foundation - Flanders (FWO), and Senior Researchers End-of-Life Care Research Group Vrije Universiteit Brussel, Bldg K, 1st Floor Laarbeeklaan 103 B-1090 Brussels</p>

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			Prof Felix Guttzwilwe (Head), Dr Matthias Bopp, Dr Ueli Zelleger, and Prof Karin Faisst University of Zurich, Institute for Preventive and Social Medicine (ISPMZ), Hirschengraben 84, CH-8001 Zurich +41446344611 – referred me to alternative contact (below)
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I also visited with a number of patients and citizen's who accessed physician aid in dying, the details of which I have not reproduced in light of confidentiality and privacy.

4. MAIN REPORT

4.1 Background

The literature surrounding this issue demonstrates overwhelming community support for legalized PAD (physician assisted death) in the form of Physician assisted suicide (PAS) or voluntary euthanasia (VE). Studies at the community level in Australia and around the westernized world have support at around 60-65%.^{1 2 3 4 5 6 7 8 9} In response to this community mindset, Australian state parliaments intermittently face bills and proposals to reform the current illegal status of assisted death practices, the most recent of which was unexpectedly in NSW in April 2013 while I was actually on my fellowship. The Northern Territory was indeed the first jurisdiction in the world to legalize physician assisted death with the *Rights of the Terminally Ill Act (RTIA)* in 1996, before the Australian federal government intervened and overturned the law with *The Euthanasia Laws Act (1996,)* based on a constitutional loop hole under its plenary powers to make laws for territories. Internationally, there are seven jurisdictions around the world where PAD is legal or decriminalized. These include: The Netherlands, Belgium, Luxembourg, Switzerland, and the US states of Oregon, Washington State and Montana.

In the Australian context, palliative care specialists have traditionally largely opposed the legalization of euthanasia, or deliberately distanced themselves from the issue with what is known as “studied neutrality.”^{10 11} This is, at least in part, an attempt to stay clearly differentiated from any practices that deliberately shorten life. While I understand the motivations behind this approach, I feel that the level of debate surrounding this issue has been poor, ill informed, and arguably “fear based” in many respects. My aim is to use my fellowship experience to better inform our thinking and engagement with this issue going forward.

¹ Kuhse H, Singer P et al. End of life decisions in Australian medical practice. *Med J Austr* 1997; 166:191-96

² Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists and the public. *The Lancet* 1996; 347:1805-1810

³ Cartwright CM, Williams GM et al. Does being against euthanasia legislation equate to being anti-euthanasia? *Internal Medicine Journal* 2006; 36:256-259

⁴ Steinberg MA, Najman JM et al. End of life decision making: community and medical practitioners’ perspectives. *Med J Australia* 1997; 166:131-134

⁵ Steinberg M, Cartwright C et al. Survey of approval of the Northern Territory Rights of the Terminally ill Act (1995). *Lancet* 1997; 349:577

⁶ Breitbart W, Rosenfeld B, Passik Sd. Interest in physician assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996; 153:238-42

⁷ Lavery JV, Dockens BM et al. Euthanasia and Assisted Suicide. *Can Med Assoc J*, 1997; 156(10): 1405-1408

⁸ Wolf J et al. Stability of attitudes regarding physician assisted suicide and euthanasia among oncology patients, physicians and the general public. *Journal of Clinical Oncology* 1999; 17(4): 1274-1279

⁹ Valverius E, Nilstun T, Nilsson B. Palliative care, assisted suicide and euthanasia: nationwide questionnaire to Swedish physicians. *Palliative Medicine* 2000; 14:141-1489

¹⁰ Sommerville A. Changes in BMA policy on assisted dying. *BMJ* 2005; 331:686-688

¹¹ George RJD, Finlay IG, Jeffrey D. Legalized euthanasia will violate the rights of vulnerable patients. *BMJ* 2005; 331:684-685

As caregivers at the end of life, we deal daily with terminal illness, and are thus often faced with questions regarding assisted death. It has been my experience that palliative care specialists vary widely in how they confront or avoid this question, and are often uncomfortable in discussing this issue with patients and colleagues.¹² The question is why, and how ought we be addressing this question, both in our clinical practice and on a policy level?

My exploration of this issue thus has two parts:

1. To identify current attitudes and practices among palliative care specialists in Australasia regarding PAS/VE.
2. Churchill Fellowship to visit jurisdictions where PAS/VE is practiced or legalized, and engage with key palliative care and assisted death stakeholders regarding how these practices affect communities and healthcare at the end of life. My expectation is that this fellowship will broaden and deepen our understanding of how legalization may effect end of life care in Australia, and what concerns have actually been validated by the overseas experience.

In order to explore part 1, I have constructed a survey for Australasian specialists in palliative care in order to gather some simple baseline cross sectional data from palliative care experts regarding their experiences and opinions surrounding physician assisted suicide and voluntary euthanasia. The survey is an anonymous, online survey with 18 questions, distributed through the peak body representative of medical expertise in palliative medicine: the Australian and New Zealand Society of Palliative Medicine (ANZSPM).

Key questions:

1. General demographic information.
2. Frequency of requests for assisted death, and what type of response is generally given
3. Understanding of the term 'voluntary euthanasia.'
4. Opinion regarding legalization of physician assisted suicide and/or voluntary euthanasia in an Australasian context.
5. Identify the most important and relevant values that inform this opinion, compiled from the literature.
6. Potential impact legalization of PAD/VE would have on palliative care practice and services in Australasia.

Approval for the project has been obtained through the Research Ethics Board for South East Area Health Services. Unfortunately, the planned distribution of the survey in April was delayed due to policy issues within the Australian and New Zealand Society of Palliative Medicine. Thus, the survey is approved for distribution to ANZSPM members end July 2013, and data will be available for review end of September 2013.

This report primarily deals with part two of the project, the lessons from which are compiled by jurisdiction.

¹² Hudson PL et al. Responding to desire to die statements from patient with advanced disease: recommendations for health professionals. *Palliative Medicine* 2006; 20: 703-710

4.2 Background literature review and summary of the issues

4.2.1 Definitions

It is clear through even a cursory look at the literature surrounding these issues that there is a considerable amount of inconsistency in defining terms. For the purposes of this project, the key terms are defined below.

‘Voluntary Euthanasia’ (VE) refers to the situation where a physician administers a drug to end the patient’s life at the explicit request of the patient.

‘Physician Assisted Suicide’ (PAS) refers to the situation where lethal drugs are prescribed by a physician at the patient’s explicit request, for the patients to administer to themselves in order to end their own life.

‘Physician Assisted Death’ (PAD) is an encompassing term, referring to one or both of the above two activities. This is the term preferred by advocates of legalization (or ‘physician aid in dying’) as it is seen to avoid any negative connotations associated with ‘suicide’ or ‘euthanasia.’

According to the World Health Organization definition¹³, Palliative Care:

- Affirms life, and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the physical, psychological, social, emotional and spiritual aspects of care, with coordinated assessment and management of each persons needs
- Offers a support system to help people live as actively as possible until death
- Offers a support system to help the family cope during the persons illness and in their bereavement

4.2.2 Ethics

The issue of legalized assisted death, and its interface with palliative care, has been extensively explored and debated within the academic, legal and medical literature for many years.^{14 15 16 17}

¹⁸ A thorough exposition of this work is beyond the scope of this report, but the many components are explored thoroughly by the complementary texts by Johns Hopkins University covering both sides of the debate: *The Case Against Assisted Suicide- For the right to End-of-Life*

¹³ See <http://www.who.int/cancer/palliative/definition/en/> Accessed 17 July 2013.

¹⁴ Roy DJ. Euthanasia and withholding treatment. Doyle et al. Eds. *Oxford Textbook of Palliative Care* 3rd Edition, Oxford University Press 2005:84-89

¹⁵ Woodruff R. Euthanasia and Physician Assisted Suicide – Are they clinically necessary? International Association for Hospice and Palliative Care (IAHPC) 1999: www.hospicecare.com

¹⁶ Materstvedt LJ. The Euthanasia debate: Palliative Care on the slippery slope toward euthanasia? *Palliative Medicine* 2003; 17:387-392

¹⁷ Sommerville M. Euthanasia: Is legalizing it a good idea? *Australian Dialogues* June July 2011

¹⁸ Schuklenk U, Van Delden JM et al. End of life decision making in Canada: The report by the Royal Society of Canada Expert Panel on End-of-Life Decision making. *Bioethics* 2011; 25(S1): 1-73

Care, edited by Foley and Hendin (2002)¹⁹; and *Physician Assisted Dying- The Case for Palliative Care and Patient Choice*, edited by Quill and Battin (2004)²⁰.

In the broadest of terms, a review of the literature reveals the following ethical arguments in favour of legalization:

1. **Individual autonomy and self-determination.** Individuals have the right to make their own decisions about health care, and are best placed to make quality of life assessments for themselves based on their own experience of life. Population based studies of the general public universally demonstrate high public approval rates for legalization of assisted death. People want control over their choices at end of life.^{21 22 23}
2. **Avoidance of suffering.** The potential physical and existential suffering that occurs through the process of dying can arguably be avoided or minimized where assisted death is used.^{24 25 26}
3. **Harm minimization, and the presumed ethical continuum of end-of-life decision-making.** Studies from the around the world have consistently demonstrated that these practices are happening despite their illegal nature.^{27 28 29 30 31} Legalization arguably systematizes and regulates the activity, thus allowing it to be monitored, and appropriate safeguards against abuse to be set up. There is also the related notion that PAD lies on a continuum of end of life decision-making where hastened death is the 'intention,' and is therefore ethically justified in the same way.^{32 33 34 35}

¹⁹ Foley K and Hendin H Eds. *The case against Assisted Suicide – for the right to End-of-Life Care*. John Hopkins University Press, Baltimore and London 2002.

²⁰ Quill TE and Battin MP Eds. *Physician Assisted Dying – The case for palliative care and patient choice*. John Hopkins University Press, Baltimore and London, 2004.

²¹ Karlsson M, Milberg A, Strang P. Dying cancer patients' own opinions on euthanasia: An expression of autonomy? A qualitative study. *Palliat Med* 2012; 26:34-42

²² Terry W et al. Experience of dying: concerns of dying patients and of carers. *Internal Medicine Journal* 2006; 36:338-346

²³ Wilson KG et al. Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology* 2007; 26(3): 314-323

²⁴ Sullivan MD. The desire for hastened death arises from an intolerable future rather than an intolerable present. *General Hospital Psychiatry*. 2005; 27:256-257

²⁵ Dees M et al. Unbearable suffering: a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics* 2011; 37:727-734

²⁶ Dees M, Vernooij-Dassen M et al. Unbearable suffering with requests for euthanasia or physician assisted suicide: an integrative review. *Psychooncology* 2010; 19(4): 339-52

²⁷ Kuhse H, Singer P et al. End of life decisions in Australian medical practice. *Med J Austr* 1997; 166:191-96

²⁸ Deliens L et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *The Lancet* 2000; 356:1806-1811

²⁹ Meier DE, Emmons CA et al. A national survey of physician assisted suicide and euthanasia in the United States. *N Engl J Med* 1998; 338:1193-201

³⁰ Van der Maas PJ, van der Wal G et al. Euthanasia, physician assisted suicide, and other medical practices involving the end of life in the Netherlands. *N Engl J Med* 1996; 335:1699-705

³¹ Asch DA. The role of critical care nurses in euthanasia and assisted suicide. *The New Engl J Med* 1996; 334(21): 1374-1379

³² Nuccetelli S, Seay G. Relieving pain and foreseeing death: a paradox about accountability and blame. *The Journal of Law, Medicine and Ethics* 2008; 28(1): 19-25

³³ Cohen L et al. Accusations of Murder and Euthanasia in End-of-Life care. *Journal of Palliative Medicine* 2005; 8(6): 1096-1104

³⁴ Douglas C. End-of-life decisions and moral psychology: killing, letting die, intention and foresight. *Bioethical Inquiry* 2009; 6:337-347

Arguments in opposition to legalization include:

1. **A significant moral shift in terms of communal normative value (or interest) in not taking life.** In the past, communities are prepared to sacrifice this value only where it is justified on a community level. Most of the 'gain' in assisted death is for individuals. Is this gain significant enough to offset the resultant normative shift in how we value life? This is often couched in a religious sense,³⁶ but can be understood in a broader sense related to communal values.
2. **Risk of damage to doctor's role as healer, and the doctor patient relationship.**³⁷ This has a number of formulations: a) Doctors should not "play god" and are not authorized morally to take life; b) Traditional medical paradigms hold the continuation of life as paramount, and deliberate action to cause death runs counter to the role of medicine; c) legalizing and endorsing doctors capacity to take life may erode the doctor patient relationship in that the patient relies on the doctors obligation to do not harm.³⁸
3. **Potential risk to vulnerable groups, and the so-called "slippery slope".**^{39 40 41} This slippery slope has many incarnations, but essentially it states that if PAD is legalized in any society, then the potential exists for:
 - a. Pressure on vulnerable persons;
 - b. Widening of the clinical criteria to include other groups in society;
 - c. An increase in the incidence of non-voluntary and involuntary medicalised 'killing';
 - d. Progressive devaluation of life, and for 'killing' to become accepted in society;
4. **Potential "loss" that comes with the avoidance of suffering or by controlling time and method of death.** Is there some intrinsic "value in suffering" through death for human beings or communities? Is it a "good" to give individual patients and/or doctor's control over death? This is a communal value shift, elevating individual autonomy as the paramount value over other values, and thereby defining our social values going forward. Is this a good? Alternatively, it values the avoidance of suffering over other values. Similarly, is this a good?

Other significant issues:

1. **PAD overtly embraces quality of life decisions in healthcare,** based on the individual patient's life and assessment of their own best interests.⁴² What does this mean for the ethical framework around end-of-life decision making in general? What other ethically valid assessments of quality of life carry enough moral weight to validate the finality and gravity PAD? For example, what about substitute decision making in the context of a terminally ill and suffering infant? Or persons with advanced dementia and a valid advanced directive?

³⁵ Sulmasy DP. Double effect – Intention is the solution, not the problem. *Journal of Law, Medicine and Ethics* 2000; 28:26-29

³⁶ Cohen J et al. European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Soc Sci Med* 2006; 63:743-756

³⁷ Smith B. Cradled between Heaven and Earth. A Reply to my patient's family: why I couldn't offer active euthanasia when you asked for it. *Journal of Palliative Care* 2009; 25:294-296

³⁸ Hall M, Trachtenberg F, Dugan E. The impact on patient trust of legalizing physician aid in dying. *J Med Ethics* 2005; 31:693-697

³⁹ Van Delden. Slippery slopes in flat countries – a response. *J Med Ethics* 1999; 25:22-24

⁴⁰ Pereira J. Legalizing euthanasia or assisted suicide: illusion of safeguards and controls. *Current Oncology* 2011; 18(2): 645-655

⁴¹ Pollard BJ. Can euthanasia be safely legalized? *Palliative Medicine* 2001; 15:61-65

⁴² Quill TE. Terri Schiavo – A Tragedy Compounded. *N Engl J Med* 352; 16:1630-1633

2. **Justice and equity in access issues**, arising out of differing formulations of legalized assisted death.⁴³ Physician assisted suicide relies both on decisional and executorial autonomy, where the person must be able to be the functional agent of death, precluding people with certain types of illnesses and those with already significant disability from accessing PAD. This is potentially discriminatory in terms of access for people with certain types of functional impairment. The alternative involves **agency issues**, in that voluntary euthanasia requires an increased level of agency on behalf of the practitioner, where they must directly administer a lethal agent, arguably resulting in increased moral responsibility for the action and outcome.
3. **The nature of suffering is significantly debated.**⁴⁴ Does suffering refer only to physical suffering or does it also include existential suffering? Should the practice of PAD be widened beyond terminal illness, based on the patient's assessment of best interest/acceptable quality of life?

4.2.3 Interface with Palliative Care

By traditional definition alone, palliative care and assisted death/euthanasia are already at odds. The widely regarded founder of Palliative Care, Dame Cicely Saunders, has stated quite clearly since the late 1950s: "hospice and Palliative Care developed to prevent Euthanasia."^{45 46} Palliative care, according to the WHO, neither hastens nor postpones death, thus any practice intentionally used to cause death is essentially "at odds" with best practice palliative medicine. On the other hand, supporters of assisted death practices hold that relief of suffering in whatever terms as defined by the patient is the key goal in palliative medicine. Where the patient (and sometime the doctor) believes they need this assistance in order to achieve a 'good death', then such practices can be seen as a specific palliative intervention.

Other significant issues at the interface include:

1. The claim or belief by some palliative care groups that all suffering at the end of life can be relieved by good palliative care, thus if each person can access appropriate palliative care services, assisted death practices are unnecessary.
2. Fear that assisted death practices will be seen to negate the need for good palliative care services, thus reducing the already scarce funding available for palliative care. While this is seen as a risk in publically funded systems, it may be a more significant risk in privately funded health systems, where arguably, the individual or public interest may not be the overriding value.
3. The claim that palliative care frequently involves either direct euthanasia, or actions on a scale of end of life decision making that specifically hasten death and are thus ethically indistinguishable from euthanasia. Therefore, why not legalize it so we can monitor and regulate this activity?

4.2.4 Methodology

My subject matter is highly complicated, and the goals and aims of my fellowship very broad. In order to formalize my discussion, I used semi-structured interview methodology. Appendix 1 outlines the semi-structured pro forma used to guide my discussions. On some occasions, such as in the context of individual patient contact, information was gathered primarily through direct

⁴³ Kitchener B, Form F. Conditions required for a law on active voluntary euthanasia: a survey on nurses' opinions in the Australian Capital Territory. *J Med Ethics* 1999; 25:25-30

⁴⁴ Cassel EJ. The nature of suffering and the goals of medicine. *New Engl J Med.* 1982; 306(11): 639-45

⁴⁵ Saunders C. Care of the Dying 1: The problem of euthanasia. *Nursing Times* 1959: 60; 1

⁴⁶ Saunders C. Voluntary Euthanasia. *Palliat Med* 1992: 6; 1-5

observation and reflection on the reported issues. Where themes emerged, I directed specific questions regarding those significant issues in my subsequent interviews. These themes are reflected through the reporting, and highlighted in the take home messages component of each jurisdiction.

It is important to note that the fellowship goal was to gather information 'on the ground,' so to speak. Accordingly, this report reflects a combination of synthesized material from semi-structured interviews, general discussions and reflections from key persons involved in these practices and/or their interface with palliative medicine, as well as my own observations and reflections on the experience. This makes my report a combination of empirical data, anecdotal reports from key experts in the area, and my own reflections. I do not claim or hold the content in this report rigorous in terms of scientific or qualitative research. This would be beyond the scope of the fellowship. It should, however, help to identify key areas for in depth research going forward, and contribute significantly to the debate in Australia regarding potential legalization.

The report is also very long, so in the interests of brevity, I would direct you to the take home messages at the end of each jurisdiction outline, and to the discussion and reflections at the end of the paper.

4.3 THE USA

4.3.1 Social and contextual Backdrop

This debate in the USA is pitched in the context of extreme liberalism, where individual autonomy and self-determination is a strong community value, and there is a strong and politically active religious based 'right'. It also exists in the context of a multifaceted, fragmented and insurance based health system surrounding end of life care. Medicare refers to the universal access government supported funding system for citizens over the age of 65, and is (in some states) accessible to those with serious life limiting illness. Medicaid is the state insurance scheme set up for socially disadvantaged groups or 'welfare' groups. Then there are wholly private and employment related insurance systems. Once a person is classified as 'terminal', they partially transition from their primary insurance group where patients have had their 'active' healthcare, to 'hospice' which focuses on comfort care related to their primary disease and is primarily community based. Not all patients choose to access hospice even where funding is not a barrier, and not all patients maintain a single family physician.

There is significant disillusionment and distrust with the health system, very high costs in terms of percentage GDP, and decentralization and fragmentation of services. Confounded by a mobile population base, this leads to significant discontinuity in health care for a single individual over time.

In terms of palliative care, there is a history of underdevelopment of end of life care services, which is rapidly improving over the last decade. Palliative medicine is a relatively young specialty, which requires one (or sometimes two) years of further training in addition to previous fellowships. Most come through family medicine, but may come from other subspecialty backgrounds including internal medicine, critical care and anaesthetics. Inpatient consult services within hospitals are now well developed, but community based subspecialty medical care is variably available. Most hospices have access to a 'board certified' palliative medicine physician, but hospice are primarily community based service providers with specialist nursing input, physical aids, hygiene and domestic assistance, social work, chaplaincy, and some allied health inputs. Some family physicians stay involved, and others leave the medical side to the hospice director. Some providers also suggested that the tight monitoring of schedule medications by the FDA was partially contributory to physician discomfort with use of many palliative medications.

Discussions with the pro lobby groups revealed the followings themes:

- Many individual lobbyists reported specific cases of deaths where suffering was uncontrolled. Some of these cases had palliative care involvement, and some did not.
- Activism in this area was seen to have come directly out of the HIV/AIDS crisis through the 1980s-1990s where many young men were dying with poorly controlled symptoms of a 'new' disease. This activated a strong politically active social demographic supportive of facilitating some sort of control over choice in the context of terminal illness.
- The 'anti' lobby was seen as synonymous with the religious right, most particularly the Catholic Church as the most powerful and well-funded mechanism of resistance to legalization. Some supporters specifically riled against that interference in itself, and in some cases this became the primary driver in a decision to support the legalization
- There were many parallels drawn with the issue of abortion in terms of privacy and risk of vilification, physician response and concerns, and the nature of the intervention.
- Access to assisted death was seen primarily as a palliative intervention, in that its goal is to relieve suffering in life limiting illness.

4.3.2 Oregon State – Portland USA

4.3.2.1 Background

Oregon legalized assisted suicide with the *Death with Dignity Act DWDA* (1995).^{47 48} It allows a physician to prescribe a lethal dose of medication to a competent, adult patient, whereby the patient must be able to take the medication by him or herself. The patient is required to put in a written request for the medication to the prescribing physician, along with two verbal requests at least fifteen days apart. The act prohibits a physician from directly acting in a way that would end a patient's life, thus prohibiting active euthanasia. Two physicians are required to diagnose the patient as suffering with a terminal illness that will lead to death within 6 months. The act prohibits provision of a prescription where the patient is also suffering from depression, but the act relies on physicians to accurately diagnose depression, and also to assess where depression is significant enough to warrant impair judgment and thus refusal of the request.

Data from the use of the act are compiled by the Oregon Public Health Division, and reported for public record yearly.⁴⁹ Since the law was passed in 1997, a total of 1050 people have had a Death with Dignity (DWD) prescription written, and 673 patients have died from ingesting the prescribed medication. Last year (2012), 115 prescriptions were written and a total of 66 died consequent to ingestion. Assisted death accounts for 0.2% of all deaths in Oregon. The majority of patients were 65 years of age or older (67.5%), white (97.4%), well educated (42.9% university level), and had cancer as a primary illness (75.3%). 97.4% died at home, and most were enrolled in hospice by the time of death (97%). All cases had some form of health insurance, although private insurance accounted for only 51.4%, where the rest relied on Medicare or Medicaid.

The most common reasons patient put forward for accessing DWD were:

- 1) Loss of autonomy (97%)
- 2) Decreasing ability to participate in activities that made life enjoyable (92.2%), which is essentially individual assessment of poor quality of life
- 3) Loss of 'dignity,' which is not specifically defined (77.9%)

Complication rates were low, with a total of six patients regaining consciousness after ingestion of the prescribed medication since 1997 (less than 1% overall). The range of time from ingestion to death was 10 minutes to 3.5 hours, with a median of 20 minutes. The number of participating physicians has steadily risen, with 22 back in 2000 to 61 in 2012.

4.3.2.2 Practical Issues

Patient initiates the request to their attending physician. If the institution or individual physician does not participate, they are referred to another physician who is known to be comfortable with prescribing life-ending medications. The patient advocate or ombudsman for the institution (or a representative from an advocacy group such as Compassion and Choices) serves as facilitator and

⁴⁷ Rothschild A. Oregon: Does physician assisted suicide work? JLM 2004; 12: 217-225

⁴⁸ Chin AE, Hedberg K et al. Legalized physician assisted suicide in Oregon – the first year experience. N Engl J Med 1999; 340:577-584

⁴⁹<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/>. (Accessed 23 April 2013). More detailed information can be found at: <http://www.healthoregon.org/dwd>.

case manager for the process. The case manager ensures compliance with the act, and aids the patient in negotiating the process

The patient advocate arranges an appointment or review with a prescribing physician. This 'list' of participating providers is not publically accessible, and privacy of the individual participant is protected where possible. In Oregon, most of the prescribing physicians are board certified specialists in palliative care or family physicians with advanced training in palliative care. At this appointment, the patient fills out the formal written request form, and the prescribing physician fills out page one of the initial assessment form. The advocate arranges a consulting physician review, often provided by the patient's attending physician/ specialist. Some consulting physicians are not comfortable prescribing life ending medication, but are happy to certify capacity and prognosis. If there are any concerns regarding depression impairing individual capacity, they are required to refer to psychiatric evaluation.

After the required 15 days, the patient again meets with the prescribing physician and reiterates their request. The prescribing physician completes the second page of the required form and makes out the prescription. The physician is required to get the prescription filled at cooperating pharmacist. In the past, the advocate has been an agent for this requirement, but this is no longer allowed. The prescription is usually Secobarbital 9g, which comes as 90 capsules emptied into a glass of water and drunk within one minute. It takes about 5 minutes to induce sleep, and then usually takes about 40 minutes to cause death (range 1.5-6hours). The alternative is Phenobarbital, which is a liquid 250ml glass. It can be more expensive (\$1400 vs. \$160 depending on the compounding pharmacist and drug company), but takes effect more quickly and is easier for the patient to self-administer.

The patient then takes the medication home, and takes it at a time of their choosing. The patient advocate and prescribing physician are rarely present. Members of the advocacy group are often present. Some prescribing physicians chose to be present, but most do not. Hospice nurses are usually aware that the patient plans to take life-ending medications. Although most hospice organizations do not participate, hospice workers usually step out of the room while the patient takes the medication, they come back in after the patient dies to help facilitate funeral home, follow up on the bereavement issues, and inform the coroners office of the expected death and use of the DWD act. It is usually the hospice worker who informs the primary physician that the patient has taken the prescribed medication, so that the prescribing physician can complete the notification form as per the Act.

4.3.2.3 Themes from semi-structured interviews

1. Pre legalization

a. Position

- A majority of physicians I spoke to were initially opposed to the legislation, but have subsequently become supporters and participants in the process.
- It is significant to note that it was not possible for me to meet with any of the prominent opponents to the legislation in this state, although some of my interviewees were opponents initially and have now become supporters.
- Non-physicians (ethicists, patient advocates) were either ambivalent or supportive of the legislation at the time of its passing.
- I spoke individually with two patients who were accessing assisted death, and both were consistently in support pre legalization and now that they were accessing the act.

b. Values informing support for legalization

- 1) Individual autonomy and facilitation of patient choice. Passionate resistance to the notion that zealot religious groups can dictate to liberalists how they should die.
- 2) "Dignity" as understood to mean the individual patients sense of self, and how they evaluate their own quality of life and what is important to them in a good death;
- 3) Relief of Suffering and harm minimization. Multiple reports of the individual patient whose suffering changed a physicians mind in terms of acceptability, and historical aspect to legalization in the context of 'poor deaths' witnessed during the AIDS crisis through the 1980s; also multiple reports of covert practices involving deliberate overdosing of symptom control medications in order to hasten death. Therefore, why not legalize?
- 4) Value of a pluralist society, in that difference to the social norm is not a valid argument in terms of opposition e.g. sanctity of life from religious heritage. A significant number of responders were specifically supportive in order to be 'anti-zealot' (in light of the opposition being heavily weighted by the catholic church).
- 5) Palliative specialists felt that the key value was achieving the patient's goal or perspective on what would be a good death.

c. Concerns regarding legalization and key opposing values

- 1) Potential for family or societal pressure to access the law. It was felt that the law adequately protected against overt pressure to relieve the burden of illness given the number of health providers required to be in direct contact with the requesting patient. However, concern about covert, subtle or indirect family/society pressure was expressed
- 2) Rate of potential complications or 'treatment failures', and what potential suffering this might cause.
- 3) Risk to vulnerable groups and the slippery slope was seen as a significant concern
- 4) Prescriptive interference in medical practice potential invasive and restrictive.

2. Legalization

a) Strengths

- Facilitation of patient choice in death as defined by their sense of self.
- Adequate protection against the slippery slope as the bar is set quite high.

b) Weaknesses

- Generally it was felt that the law was well written and weaknesses were relatively minor details. The main concerns were:
 - 1) Inadequate funding of the palliative care as an alternative option. Inadequate resources and access to appropriate palliation of symptoms is not consistent or equitable. Inpatient services are well developed in some institutions, particularly since implementation of the Act, but community resources and Hospice structure seen as inadequate for specialist symptom control.
 - 2) Oregon residency requirement seen as onerous and a barrier to access.
 - 3) Practical restrictions too onerous for physicians, and again seen as a barrier to access e.g. the inability for a physician to use an agent to fill a script at a participating pharmacy.
 - 4) Palliation of uncontrolled symptoms was not incorporated as compulsory.
 - 5) Justice in terms of access for patients with functional impairment was recognized as an issue, but not a significant problem.
 - 6) Depression was seen as an overplayed issue. Many of the primary features of depression were present in terminal illness anyway. Adequate screening could be done a medical level, and this consisted primarily in differentiating suicidality from intention

related to terminal illness. “If I could wave a magic wand and cure your illness right now would you still want to access the medication?” was one screening phrase I heard a physician use; or assessment that most patients were light and upbeat about the gain in control that having the medication gave them

c) Changes over time

- Two interviewees originally came out publically against the legislation then shifted position based on the religious zeal of opponents
- Fears of the slippery slope and risk to vulnerable groups have been allayed
- Excellent studies continue to be conducted by the medical researchers in this field, which has helped legitimize the practice by reassuring people that practice is being monitored and reviewed consistently
- Absolute numbers are very small, so PAD has not become an overriding trend.
- There have also been very few complications or failures of intervention. This has allowed physicians and the community to become more comfortable with the law
- While initially the process was ‘veiled’ it is now fairly transparent and open
- Invasion into medical practice not an issue, and useful to have guidelines in this context
- Some who most frequently practice with the law felt that there may be room in the future for other quality of life assessments, such as substitute decision making in the case of advanced dementia with a valid advanced directive, provided adequate safe guards against abuse were written in.

d) Patient Drivers^{50 51 52}

1. Individual autonomy as understood to drive choice and control, and the notion of patient centred care as a defining feature of practice.
 2. Relief of suffering in a philosophical sense.
 3. “Dignity” as understood to be defined by the individual patient. Pride in self (misplaced according to some opinions expressed), and sense of self as physically independent and in control.
 4. Concept of legacy and memory for family/friends: notion of being remembered when their sense of personhood resembles some consistency to how they have lived
 5. Relief of anxiety – ‘backup’ in case they feel they need it
- There was a sense of abandonment from patients when they approach their own doctors about the issue, where their own physicians were not comfortable participating.

e) Clinician Response⁵³

- Main figures opposed to the legislation seen as driven by religious beliefs.
- Clinicians have generally adjusted well to its integration, and each year more physicians are comfortable participating. Most report a staged response where an individual patient they know well requests, and where they feel comfortable facilitating that particular patients wish. Gradually, the scope becomes wider and each broadening step makes them more comfortable with the principle and the process

⁵⁰ Pacheco J et al. A longitudinal study of attitudes toward physician assisted suicide and euthanasia among patients with non-curable malignancy. *Am J Hosp Palliat Care* 2003; 20:99-105

⁵¹ Breitbart W et al. Depression, hopelessness, and Desire for Hastened Death in Terminally Ill patients with cancer. *JAMA* 2000; 284(22): 2907-2911

⁵² Breitbart W et al. Impact of treatment for depression on desire for hastened death in patients with advanced AIDS. *Psychosomatics* 2010; 51:98-105

⁵³ Ganzini L, Nelson HD et al. Physician’s experiences with the Oregon Death with Dignity Act. *N Engl J Med* 2000; 342:557-63

- No significant negative impact on the doctor patient relationship; seen to be partially due to the involvement of palliative care physicians; seen as thoughtful, deeply reflective, effective communicators with patients, and gracious 'in their respect for life' for the individual facing death.
- One palliative care physician reported participation in the law based on the notion that this was an act of beneficence for his own well-known patients at the end of life. He felt comfortable with prescribing where he knew the patient well, and saw it to be consistent with their values and goals. He now finds himself referred new patients for this expressed purpose, whom he does not know well and cannot know in the course of just two consultations. He prescribes in these cases to facilitate access for the individual patient, but is not as comfortable with it.
- 1 family physician, who is publically open about his participation, offers to be present if the patient requests, based on priority of non-abandonment. This particular physician is present in more than 50% of cases where he is the primary prescriber

3. Palliative Care Interface

- The silver lining of the legislation is that it helped opened up and improve palliative care services. Some respondents felt that Palliative care blossomed as a direct result of the legislation, as it opened everybody's mind to the potential alternatives to assisted death. Physicians needed something else to offer, so access to and involvement with palliative care services opened up. Others felt that this expansion was a separate coincidental phenomenon to the law, and was based primarily on local champions in palliative care.
- Most people felt that Palliative care services were underdeveloped, and there continues to be a significant need for specialist services, particularly in the community. Inpatient consult services had improved significantly over the preceding decade, and were seen as fairly robust. Oregon was ranked as one of the leading states in terms of opioid use per head of population, and hospice enrollment at end of life
- Referral and enrollment in hospice were high among patients who accessed the act
- Many hospice organizations were catholic and did not allow their employees to participate in the law. In reality, this meant that hospice workers who were case managing patients who accessed death with dignity stepped out of the room when the patient was actually drinking the medication, but provided care prior and following ingestion.
- The concern that health insurance funds may reduce funding for palliative care services was met with shock (like it had never been considered!), and dismissed as not happening on the ground. Terminal illness diagnosis results in automatic insurance coverage under the state insurance system, so financial barriers to hospice or palliative care is not an issue.
- Involvement of palliative care specialists in this process was seen as a great strength in terms of its acceptability
- When asked if anything is lost in people not going through those last few days of natural dying, answers varied. Palliative medicine specialists generally said they don't know but are comfortable with ambivalence. Most other interviewees said maybe, but that was not significant. This notion was seen as akin to presuming some notion of 'redemptive suffering,' which was not accepted as something that should be 'enforced.'
- When asked if there is a potential conflict of interest in terms of frame of practice in palliative medicine, answer was no. Awareness that palliative care specialists often make decision deliberately to hasten death. The notion of primary versus secondary intention for death is blurred, and there is recognition that sometimes death is seen as the best thing.

- Seen as a palliative tool to facilitate good death for those patients who held a certain notion of 'dignity' to be crucial to how they would like to die.

4.3.2.4 Take home messages

- Key justification remained respect for individual autonomy and control/self determination. This reflected the overriding communal values for the region.
- PAD was performed within the context of palliative care and general practice.
- Is this a good for society? Strong supporters felt that it was a good. Others felt it was not a good but seen as not a harm. Harm was measured in that it did not cost a significant amount of money, no significant social harms had resulted, and the numbers were small. This was seen as a reasonable trade off for the gain of patient choice.
- The issue of abandonment by primary carers who were not comfortable with DWD was a significant issue for patients and for doctors who participated. The best model involved care by the primary physician to the very end, where the patient's values and history were well understood, and relationship was already established.
- The significant issue was how individual patients viewed themselves, and how they defined a good death. The individual patient's values were the key defining issue in end of life decision-making.

4.3.3 Washington State – Seattle, USA

4.3.3.1 Background

The Death with Dignity Act in Washington State was passed in November 2008, again after a voter initiative.⁵⁴ The Act is almost identical to the Oregon DWD Act passed in 1997. Patient must make an initial oral and written request, then wait 15 days until a second oral request can be made. At the first review, the prescribing physician must:

- 1) Confirm terminal nature of the disease, with expected prognosis less than 6 months
- 2) Confirm Washington state residency
- 3) Determine patients competency, and that the request is voluntary. If there are any concerns regarding competency or mental health disorder, they should be referred for psychiatric or psychological assessment
- 4) Assess informed consent based on patient awareness of diagnosis, prognosis, risks and expected result of taking the medication (death), and awareness of the alternatives such as palliative care, hospice and pain control.
- 5) Recommend the patient inform next of kin, have someone present at ingestion, and not take in a public place.

A second or consulting physician must:

- 1) Confirm the diagnosis and expected prognosis
- 2) Independently determine competency and the voluntary nature of the request

At the second oral request/time of prescribing, the prescribing physician must:

- 1) Offer patient opportunity to rescind
- 2) Verify informed decision
- 3) Deliver the prescription directly to the pharmacist.

The pharmacist then dispenses the medication directly to the patient, along with instructions on how to take it.

Forms documenting the above procedures are collated and sent into the Department of Health Washington for data collection and monitoring, including: written request by patient, prescribing physician certification of above assessments, consulting physician certification of verification, and the psychological assessment if required. The pharmacist also sends a form certifying that the medication has been dispensed and on what date. After ingestion, the death certificate certifies the primary illness as the cause of death, but the prescribing physician is required to send a certification that the patient accessed the Act within 15 days of death. These forms are available for review on the government website.⁵⁵

In terms of numbers, the most recent figures are outlined below, and cover up to February 2011.⁵⁶ Statewide, a total of 255 people have used the Death with Dignity Act. This accounts for 0.02% of all deaths in Washington. Usually the medication is a high dose barbiturate in the form of secobarbital or pentobarbital. 65% of those who accessed the medication actually ingested the medication. 94% of these patients were also enrolled in hospice. The majority of DWD people are white, aged between 65-84, well educated, and insured with either private or public cover. 78% had cancer as a primary diagnosis, followed by neurodegenerative disease at 10%, and chronic respiratory disease and congestive cardiac failure at about the 5% mark.

⁵⁴ Steinbrook R. Physician assisted death – from Oregon to Washington State. N Engl J Med 2008; 359: 2513-2515

⁵⁵ <http://doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/> (Accessed 14/4/13).

⁵⁶ <http://doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/> (accessed 14/4/13)

The most common cited patient reasons for accessing the law were:

- 1) Loss of autonomy (90%)
- 2) Inability to engage in enjoyable activities (poor quality of life) 88%
- 3) Loss of dignity, where dignity is not defined (75%)
- 4) Loss of control of bodily functions (52%)

Burden on family or caregivers was about 38%, and concern about symptom control was about 34%. Financial concerns were low at 4%. Complication rates were low with time from ingestion to death averaging about 45 minutes.

4.3.3.2 Practical Issues

Physicians and other clinicians are completely free to opt in or out of actively participating in the Act. Similarly, healthcare institutions each individually decide to opt in or out of participating by internal policy. The patient is required to initiate a request. There is no advertising material or patient information pamphlets at the point of care. Step one is to essentially find a willing prescribing physician. What happens next depends on the institution or provider with whom the patient has initiated the request. Non – participant organizations/providers refer the patient to the Department of Health Website or to Compassion and Choices Washington in order to access more information and take the process further. ‘Clinical participants’ response will vary widely depending on how the institution has set itself up to deal with this issue, and how familiar and comfortable the prescribing doctor is with the process. Essentially prescribing and consulting physicians act out of individual volition, thus will sometimes be able to act as a solo agent without external input if they are comfortable. Only two institutions in the State have specific structures in place to facilitate this option for patients internally. One of these is the Seattle Cancer Care Alliance, the results of which have been recently reported in the *New England Journal of Medicine*.⁵⁷ According to the SCCA data, 40% of people who inquired about DWD did not pursue it, 25% of patients who initiated the process did not complete, thus only 35% of initial inquiries were followed through with a prescription. 60% of those patients actually went onto ingest. In terms of staff involvement, about 1/3 of their physicians were willing to be either prescribing or consulting physicians. These findings are consistent with the literature, and statewide data. Organizations who do not have a system set up for participation refer to Compassion and Choices for support and next steps.

Compassion and Choices intake officer do a medical and demographic history. Each person is assigned a client number and case manager who helps the patient through the process and is usually present at the time of ingestion/death. These case managers are volunteers, most of whom have a healthcare background such as social work. The organization puts these volunteers through a one day training programme, and has systems set up to provide them with access to medical and psychosocial expertise where required. Compassion and Choices also help patients with other ways of hastening death such as the voluntary stopping of eating and drinking, or refusal of treatment. However, 75% of their work in Washington involves DWD. They have information packs for physicians and for patients, which are available in hard copy. For further information, please see the website: <http://compassionwa.org>.

Data and notification are required to be sent to the Centre for Health statistics for collation. In reality, reporting of data related to DWD relies heavily on the Compassion and Choices as the

⁵⁷ Loggers E, Starks H et al. Implementing a Death with Dignity Program at a Comprehensive Cancer Care Center. *New Eng J Med* 2013; 368: 1417-24

case managers from this organization ensures the process is compliant with the legislation, and often close the loop for the prescribing physician in terms of ingestion.

At the time of patients choosing, the Compassion and Choices case manager is often there. The hospice worker can choose to be there or otherwise, depending on their preference and their employer's policy, and the prescribing physician is rarely present (5%). The majority of prescriptions are for secobarbital 9g, which is a high dose barbiturate sedative. The dose requires emptying 90 capsules into a glass of water. The alternative is 250mg syrup of pentobarbital. It is bitter in taste, and nauseating, so antiemetics such as maxalon and ondansetron are prescribed as pre-medications. Unconsciousness usually happens within about 5 minutes, and death by about 45 minutes. There are obviously variations in this based on pharmacodynamic and absorption issues.

The funeral director is then notified, and the death certificate filled out by either the family physician or hospice medical director with cause of death certified as the primary terminal illness. The prescribing doctor relies on the family or case manager to let him/her know that DWD has been used, so they can fill out the compliance form after death.

4.3.3.3 Themes from semi-structured interviews

1. Pre-legalization

a. Position

- There was a fairly even split between people who were for the legislation, as well as against the legislation.
- Of note, those who were opposed prior would be more likely to vote yes now, and those who voted yes found that they developed more discomfort as the process unfolded.

b. Values informing support for legalization

- 1) Autonomy and self-determination was the overwhelming defining value. Highly liberal and libertarian social fabric: "The wild west, lift yourself up by your boot straps" culture.
 - 2) Relief of suffering for the individual patient as per their assessment of their needs
 - 3) Harm minimization based on individual horror stories where patients and families tried to hasten death outside of legal sanctions, particularly where family members were feeling obliged to assist loved ones based on patient wish, leading to complicated grief and post traumatic stress disorder. What is open and overt is better than unregulated activities that were happening everywhere. There was also experience that end of life care was managed 'pot luck' dependent on who your physician was, and this fragmentation required that people wanted more control
 - 4) Erosion of the doctor patient relationship and the trust that allowed any 'best interests' assessment by physicians. Some non-clinicians felt that the healthcare system was so 'broken' that the potential issues with doctor patient relationship were largely irrelevant. Doctors were providers, and patients were clients accessing healthcare.
- There was no acceptance of substituted judgment in terms of assessment of quality of life, and there was reluctance to accept the principle of a valid advanced directive as sufficient.

c. Concerns about legalization

- 1) Protection of the vulnerable- unable to be guaranteed; fear of the slippery slope.
- 2) Uncertainty of prognosis emerged as a major concern.

3) Physicians role as healer and the issue of patient trust in the doctor/patient relationship of significant concern to physicians (some felt this was already broken thus not relevant in the debate).

- The notion that this practice would devalue life in terms of community values was not thought to be relevant in the Washington State context.
- The notion of suffering as a potential good was universally rejected.

2. Legalization

a. Strengths

- Legislation had been tried and tested in Oregon so there was a certain reassurance that the slippery slope and disadvantage to the vulnerable had not occurred.
- Communal values had been clearly stated. 80% of people turned up to vote in the referendum and 65% had come out in favour of legalization. There was a very strong sense that the decision had been made by overwhelming referendum. People/patients had spoken and they wanted access to this option. Institutions, providers and ethicists felt that the community had clearly spearheaded the move, and it became primarily about how to implement it or opt out of provision from within health care services.
- Constructed to minimize potential extension to other end of life situations where individual autonomy was less clearly the primary decision making impetus e.g. the system of accessing assisted death relies not just on decisional autonomy, but also on executional autonomy, in that the individual has to be able to manage the process physically without physician help.

b. Weaknesses

- Justice in terms of access issues. People needed to be of high functional status and have enough time before they deteriorated. Potentially open to discriminatory practice such as in the case of ALS patients, patients with dementia and a valid advanced directive, patients whose health was managed by the Seattle health services, but were not technically residents of the states e.g. Alaska. Essentially, these were seen as the "sacrificial lambs" for the cause. Yes there was a justice piece, but there was no way to allow their access and feel reassured that there were adequate safeguards against the slippery slope. This is the price paid for clear, well-defined lines, and minimizing potential abuse by family or medical practitioner.
- Risk of depression not adequately controlled for. Technically, patients can be depressed but maintain decisional capacity and therefore have access to the law. On the other hand, some providers felt that the risk of depression or a previous history of depression was being used as an excuse or barrier to access based on physician reticence.
- The requirements meant that people have to manage the process alone without help from their healthcare providers. The notion that people have to manage the death process in isolation caused discomfort for some palliative care physicians.
- Overly reliant on a partisan organization (Compassion and Choices) rather than on an independent impartial process. Compassion and Choices had by default become the go-to place for assistance from both patients and healthcare providers. As a strong and powerful advocacy group, this was seen as a significant conflict of interest. In the context of legalization, healthcare providers who participated would have preferred an impartial facilitatory and monitoring organization.
- On the other hand, reporting systems and waiting periods were though to be too burdensome by some supporters.

c. Changes Over Time

- Fears about protection of the vulnerable were allayed as it became clear that these were not the groups who accessed the law. By and large, the law was used by well educated, white, men, 80% of whom had cancer as a primary diagnosis. There was an overwhelming feedback that there was a certain personality type that accessed the law – controlling, highly independent, well educated, and who saw their sense of self primarily tied up in functional independence and self determination.

d. Patient Drivers^{58 59}

- 1) Control and individual autonomy/self determination. Typed as ‘control freaks’ where their determination to hasten death would remain fixed regardless of legality. Sense of self-identity highly reliant on control and independence
 - 2) Fear of functional decline and perceived effect on quality of life
 - 3) “Loss of dignity” (arguably primarily related to the above 2 issues). Essentially, this was thought to relate to the individual’s sense of self, and patient centred care required us to recognize where this control was a crucial piece of their sense of self.
- Only a very small proportion of patients accessed the law based on fear of uncontrolled symptoms such as pain.
 - Most patients had cancer as their life limiting illness. Patients with chronic disease or acutely life limiting illness were much less likely to access the law. Thus, cancer doctors and centre were much more likely to face the question than palliative care services in other settings.
 - Variability in physician support and participation was perceived by some as patient abandonment.

e. Clinician Response

- Clinicians who were originally opposed were more likely over time to partake in the process because: 1) they felt reassured that the potential risks to vulnerable groups and doctor patient relationship; 2) the numbers of patients accessing the law were low; 3) and perhaps the most important reason reported, they opposed until they had ‘that one patient’ who fit the bill, and they could see that it may well be the appropriate action in that particular circumstance.
- Despite legalization, there was a general ‘veil’ across the whole process, which made clinicians uneasy. Within healthcare organizations/groups, no one knew who were the prescribing doctors or the consulting physicians from among their colleagues (Compassion and Choices had by default compiled a list, and facilitated link ups where requested by physicians or patients). Some Palliative care physicians felt there was no safe and collegial forum where they could discuss these cases and learn/debrief surrounding this issue. Potential reasons given for this: 1) privacy and self protection against vilification; 2) professional respect and judgment given the AMA stance was opposed to legalization; 3) respect for preferences of other patients who were not in favour of PAS, and potential fears that may compromise their relationships with other patients.

⁵⁸ Starks H, Pearlman RA et al. Why now? Timing and circumstances of hastened deaths. *J Pain and Symptom Management* 2005; 30:215-226

⁵⁹ Pearlman RA, Hsu C et al. Motivations for Physician assisted suicide. *J Gen Intern Med* 2005; 20(3): 234-239

3. Palliative Care Interface

a. Role and perspective pre and post legalization

- Palliative care groups were largely absent from the debate leading up to legalization. The federal position from the palliative care representative body was formally against legalization.
- Many of the hospice services in the state were run by catholic organizations, which were the strongest and most powerful lobby groups opposed to legalization. This resulted in affiliated organizations opting almost wholly to be 'non-participants' in the process, and requiring that physicians in the context of their role within the institutions would refrain from participating. Physicians were able to follow their own decisions in the context of their private practice.
- There were only a small number of hospice programmes in the state that adopted policies allowing employees to engage in the process. All other catholic based organizations referred any questions from patients to the governmental website. Participating hospices allowed physicians to be a consulting physician, but not a prescribing physician due to the potential conflict of interest issues discussed earlier.
- There was a general reluctance from among palliative care physicians to agree to participate in the process after legalization. Reason for this were: 1) seen as a potential conflict of interest in terms of the goals of palliative care; 2) anecdotally, palliative care physicians were trying to take an impartial, 'guardedly neutral' and considered distance from the issue. This was seen not as a sense of moral discomfort, but a reluctance to be overtly supportive or opposed to the legislation, because of their deep awareness of the complexities involved in dying, and consciousness of the inevitable 'greys' in an issue of this magnitude.

b. Effect on Palliative Care Services

- There was general feedback that palliative care services had not been affected at all by introduction of the law.
- Inpatient consult services were seen to have grown significantly and 85% of acute hospitals had access to specialist palliative care services. Some providers felt there was a significant gap in terms of access to specialist input for community based patients. The quality of palliative care received was not measured or available.
- Palliative care services were seen as underdeveloped but improving. Inpatient consultative services had increased significantly, but there was general agreement that the outpatient support was variable and primarily run without significant specialist medical input.
- Referral to hospice was often very late (>50% in last 2 weeks of life), and it was not uncommon for Compassion and Choices to facilitate link up with Hospice when the patient came to discuss DWD.
- All people vehemently dismissed any issues with health insurance groups refusing to fund services based on potential access to assisted death, and did not feel that this was likely to be a significant issue going forward.
- Hospice was seen as primarily an outpatient services provision for patients in their final 6 months of life. They provide care services, specialist nursing, social work and some allied health input based on community visits. Not all had specialist palliative care medical oversight, although most who did not have in house medical direction had an affiliated family physician who had an interest or further training in palliative care.
- Palliative medicine was seen as a young and rapidly developing specialty, and as such there was seen to be a long way to go in terms of specialty service provision across the

board. This was not seen as an issue related to assisted death, but part of the historical context of developing palliative care services.

4.3.3.4 Take home messages

- Legalisation was achieved by public vote (referendum), thus the community value of autonomy and individual choice was the leading value driving the reform.
- Physicians who were initially opposed to the practice have been more likely over time to feel comfortable with participating.
- There is a 'veil' over the practice despite its legalization, and arguably an overreliance on a partisan organization, which made physicians more uncomfortable with the process.
- Patient drivers included: 1) autonomy and self-determination; 2) loss (or fear of loss) of functional status/bodily functions; 3) Personal 'dignity' in so far as they relate to the above two issues. Uncontrolled pain and symptoms, and financial concerns were not significant drivers.
- The slippery slope in terms of risk to vulnerable groups had not eventuated, and concerns regarding this issue had relaxed over time.
- Palliative care groups had not been overtly active politically pre or post legalization, but the significant proportion of services provided by the catholic church meant that most services declined to participate in the practice. Palliative care specialists generally favoured neutrality, although some participated as consulting physicians.
- There was already a paucity of specialist palliative care services available, but this was not related to the legalization of assisted death.
- Pluralism was seen as a significant community piece, in that provided there is no harm to the other individuals in the community, the benefits of providing access to this control for the small subset of patients who access the law justify its legalization.
- When asked if this was a 'good' in an ideal society, most respondents were unsure or felt that it was at least not a bad: "its ok to die."

4.3.4 Montana

In 2009 the Supreme Court of Montana found in *Baxter vs Montana* that state law as it stood protected doctors against prosecution when helping terminally ill patients to die. The initial case claimed on the basis of a constitutional right to privacy, freedom, and 'human dignity', but the Supreme Court ruling based its finding on the lack of formal statutes around this question, finding no basis for criminal prosecution in this context. This ruling did not legislate to formalize assisted death practices or establish the right of a terminally ill patient to access assistance in death. There have been subsequent attempts to formalize an official legal position both for and against assisted death, but neither succeeded at a parliamentary level.

Thus, assisted death is not illegal in Montana, but there is no formal process whereby it is implemented or monitored. This makes accessing data surrounding the issues, and talking openly with physicians about their practice, exceedingly difficult.

The primary advocacy group for legalization of assisted death, Compassion and Choices, was unable to provide any estimates or specific information regarding implementation of assisted death in end of life care in Montana. Therefore, it will not be covered specifically in this report. It does raise the issue, however, of the potential harms that may come of complete deregulation or 'arms length' approach from a legal perspective. Practices are "looser", more veiled, private and without formalized safeguards against abuse. The full extent and effects, including significant potential harms of the practice, cannot be reviewed or assessed where regulation is absent.

4.3.5 Summary and take home messages – Assisted Death USA

The primary communal value behind legalized PAD in the U.S.A. is respect for individual autonomy, and self-determination.

Primary patient motivators:

- 1) Autonomy/ and loss (or fear of loss) of control and independence.
- 2) Fear of suffering – as a reassurance that there is an alternative to unrelieved suffering.
- 3) Loss of control of bodily functions integral to perceived quality of life.

Dignity can be seen as a composite of:

- 1) The control/autonomy (as above) being imperative to their sense of self-identity
- 2) The notion of legacy and memory that is reflective of this sense of self – “I want my family’s last vision of me to be....”

On a social level, assisted death is seen as a ‘good’ in the following ways:

- 1) Harm minimization where harm is understood to include: a) palliative intervention are insufficient or have failed, and a patient suffers at the end of life (physical or existential); b) patients have attempted suicide in the context of terminal illness; c) unregulated ‘hastening death’ practices from within the medical profession, such as deliberate and disproportionate opioid infusions with the secondary intent to hasten death.
- 2) Improvement in end of life care, in that it has put the discussion on the table for patient and doctor, and facilitated some control for patients in realizing their vision of a good death, resulting in better end of life medical interventions overall.
- 3) In an aging population, improvements in survival and length of life do not necessarily always equate with improvements in quality of life for the individual, and DWD makes this component of health decision-making overt, and acceptable for the individual patient to control.
- 4) Assisted death has not had any perceived detrimental effect on palliative care services, and can function within palliative care service provision.
- 5) The Slippery Slope in terms of risk to vulnerable groups has not been demonstrated by the data on vulnerable groups and patient drivers.
- 6) Legalization of PAD was driven by the community, based on the primacy of individual autonomy as the overriding communal value.

4.4 The Netherlands

4.4.1 Social and Contextual Back drop

Healthcare in the Netherlands is set up around different funding systems based around goals of care: short term or curative treatment; and 'long term' care needs such as disability, functional impairment, chronic illness, and care of the dying. Long-term treatment is funded through a state controlled mandatory insurance scheme, and uses approximately 30% of all health care costs. Short-term care is funded through obligatory insurance with private companies, with a defined set of 'compulsory' insured treatments. This insurance is funded 50% by employers, 45% by the insured person, and 5% by government. Affordability is facilitated through allowances based on income and income related pressures. Premiums are fixed and unrelated to health status to ensure equitability, so insurance companies are compensated for insuring high-risk groups. Hospitals and insurers are private but not for profit. Long term care is primarily facilitated through GP's ('huisartsens'), and GP's are mandatory to access short-term specialist services.

Palliative Care services have grown considerably in the last 5-10 years, but due to the timing of legalization back in 2001, palliative care services were arguably underdeveloped, in alignment with European trends in general. Community based palliative care is primarily run by GPs, with the assistance of home care services including some specialist nursing expertise. Low care hospices are run primarily outside the major hospitals, largely by volunteers or as subsets of aged care homes. Volunteers also visit people in their homes, and in the so-called "almost-at-home homes."⁶⁰ Some are independent and belong to the "Volunteers Hospice Care in the Netherlands" (VHN), and some are Christian based. Since 1996, there are some high care hospices staffed by physicians who have specialized training in palliative care. These are primarily used for complex acute symptom control, with terminal care provided in the community setting wherever possible. These high care hospices are attached to 'Centers of Excellence' with a focus on research and teaching (Cancer Care Centers and academic hospitals), and provide phone consultancy service by phone to the regionally placed GPs.

There had been a policy of pragmatic tolerance for euthanasia within legitimate medical practice in the Netherlands for decades before legalization. Prior to 2001, the Dutch *Criminal Code* prohibited taking the life of another person or assisting in suicide, even at their request. However, historically through the mid 1900s, Dutch prosecutors had refrained from prosecuting doctors who committed euthanasia. This was partially formalized with the *Schoonheim* decision (Nederlandse Jurisprudentie 1985, no. 106), where a general practitioner was prosecuted for killing a 93-year-old woman near the end of her life, who had requested euthanasia. The court accepted the argument that the killing was justified, because the doctor had resolved in a responsible way the conflict between the professional duty to preserve life, and the duty to spare a patient from suffering, relying on the notion of necessity.⁶¹

In practice, medical practitioners accepted euthanasia as an acceptable option in the relief of intractable suffering, and this was a fairly normalized possibility in terms of end of life care. Like the experience in the United States, the light was thrown onto this issue with the AIDS crisis, where GPs looked to the Dutch Medical Association for advice and support surrounding requests

⁶⁰ Broeckaert B. Janssens R. Palliative Care and Euthanasia – Belgian and Dutch Perspectives. A synthesis of both authors own writings compiled 2003. Copy provided by interviewee.

⁶¹ Mendelsohn D, Stoltzfus Jost T, Ashby M. Legal aspects of end of life treatment in Australia, Canada, the United States, the United Kingdom, Poland, France, Germany, Japan and The Netherlands. *Proceedings of the 10th World Congress on Pain*. Progress in Pain Research and Management Vol 24. Ed. Dostrovsky et al. IASP Press, Seattle 2003.

for euthanasia from within this population subset. As a result, guidelines were developed to help formulate physician assessment. Given the pragmatism of the legal response historically, it was possible to be more open about how euthanasia was practiced, and in what contexts it is considered justifiable. These guidelines subsequently formed the basis of the formalized law. Dutch physicians were therefore critically involved in the enactment of the legislation. The subsequent development of palliative care specialty services has happened since the enactment of the legislation as a separate phenomenon.

4.4.2 Components of the legislation

In April 2001, The Dutch parliament adopted the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (TLRASA), which also amended the *Criminal Code* and the *Burial and Cremation Act*. The statute came into effect in 2002, and legalizes the practice of euthanasia and assisted suicide by physicians where specific substantive and procedural requirements are met.⁶² Namely, euthanasia and assisted suicide by physicians are not illegal where a physician fulfills the 'due care' criteria outlined in Section 2 of the TLRASA, and if the physician notifies the municipal pathologist.

The 'due care criteria' requires that the physician:

1. Holds the conviction that the request by the patient was voluntary and well considered.
2. Holds the conviction that the patient's suffering was lasting and unbearable.
3. Has informed the patient about the situation and about his or her prospects.
4. Holds that the patient had the conviction that there was no other reasonable solution.
5. Has consulted at least one other, independent physician, who has seen the patient, and has given written opinion on the requirements of due care.
6. Has terminated a life or assisted in a suicide with due care.

Section 10 of the TLRASA further requires that a doctor who performs euthanasia or assists with suicide must notify the local coroner of the death, providing a detailed report on compliance with due care requirements. The coroner must in turn notify a regional committee established under the act for reviewing euthanasia cases, and may refer to the prosecutor if he objects to the burial or cremation of the patient

All deaths by euthanasia are reported to regionally based review committees who determine whether the physician has acted in accordance with the law. If there is concern that there has not been due care, the physician is referred to the prosecutor. There are five regionally based review committees, consisting of a lawyer, an ethicist a medical practitioner.

The statute extends to requests from children aged 16-18 years after consulting with the child's parents, and requests may be honoured for children between the ages of 12-16 years only if the child's parent or guardian agrees. Requests can also be honoured via advanced directives anticipating a future state of poor health, even where the patient is then incompetent to make medical decisions.

Of note, the statute does not require that the patient be in a terminal condition, and the suffering does not have to be physical. In case law since enactment of the legislation, the Supreme Court of the Netherlands recognized that the patients "unbearable and hopeless

⁶² Mendelson D, Stoltzfus Jost T, Ashby M. Legal aspects of end of life treatment in Australia, Canada, the United States, the United Kingdom, Poland, France, Germany, Japan and The Netherlands. *Proceedings of the 10th World Congress on Pain*. Progress in Pain Research and Management Vol 24. Ed. Dostrovsky et al. IASP Press, Seattle 2003.

suffering” could be mental rather than physical. Psychiatric patients are included in this group. Unresolved areas include treatment of a severely abnormal newborn, and the patient in a persistent vegetative state in the absence of an advanced directive.⁶³

4.4.3 Data and trends^{64 65 66}

In terms of numbers, assisted death accounts for just less than 3% of all deaths. According to reported cases, between 2002-2007 there were a total number of 10319 cases of VE. 54% are male, and 53% were aged between 60-79 years. The older population (>80 years) had a lower proportional use of euthanasia compared with all deaths in that age group. 87% had cancer as the primary diagnosis. 81% of VE happened at home (34% of all deaths in NL are at home, and 45% of all cancer deaths occur at home). 99.7% of reviewed cases were found to fulfill due care criteria (0.3% referred for prosecution). There has been a gradual increase in the reporting rate of VE, from 41% in 1995 (pre-legalization) to 80% in 2005.

A little less than 50% of physicians in NL have performed VE, with a further 30% who would be willing to perform it, but as yet have not. The estimated shortening of life is less than 1 week in 45%, and 1-4 weeks in 35% of cases, leaving about 10% of cases shortening life by more than one month.

4.4.4 Practical Issues

The vast majority of euthanasia happens at home with the help of the patient’s general practitioner. Most patients have a short prognosis of less than 1 month, and the process of discussion, and decision regarding this course, have happened over a number of months prior. Initially after legalization, physicians would wait for the patient to bring up the option, but over the last 5 years, general practitioners have become more relaxed about putting the option of euthanasia on the table for the patient to consider if they so desire. This is more by way of letting the patient know that their physician is comfortable with the practice if the patient wishes to pursue it. Palliative care specialists and units do participate in euthanasia. In the inpatient/subspecialist centre’s, it is policy to allow the patient to bring up the subject. If the option is broached with a non-medical clinician, the patient is advised to discuss this option with the doctor. The physician then explains the procedure involved, and what the law requires. In the palliative care inpatient setting, the majority of patients who bring up the option of euthanasia do not go on to use it as a mode of death. However, there is a subset even within specialist palliative care units, who persist with their request and desire, regardless of what palliative interventions are instituted or available to them.

⁶³ Mendelson D, Stoltzfus Jost T, Ashby M. Legal aspects of end of life treatment in Australia, Canada, the United States, the United Kingdom, Poland, France, Germany, Japan and The Netherlands. *Proceedings of the 10th World Congress on Pain*. Progress in Pain Research and Management Vol 24. Ed. Dostrovsky et al. IASP Press, Seattle 2003.

⁶⁴ Chambaere, K. Medical End of Life Practices in Flanders and Brussels, Belgium. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 3, 2010

⁶⁵ Cohen, J. End-of-Life decisions and place of death in Belgium and Europe. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 31, 2007

⁶⁶ Smets T. The Euthanasia practice in Belgium. Behaviours and attitudes regarding reporting and adherence to legal safeguards. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. January 14, 2011.

The physician then determines voluntariness, competency, and 'unbearable suffering' where all other options have been exhausted. A second opinion is sought, usually by SCEN (Support and Consultation in Case of Euthanasia in Netherlands) physicians, who are specifically trained through the Dutch Medical Association to serve as consulting physicians to ensure compliance with the law and support the clinicians involved. This second opinion must be independent, abreast of the due care criteria, and bound to protect the primary practitioner from potential prosecution if they do not fulfill the due care criteria in their act. SCEN physicians now account for the majority of second opinions (90%). Their training involves a 2.5 day training programme, covering the legal guidelines, the technical aspects of performing VE, and a standardized written report on their review of the patient based on the legal requirements.

The type of medication is not legislated. Over time, however, the recommendations of the federal pharmacist organization have become expected practice, and any diversion from this is scrutinized closely at the review committee level after the event. The most common technique is intravenous administration of a barbiturate alone, or intravenous barbiturate followed by a muscle relaxant. It is also possible to use an oral barbiturate, which is more common in the assisted suicide group used occasionally in the community setting. The reason for intravenous preference is to ensure there are no complications. A physician must administer the medication, so that any complications can be medically managed. Most physicians use a second dose of intravenous barbiturate as a second line intervention. Complications are rare, and associated with either faulty intravenous access, or more rarely, aberrant metabolism of the drug outside the normal range.

After euthanasia is completed, the physician must call the coroner, who comes to the bedside to review the body and determine whether there are any irregularities. The coroner informs the prosecutor by phone that a death by euthanasia has occurred, and if satisfied approves the body to be removed for usual funeral arrangements. The physician is then required to report the death to the euthanasia review committee giving justification based on the due care criteria. There is a standard form for the reporting physician to fill out, and the Dutch Medical Association has developed a standardized form for the SCEN doctors/secondary consultation, which may also be submitted.

There are a total of five regional review committees consisting of a lawyer, a doctor and an ethicist. They are required to judge the appropriateness of the case, or state that it lies outside of their brief and refer the case to the public prosecutor. Examples of where this may occur include euthanasia on a minor under 12 years, or in a patient deemed to be incompetent. In reality, this very rarely happens, as reported cases are self-initiated by physicians thus are almost always consistent with the legal guidelines.

4.4.5 Themes from semi-structured interviews

1. Pre-legalization

a) Position

- Euthanasia was an accepted part of good medical practice prior to legalization, and community support was very high pre and post legalization.
- Legalisation was 'a good', in that it regulated accepted practice and allowed for monitoring.
- 80-90% doctors and the community supported legalization, and support is well above 90% now.

- Legalisation was seen as formalization of good practice, instigated by brave doctors and brave judges, who accepted that in some circumstances the termination of life was in the patient's best interests.
- Fundamentally seen as shared decision between patient and physician. It is not a patient's right legally, and nor is it a duty of the attending physician. It must be agreed upon from within the doctor-patient relationship.
- Many stories of the "horrible deaths" witnessed, seen as uncontrollable and undignified.

b) Values

- 1) Relief of unbearable suffering without prospects of improvement with other medical intervention; main priority was the appropriate relief of suffering for patients from within the medical context; the professional role of the doctor was very important, not just in the development of the legislation parameters, but also as the subsequent safe guard against the 'slippery slope.'
- 2) Need to respect patient autonomy, and the notion of patient centred care. This was important, but considered a less important issue, particularly at the time of legalization. It has become a more prominent issue as the debate has continued today, where advocacy organizations are looking to set it up as a patient 'right' rather than an understanding and shared decision making process between patient and their primary physician/ general practitioner. These groups feel that the presence of a significant medical condition should not be required, and that the patient's individual quality of life assessment is the primary ethical issue.
 - For palliative care clinicians, there was a theme of focus on the individual patient perspective in terms of how they viewed a good death.
- 3) General acceptance that a patients **own** quality of life assessment in terms of "a life worth living" was the most important defining issue in determining the appropriateness of action.
- 4) No 'sanctity of life' ethic. The Netherlands was seen as a primarily secular society, with no strong religious overtones holding that life in and of itself is valuable or "sacred". The Church was seen as having lost its sway back in the 1960s.
 - This was confounded by the shift in medical technology, making all sorts of life sustaining practice possible, but raising the question of what life components were considered of a quality 'worth' saving.
 - There is also a very strong culture historically based around refusal of treatment in light of quality of life assessments, and geared toward desired quality of death.
- 5) Harm minimization, in that many practitioners were functioning solo in performing VE (and therefore unprotected) prior to legislation. Events were veiled and lacked quality assurance and knowledge. Now, the improvement in "quality of care" in terms of process, and of technically proficient euthanasia is seen as very important
- 6) Transparent and honest recognition of practice. The Netherlands had a Calvinist background with a non-religious current context. The Dutch do not want to do things in hiding. Openness is the right way, especially when you believe your actions to be right. Legalized euthanasia was seen as 'a good' reflective of the braveness of the legal and medical community.

c) Concerns

- The practice was generally accepted so the debate was not a strong one in terms of opposition.
- Main objections were principled ones, based on religious convictions: life is sacred; and it is not the role of the doctor to take life.
- Concerns about the slippery slope were discussed, but mainly in the context of criticisms from abroad. These international criticisms resulted in a research focus on evaluating the effects of legalization. Most interviewees felt there had not been a significant slippery slope. It was still seen as difficult to get a request fulfilled, particularly if you were not a patient suffering with metastatic cancer with no curative options available. One prominent thinker felt that there has

been a slippery slope in the context of legalization, but that this was an evolving process of recognizing the boundaries and exploring the grey zones around what was easily acceptable and what was more controversial in accordance with the 'spirit' of the law.

2. Legalisation

a) Strengths

- Reporting system creates transparency.
- Doctors feel supported by the law, in that it formalizes a widespread but cloaked practice in what was previously a legal grey zone. Legalization made an accepted but risky practice into a smooth process, without the dangers of extremist views and reactions.
- The due care criteria are broad enough to allow flexibility within the complexities of the doctor patient relationship, and accepting of quality of life assessment on behalf of both patient and physician. This means that medical hopelessness and unbearable suffering are **both** required.
- In practice, accessing euthanasia requires a physical illness because doctors generally regard this to be crucial, but time of life left/prognosis is not important. The extent of suffering and the availability of alternate treatment options is the relevant issue.
- Highly dependent on physicians for assessment of validity of requests, and for monitoring which cases are granted access. This is seen as a way to ensure that all other medical options have been exhausted before euthanasia is agreed to e.g. depression should therefore be diagnosed, and treatment options assessed.
- High quality of care, as physicians now aware of how to do perform VE well, with minimal chance of complication. Euthanasia was more prone to mistakes/complications prior to legalization.

b) Weaknesses

- Reporting system is only by the physicians themselves. This makes it a subjective thing that can easily be presented as in accordance with the law, even where the details of the case may be more controversial. According to the 2010 review, 20% of cases that technically define as euthanasia remain unreported. Doctors report these cases to be ones where they deliberately ended life with lethal drugs at the explicit request of a patient, but for some reason did not define the death as euthanasia and report it.⁶⁷ This is an issue for further analysis.
- Broad grey zone: the law is seen as very general, and not very specific or prescriptive about the parameters of practice. It defines euthanasia, outlines the 'due care' requirements, and then spends the majority of its prescription outlining the review process. The 6 parameters were kept broad in order to allow for the practical complexity of clinical practice and relationship, but this broadness allows for more openness in access. This has meant that the review committees have become the arbiters of interpreting the criteria, and making more concrete rulings regarding the boundaries of decision-making. For example, 3000 cases have been reviewed, and we know recognized that "serious suffering" requires a "significant medical condition" and cannot be existential in the purest sense. Similarly, it has become clear that the length of prognosis is **not** a significant issue or absolute requirement to validate practice. A patient with an extended prognosis in terms of life expectancy will result in the committee looking more closely at the case in term of justifying suffering and alternative options, but not necessarily result in a negative ruling.
- Physician reluctance in controversial cases seen as a barrier to access. The broad grey zone results in debate about where the lines should be drawn, and reluctance on the side of physicians to grant requests from patients where the parameters are questionable. For example, in the case

⁶⁷ Onwuteaka-Philipsen BD et al. Trends in end of life practices before and after the enactment of the euthanasia law in the Netherlands from 1990-2010: a repeated cross sectional survey. The Lancet 2012; 380:908-15

of dementia, where free will is diminished, or where patients may be incapable of expressing the extent of their suffering. Main groups highlighted to be in this grey zone and thus running into to access barriers include: dementia; those with psychiatric disease; medical diagnosis other than cancer; and the very old who are tired of living.

- Some people thought that there was evidence of a slippery slope in the Netherlands, in that access groups are gradually broadening over time. This slippery slope warrants further attention and scrutiny, but it is small in terms of significant numbers, and was not seen to negate the 'good' of the law.

- Law requires there be "no reasonable alternative" to euthanasia, so the patient must be in a 'medically hopeless' category. In terms of palliative care, therefore, physicians must facilitate/provide access to good end of life care before it technically being legal to perform euthanasia.

- Allowing access for psychiatric patients was not seen as a weakness, because the cases had all been ones with untreatable, refractory psychiatric illness. That is, euthanasia has been used in patients under long term care of a psychiatrist, through multiple lines of treatments without significant improvement, over many years. Thus, euthanasia is used only in depression where the "medically hopeless" criteria are fulfilled. Treatable depression was not a legally acceptable criterion. The use of VE in the case of refractory depression was also seen as a very rare occurrence.

- Physicians themselves were still seen by some as a significant barrier to access, as physicians generally feel uncomfortable with prognoses that are not clearly short. Some interviewees felt that GP's found all types of ways to avoid performing euthanasia, instead relying on palliative sedation in an incongruous context (i.e. outside to DMA guidelines) such as via the disproportionate use of opioid infusions in order to hasten death. The use of "palliative sedation" has increased significantly since the implementation of the law – this is potentially more harmful as it is unregulated and not transparent. In reality, the patient asks their physician "please help"; the physician answers "I will be there for you" but does not necessarily agree to the procedure; at the crucial time the physician opts for another course. The legal structure is highly dependent on physician assessment of what **ought** to be unbearable suffering. In reality, the doctors often 'balk' at overtly agreeing to euthanasia and following through with it.

- SCEN doctor assessment/second opinion is perceived by patients to be some kind of test. This creates stress and discomfort in a time of already intense suffering.

- Technically, foreigners can access euthanasia in the Netherlands if a Dutch physician agrees to perform it. Locals feel they have not seen the "euthanasia tourism Switzerland has had."

c) Changes over Time⁶⁸

- Most moderate groups who were politically opposed to legalization are now in support, as the practice has not demonstrated significant risk to vulnerable groups, and the slippery slope *in general* has not eventuated.

- There was an unexpected drop in numbers of euthanasia cases in the 2005 study, which has since returned to baseline in 2010. One researcher's possible explanation was that patients were perhaps pushing euthanasia as a 'right' thus pressing doctors to agree to their requests. Doctors were transiently reluctant, because they always have to convince themselves that it is the right thing to do. The decision is a shared decision between doctor and patient, and not one that patients can enforce on their physician. The professional responsibility piece was considered very important in terms of monitoring the practice.

⁶⁸ Onwuteaka-Philipsen BD et al. Trends in end of life practices before and after the enactment of the euthanasia law in the Netherlands from 1990-2010: a repeated cross sectional survey. The Lancet 2012; 380:908-15

- This intricate reliance of the practice as embedded in medical care now arises as the subject of debate, where those groups who arguably may want access to euthanasia are being denied by the medical rejection of their case. This is primarily relevant where the suffering is non-medical.
- Some interviewees felt that the slippery slope *was* a recognized issue in the Netherlands. The review committees have continued to try to define the borders of the practice, which has resulted in some expanded access to euthanasia, and the debate is ongoing in terms of where to draw the lines. 10 years ago there were no reported cases of euthanasia where patients did not have a serious and lethal medical disease. Between the 5 and 10 years mark, there have been an increase in the number of dementia patients and increase in the number of patients with psychiatric disease. The extent of disability and physical deterioration seen to constitute 'unbearable suffering' continues to be contentious issues. However, the vast majority of patients are still those with cancer, autonomous, with a significantly poor prognosis. These slippery slope issues are small in terms of numbers, but need to be recognized and continue to be debated from within the Dutch context.
- Undiagnosed depression was recognized as a potential issue, but not one that in reality counts as a significant problem in the broad scheme of things. There was a reluctance to make 'sadness' and 'hopelessness' in the face of terminal disease a psychiatric illness. One centre had made a psychiatric assessment mandatory prior to accessing euthanasia, but has since abolished it as a requirement because it was not seen to contribute significantly to the end of life assessment.
- Health insurance and funding for end of life services has not been an issue. Alternative care for these patients is not expensive, and health insurance agencies would not want the 'image' that would come with using VE to escape the cost of ongoing medical care. There were only small financial barriers related to accessing hospice care, which involved a small copayment, but this was not a significant issue in relation to euthanasia.
- As time has gone on, review committees have been more stringent in the review of how and what medications are used. Any practice outside the recommended process is more carefully looked at.
- Patients have shifted more to expect that this is a *right* that they have rather than a shared decision. However, the law is structured so that both patient and physician need to be comfortable that it is the right decision.
- Some felt that it had led to an improvement in palliative care services. Physicians are more alert to the need to address all alternative measures before allowing a patient to access euthanasia, thereby promoting palliative care practice.
- Extension of the law to include dementia and psychiatric patients was seen by some people as an improvement; the absolute numbers of these account for a small proportion overall (2011 = 13 intractable psychiatric illness; 2012=12).

d) Patient Drivers

- There have been some qualitative studies of families and patients^{69 70}, but most data comes from physician's reporting the motivations of their patients.
- Most drivers related to the patients explicit notion of a dignified death, where they want to control the extent of their suffering, where they assess their ongoing life to be without meaning, or where they cannot live in accordance with their own standards of quality. These standards often involve living independently.
- Physical symptoms and disabilities were relevant more in how they inform a 'dignified death' rather than in being uncontrolled/untreated *per se*.

⁶⁹ Ruijs CDM, Kerkhof AJFM et al. Depression and explicit requests for euthanasia in end of life cancer patients in primary care in the Netherlands: a longitudinal, prospective study. *Family Practice* 2011; 28(4): 393-399

⁷⁰ Maessen M, Veldnik JH et al. Trend and determinants of end of life practices in ALS in the Netherlands. *Neurology* 2009; 73(12): 954-961

- Of all patients facing death, the majority of patients are **not** those with very specific/explicit ideas about how they want to die. Most patients let their physicians decide what is best, and trust in their judgment. There was a high level of trust in physician decision-making.
- There have been stable patient characteristics over time e.g. cancer, younger (50-70).
- “Dignity” is relevant *as defined by the patients themselves*. It is not usually related to physical pain. In practice, loss of independence was a much more important patient driver (increasing dependence on caregivers in terms of personal activities of daily living.)
- Hopelessness is key, in that patients feel there is no hope or prospect of improvement, and no hope for improved quality of life.

e) Clinician Factors

- Positive response both pre and post legislation.
- Doctors who initially opposed legalization have changed to be more supportive over time.
- Specialist clinicians are less commonly involved, as the vast majority of VE is performed by GPs in the home.
- In hospital, there have been some issues with nursing staff feeling unsure of how much responsibility they have for the procedures. Ultimately, the prescribing physicians are required to inject the medications.
- The Dutch experience has demonstrated that physicians can be trusted. It is reassuring that general, Dutch physicians are willing to discuss their actions, be transparent and open about what is difficult, and to be monitored from outside the ranks.
- Euthanasia is not seen as the ‘easy way’ for physicians to manage end of life issues.
- In order to feel comfortable performing euthanasia, clinicians needed to develop, or have already established, a specific relationship with the individual patient. This allowed them to understand the patient, and in particular, their goals and values. This relationship was seen a crucial piece in the determination of *untreatable* suffering.
- Physicians who do not participate in VE are not allowed to block access. They are required to refer to colleague/alternative.
- Some clinicians report that there is always discomfort in performing VE, and that they do it for the patient. There are significant personal and professional anxieties, and implications for the physician’s personal life and practice, that do not lessen over time.
- Others felt that they have never had discomfort with the practice in the context of their role in relieving suffering.
- On average, a GP is confronted with a request one in every three years. Doctors that perform euthanasia do so about every year. Thus, a referral system has developed for when doctors who are uncomfortable euthanasia, hand over the patient to someone who is comfortable VE.
- There are issues with equity in access based in individual clinician assessment of eligibility. The NVVE has set up a ‘consult’ clinic for patients to access when their GP has said no to euthanasia, in an attempt to create alternative avenues for accessing PAD where the GP has not initially aligned with patient perspective. This is called the ‘Levenseinde Clinic’. Data from the NVVE hold that there are about 10000 requests per year, with about 3000 acts of voluntary euthanasia actually performed. Half of the remaining 7000 died prior to VE. That still leaves 3500 with a wish for euthanasia that is not fulfilled. The NVVE estimates that about 1000 of those try to find a way to suicide in another way. In an attempt to create an alternative, the Clinic has been set up, with ambulant teams of doctors and nurses who consult to individuals in their home when they have had a request for euthanasia declined. The clinic practitioners engage the local GP for information and input. About half of those cases where they intervene, then go on to receive euthanasia by their own GP, suggesting that the education and advice service alone shifts the GPs thinking and awareness of the situation. This has made doctors more open and responsive to patient questions in this regard.

4) Palliative Care Interface

- General consensus was that this notion that there is an insufficiency of palliative care services in the Netherlands is unfair, and not representative of the palliative care actually provided and available. Most figures, in particular, do not account for the significant number of patients cared for by general practitioners or within the aged care communities.
- 40% of all patients in The Netherlands died at home, and 60% of cancer patients died at home.
- Nursing homes and care for the elderly homes (two separate systems) often had small number of hospice beds, and were seen as palliative care organizations by locals.
- Most interviewees felt that palliative care services were accessible, well developed and comprehensive.
- GPs were primarily responsible for palliative care in the community. It was recognized that there is likely to be a variation in GP expertise regarding palliative care. Home care and hospice organizations usually have palliative care nurses to provide extra support outside of specialist units.
- Specialty units and services have been increasingly available for GPs to consult. Since 2002, expert hubs provide consult services usually by phone to the local GPs, and this was seen as adequately resourced and accessible. These expert centres' were also responsible for education and research, and now provide accessible education courses for GPs in palliative care, as well as courses for specialists in hospitals.
- Palliative care services have grown since legalization, and alongside euthanasia practice. This was seen as an historical issue related to timing rather than one of direct relationship.
- Euthanasia was seen to have had a positive influence on end of life care, in that both palliative care and euthanasia were part of the same process whereby GPs cared for patients in their homes at end of life.
- Even with access to specialist palliative care, there will still be a percentage of patients who ask for access to euthanasia.
- Many patients who initially request euthanasia do not follow through in the context of specialist palliative intervention.
- Palliative care organizations considered euthanasia to be a matter between doctor and patient, and have officially maintained a neutral stance regarding VE pre and post legalization.
- Some Christian based hospice organizations do not participate in euthanasia, but refer the patients to someone who is happy to discuss the options with them, including transfer to another facility where necessary.⁷¹
- Most interviewees recognized the potential for deficiencies in knowledge and expertise from within the generalist services, but nevertheless held that this generalist setting was the appropriate place for the majority of palliative care services to individual patients.
- There was a general consensus that legalizing euthanasia meant that it was obligatory to ensure there was good access to palliative care services around the Netherlands to ensure that alternative were offered to patients.
- Euthanasia was generally considered to be a part of palliative care.
- Prior and through legalization, palliative care was developing independently, but as time goes on, the services are becoming more integrated; some felt that there has been a directly positive influence on improving pall care since the law as it requires all options to be exhausted.

4.4.6 Take home messages

- The debate continues: even where there has been legalization of assisted death, the debate continues over the parameters whereby this act should be accepted.
- Euthanasia is seen as part of the end of life care spectrum, and part of palliative care practice at the end of life as a matter of normalcy.
- PAD arises from within the doctor patient relationship, and does not function as a 'right' for patients to access, conferring a duty on physicians to perform. It must be agreed on by both parties, in accordance with the due care criteria.
- The issues of transparency and adequate monitoring are significant.⁷² One of the major "benefits" of legalization is the notion that it should make these practices transparent and easily monitored. Regardless of this very open acceptance of euthanasia practice, both culturally and legally, only 80% of cases are reported.⁷³ Why are the other 20% not reported? Researchers suggest that this is perhaps the result of physicians not actually defining what they do as euthanasia in these cases. Doctors in this group report that: 1) they ended life; 2) they used drugs that were seen to be lethal; 3) they acted at the explicit request of a patient. However, they then did not label their action as euthanasia. It is arguable whether these physician's actions were actually lethal. Most of these cases involve the use of opioid infusions at the end of life, and it is unknown whether the physicians were aware that the doses they used may not have had any life shortening effect. I believe this demonstrates confusion within the medical profession about how they define euthanasia, and how they understand and report their own actions.
- Some interviewees felt that there *has been* a recognized slippery slope in The Netherlands.
- Ongoing research and monitoring is crucial to truly follow up the implications of practice to inform the debate in an international context.
- It should not be seen that there is a direct choice between palliative sedation and euthanasia as alternatives to treat the same issues. They are seen as distinct entities with entirely different goals and justifications. Some reporting may confuse high dose disproportionate opioid infusions as palliative sedation and/or euthanasia, thus skewing the data.
- Legalized euthanasia is seen as a 'good' in end of life care for some patients, based primarily on the patient and physician assessment of futility in terms of ongoing life and treatment alternatives.
- The importance of physician knowledge and understanding of the patient's individual values is crucial in their comfort with performing this procedure. Even in recognizing this, many physicians still struggle with it on a personal and professional level.
- The Dutch context is unique in terms of its widespread long-term acceptance of euthanasia as an appropriate palliative technique. In the European *Pallidum* project on palliative care, a questionnaire was sent to caregivers involved in palliative care around Europe. In general, 89% of respondents rejected euthanasia, with only 5.3% of respondents who could conceive of extreme situations where euthanasia can be part of palliative care. By comparison, research in The Netherlands from 1995 revealed that 88% of Dutch physicians involved in end of life care could conceive of situations

⁷² Onwuteaka-Philipsen BD et al. Dutch experience of monitoring euthanasia. *BMJ* 2005; 331:691-3

⁷³ Onwuteaka-Philipsen BD et al. Trends in end of life practices before and after the enactment of the euthanasia law in the Netherlands from 1990-2010: a repeated cross sectional survey. *The Lancet* 2012; 380:908-15

where VE/PAS is justifiable, 54% had carried out VE/PAS, and only 8% would not carry it out, but would refer to a colleague who may.⁷⁴

- Is anything lost in 'short cutting' the process of death via euthanasia? Response was based on the individual person. The most common perspective: if they do not want to walk the complete road of deterioration and dying, that is their prerogative, and 'loss' is related only to their individual perspective.
- Most people want to live. This means that there is no significant danger in terms of numbers, and significant risk to vulnerable groups with expanded access, because most people will still choose *not* to hurry death.
- VE currently functions within the physician patient relationship, as a shared decision based on trust. However, a growing number of people want VE as a right, where it is not dependent on physician assessment, but arising out of patient autonomy.
- The suffering of patients is intricately related to the patient's notion of self, in particular, their functional independence from others, the irreversible nature of their conditions (hopelessness in terms of unbearable suffering and medical intervention), and the loss of autonomy that accompanies the natural history of disease.

⁷⁴ Broeckaert B. Janssens R. Palliative Care and Euthanasia – Belgian and Dutch Perspectives. A synthesis of both authors own writings compiled 2003. Copy provided by interviewee.

4.5 Belgium

4.5.1 Background^{75 76 77}

VE/PAD was legalized in Belgium in May 2002, where the conditions of 'prudent practice' are met. These include:

- Continuous and unbearable suffering of the patient, related to an incurable illness
- Persistent, well considered, and voluntary request by the patient
- Patient is fully informed of diagnosis, prognosis and treatment options.

Two other laws relevant to end of life care were also passed in Belgium at the same time.

1. Law on palliative care, which states the right of every patient to palliative care, and prescribed measure for the development of palliative care services in Belgium.
2. Law on patient's rights in regards to health information and consent to health procedures, including the role of substitute decision makers.⁷⁸

The Belgium model is therefore unique, in that it recognized overtly that, in order to justify the availability of legalized assisted death, adequate and well-developed palliative care services were required. This commitment to palliative care was therefore enshrined into legislation at the same time.⁷⁹ Unlike the Netherlands, legalization in Belgium followed a very short public debate, and was not preceded by legal tolerance or notification procedures. However, the law and procedures implemented are based largely on the Dutch model.

VE is legal where physicians fulfill due care criteria, similar to the Dutch model. This requires the patient's request to be voluntary and well considered. The patient must request euthanasia verbally at least twice on separate occasions, and the request must not be the result of external pressure. Their suffering must be unbearable and irreversible, can be psychological or physical in nature, and usually resulting from a medical condition or disease. They must be informed of the current situation and prospects, including all treatment options. There must be no prospect of improvement. An independent second opinion is required, and this doctor must see the patient and document the opinion in the patient's medical record.

All notifications go to one central federal committee, consisting of 16 members including physicians (some of whom are palliative care experts), lawyers, community representatives and public health figures. The initial reporting is anonymous, however, and patient and physician are only identified if there are concerns related to the details of the case, where the identifying portion of the form is then unsealed and reviewed.

⁷⁵ Chambaere, K. Medical End of Life Practices in Flanders and Brussels, Belgium. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 3, 2010

⁷⁶ Cohen, J. End-of-Life decisions and place of death in Belgium and Europe. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 31, 2007

⁷⁷ Smets T. The Euthanasia practice in Belgium. Behaviours and attitudes regarding reporting and adherence to legal safeguards. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. January 14, 2011.

⁷⁸ Chambaere K, Bilsen J, Cohen J, Onwuteaka-Philipsen B, Mortier F, Deliens L. Trends in Medical End of Life Decision Making in Flanders, Belgium 1998-2001-2007. *Med Decis Making* 2011; 31:500. Found at <http://mdm.sagepub.com/content/31/3/500>. Accessed 24/5/13.

⁷⁹ Bernheim J et al. Development of palliative care and legalization of euthanasia: antagonism or synergy? *BMJ* 2008; 336:864-867

VE accounts for approximately 1% of all deaths. Belgium has a population of 11 million, and there have been a total of 1917 reported deaths due to VE between 2002 and 2007. 53% are male, mostly between the ages of 60-79 years, with older patients underrepresented proportional to total numbers of deaths. 83% have cancer as a primary diagnosis, with very few having more controversial diagnosis such as dementia or psychiatric illness. 53% is performed in hospital, and 42% is performed at home. Reporting rate of VE in Belgium is fairly low at 53% in 2007. In reviewing risk to vulnerable groups, the elderly have lower likelihood than younger patients, and people with lower education level have a lower likelihood than patients with a higher education level. "Life ending acts without explicit requests" (LAWER) have actually reduced from 3.2% in 1998 to 1.8% in 2007.

Palliative care in Belgium⁸⁰ is well developed, with 25 palliative care networks, consisting of community, hospital based consultant services, and 500 palliative care beds nationally. In terms of palliative care development, there has been a gradual rise in palliative care expenditure in Belgium since 2002, with European rankings putting Belgium as 2nd overall, as compared with UK (at number one), Spain, France, Germany, and the Netherlands (NL ranked 3rd overall). Approximately 30% of all deaths in Belgium are involved with specialist palliative care services. In terms of the interface, 75% of physicians feel that euthanasia can be part of good end of life care, and only 10% feel that the euthanasia law impedes development in palliative care. However, the vast majority of physicians feel that further improvement in palliative care would reduce the frequency of euthanasia. There were strong associations with Roman Catholic religious convictions in factors associated with opposition to euthanasia. Overall, there was no perceived antagonism between euthanasia and palliative care. They are thought to be synergistic in Belgium.^{81 82} Euthanasia occurred often within the context of palliative care, and they continue to coexist. The 2003 Flemish Federation for Palliative Care position statement quotes: "Palliative Care and euthanasia are neither alternative or antagonistic... euthanasia may be part of palliative care...Caregivers are fully entitled to ethical limitations, but they must be expected to state these limitations candidly, clearly, and above all in due time."

4.5.2 Practical Issues

Euthanasia only occurs within the bounds of doctor patient agreement. That is to say, patients do not have a right to access assisted death, and doctors do not have a duty to perform it. VE must be agreed upon. Attitudes of doctors vary.^{83 84} About 63% of Belgium doctors are prepared to perform euthanasia, with a further 19% neutral. 40% of all doctors (and 66% of palliative care doctors) have received an explicit request for VE. Only 55-60% of all requests are granted, and some people feel that doctor procrastination is quite common.

Like the Netherlands, medical associations felt they had a professional responsibility to safeguard the practice of VE, and therefore created an organization whereby physicians could turn to with

⁸⁰ Desmedt MS et al. Palliative inpatients in general hospitals: a one day observational study in Belgium. *BMC Palliative Care* 2011; 10:2-8

⁸¹ Bilsen J, Cohen J, Chambaere K. Medical End-of-Life practices under the euthanasia law in Belgium. *N Eng J Med* 36;11:1119-1120

⁸² Berheim JL, Muille A. Euthanasia and Palliative Care in Belgium: Legitimate concerns and unsubstantiated grievances. *Journal of Pall Med* 2010; 13(7):798-799

⁸³ Sercu M, Pype P et al. Are general practitioners prepared to end life on request in a country where euthanasia is legalized? *J Medical Ethics* 2012; 38:274-280

⁸⁴ Meeussen K, ven den Block L et al. Dealing with request for euthanasia: Interview study among general practitioners in Belgium. *J Pain and Symptom Manag* 2011; 41: 1060-1072

questions on euthanasia, and a formal consultation with expertise in the area. A group of doctors have therefore been trained to give independent second opinions regarding euthanasia – LEIF doctors (since 2003). They are mostly GPs, but also include some specialists and psychiatrists. These doctors complete a 20-hour training module, which includes some training in palliative treatment options at the end of life. There is also a second subspecialty group who specialize in the complex psychiatric cases that request VE. LEIF consultants see 1 consult per month or so and referrals are usually based on geographic location. Their main job is to confirm the medical condition and the presence of unbearable suffering, and to assess whether the request is consistent, repeated, and voluntary. They try to remain independent from the therapeutic relationship. About 70% of second opinions are LEIF doctors. On average, they ‘disagree’ with the request 20-30% of the time, usually on the basis that there are other therapeutic options available, or because there is some ambivalence about the request. One of the main issues currently is that about 20% of the time, the LEIF doctor ends up performing the VE at the request of the primary physician involved, due their experience and expertise. This may be problematic legally. The LEIF doctors also play an important educational role for the primary physician, who may not have had to deal with a voluntary euthanasia before.

48% of VE happens at home, and 52% occurs within hospitals. This is seen as a consequence of the suffering role of the GP in Belgium, where GPs do not function as gatekeepers to specialist services. Many patients bypass community practice and go straight to access specialist services. Culturally, specialists then tend not to refer back to GPs at end of life.

The most commonly used method is intravenous injection of 2g of barbiturate in 20mls of normal saline as a push, or 3g in 100mls saline over 10 minutes. The main complications arise from issues with IV access, or the occasional abnormal metaboliser with significant liver malfunction related to long-term benzodiazepine or alcohol use. In the case of complications, most practitioners administer a second dose of 2g of barbiturate, rather than using muscle relaxant, on the basis that there is theoretical possibility of inducing muscle relaxation in a conscious patient if the barbiturate fails to take effect.

Deaths are reported to the central review committee. There are two parts to the paper report. This first is an anonymous record of the details of the case. The second is a sealed section with personal and demographic details of patient and doctors involved. This section is only opened where there is controversy or questions regarding the legality of the action after review of the anonymous details of the case. Usually, the doctor is then contacted for more details to ascertain it’s concordance with law, and occasionally “comments” are made by way of negative feedback. 6.5% of cases have required “comments” be made back to the physician. No cases have been referred for prosecution in over 10 years of legalization.

4.5.3 Themes from semi-structured interviews

1. Pre-legalization

a) Position

- Unlike the Netherlands, Euthanasia was not a legally tolerated and accepted part of medical practice prior to legalization, and there was no case law on point to guide practice.
- Clandestine euthanasia was recognized practice within oncology and general practice groups, but key players in the field recognized that advocating for legalization of euthanasia was not viable given the lack of palliative care services. A number of subsequent advocates travelled to the UK in the early 1980s to learn about palliative care and bring it ‘back’ to Belgium hospitals.

- Legalization was a grass roots initiative, propelled by medical champions, some of which were embedded in key palliative care organizations within Belgium.
- Legalization happened quickly, preceded by a short period of intense debate at a political level. The cultural context was polarized between liberal/secular/humanist traditions versus catholic based organizations, universities and hospitals. This was also reflected within medical circles, as the majority of doctors were educated at catholic universities and trained in catholic institutions.
- Harm minimization was a key driver in accepting legalization. It was seen as a safeguard to encourage careful medical practice.

b) Values

- Relief of suffering is the primary motivator.
- Patient autonomy and self-determination significantly less relevant.
- Liberalism/pluralism as a *communal* value was very important. Accepting VE reflected the ability of Belgian society to incorporate fragmented views, and accept alternative perspectives as respectable stances. Related to this, there was a strong desire *not* to allow religious convictions sway over secular values.
- Increased control of what is valuable in life, shifting from length of survival focus, to assessment of quality of life as the primary motive for medical decision-making in a more general sense.

c) Concerns

- 3 fold: 1) Slippery slope and risk to vulnerable groups as the access parameters expand once legalization is normalized; 2) Decrease in the delivery or quality of palliative care services; 3) Erosion in confidence in the medical profession
- In Belgium, data directly contradicts concern 2), in fact demonstrating that legalized VE has been synergistic with the expansion and development of palliative care services. In terms of concern 3), data from the European Values Study in 1999 placed confidence in the Belgium service at 83.1%, and in 2008 this had risen to 92%.⁸⁵ Discussion pointed to the idea that patients found it reassuring that this option was available to them when the time comes.
- The slippery slope fear (concern 2) is more complicated. Data has shown no increased risk to vulnerable groups, including the aged, females, nursing home patients, patients with dementia, and persons of lower education status.⁸⁶ Some people expressed concern regarding the risk of “perfunctory euthanasia,” where a casual perspective on ending life may develop, leading to a potential cultural slippery slope. The other concern surrounds the expansion or “liberalization” of euthanasia to include competent minors, patients with dementia, and borderline controversial cases where there is no clear life limiting illness, such as the elderly who are weary of life.

2. Legalisation

a) Strengths

- Contributes to carefulness in end of life care and decision-making and improved quality of care in a technical sense.
- Openness about preferences for death has led to improvement in shared decision-making.
- Transparency and openness creates accountability and monitoring.
- Actually serves to protect physicians from prosecution without removing mechanisms for actual criminal behaviour completely.

⁸⁵ As reported by Jan Berheim presentation, Vrije University End of Life Research Group Workshop.

⁸⁶ Chambaere, K. Medical End of Life Practices in Flanders and Brussels, Belgium. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 3, 2010

b) Weaknesses

- No cases have been referred for prosecution. This results in criticism that the monitoring system a “toothless watchdog.” Some interviewees felt this was perhaps a result of the harm minimization goal, where the committee wants to encourage doctors to report, and would not like fear of prosecution to be a barrier. It was therefore considered a strategic choice in honour of promoting transparency, because transparency makes for peer control and quality assurance.
- Poor reporting rate: only half of the cases of euthanasia are formally reported (vs 80% in NL). Why? 1) Due to unclear definition of euthanasia on behalf of the reporting doctors. 2) Cultural piece, in that Belgians describe themselves as resistant to regulation! They do not like to follow the rule of the law, and this is seen as part of their cultural identity. Surveys demonstrate 68% feel that societal control is necessary, but 28% held the cultural perspective that VE is a private matter between patient and doctor, and needn't be controlled and evaluated.
- “Safeguards” may limit access for patients, and physician procrastination seen as a significant access barrier.
- No independent advocate for the patient. That is, one who can assess with neutral objectivity whether the patient's want or claim to euthanasia is appropriate.
- Notification system is anonymous therefore not enabling feedback or an ongoing educational contribution for physicians.
- “Unbearable suffering” is subjective versus untreatable suffering, which is objective.
- Practical restriction to people who have a fatal disease.
- Funding is still inadequate e.g. LEIF doctor consult is not funded.
- Doctors can refuse or be a “conscientious objector.” The end result of this is that the patients' values and preferences become subordinate to the physician's.
- There is no compulsory palliative care consultation.
- The second opinion is not binding. The individual physician can still go ahead with the euthanasia, but he is required to report that the second opinion disagreed.
- It is difficult for the second opinion to remain completely independent, especially when they need to take a more active role for practical reasons.
- Minors under 18 years are not legally able to access VE, and this can sometimes be very difficult for parents, both where VE is refused, and where the VE is illegally performed. This creates a barrier for the parents to be open about the death, and leads to complicated grief.

c) Changes over time

- Legalization has made the requests for VE and end of life care conversations more open, and means that these issues are more often addressed and discussed overall.
- There have been an increase in the number of requests over time, but no increase in the likelihood of the request being agreed to.
- There were many opponents from within palliative care, medical and church groups. It is generally felt that this opposition has now relaxed somewhat, and members within these groups are more accepting of the practice. This “evolution of stance” is tributary to the notion that the laws do not just reflect culture, but can change it over time.
- Surveys of public perceptions pre-law (2001) - post law (2009): public acceptance of VE was 78% raised to 90%; patients should have the right to decide over life and death 65% up to 73%; interestingly, acceptance of involuntary euthanasia based on family and doctor assessment increased from 45% to 65%.
- Surveys looking at whether the law should expand are generally favourable: agree to include competent minors 49%; dementia 79%.⁸⁷
- Alleviation of pain and symptoms has improved in the context of legalized VE.

⁸⁷ Cohen, J. End-of-Life decisions and place of death in Belgium and Europe. Doctoral Dissertation. End of Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy, Vrije University Brussels. May 31, 2007

- Overall reduction in life ending acts without explicit request: reduced from 3.2% to 1.8%; about 90% of these are “giving the patient a little nudge” in the last week of life; 6 cases had a prognosis >1 week.

d) Patient Drivers

- The relief of suffering is overtly understood to be the relief of primarily existential suffering. VE is requested by patients who struggle with no further meaning in life, or where ongoing pointless effort is required to continue living, for very little benefit. Essentially, this is ‘palliative futility’: hopelessness, for good causative reason, which is refractory to treatment.
- VE is seen as “dignified/noble” way to die – it adds value to death itself.
- Patients do not want to be a burden to their families/loved ones.

e) Clinician Factors

- Medical associations remained silent on the issue.
- Doctors have lagged behind the ideas of the people in this regard. Why? 1) They may be more conservative. 2) The issue of moral agency, where doctors feel that they may be ‘forced’ to do this, even where they disagree. 3) Confronting adverse emotional reaction due to the idea that they have somehow failed because they can’t help the patient. 4) Resist euthanasia being ‘controlled’ but legislation or patient demand.

3) Palliative Care Interface

- Legalization of euthanasia and a commitment to the development and provision of adequate palliative care services were seen as intricately connected, and required in tandem. Simultaneous laws were proposed and passed by parliament to ensure adequate and enshrined obligations to both were upheld in the light of each other.
- Palliative care services were underdeveloped 10 years ago, but have undergone significant development and improvement over the last decade and are now considered by locals as on par with the rest of the world. Most interviewees felt that this was a direct result of the simultaneous laws on VE and Palliative Care.
- Palliative care services were generally seen as comprehensive, well developed and accessible throughout Belgium, with high rates of patient satisfaction.
- There are 25 regional palliative care networks, mainly coordinated by the local GP with the help of home care teams. Clinical nurse consultants help generalists in the community do the majority of palliative care, with access to specialist advice through informal regional networks. From an insurance perspective, patient switch to palliative status attract a higher reimbursement rate in terms of specialist equipment/carer allowance/palliative leave etc.
- There are approximately 500 palliative inpatient beds in hospitals: 10 PCU beds per 300000, with a 1.5 nurses per bed ratio.
- Spending on palliative care at a federal level continues to rise significantly and deliberately.
- Some of the driving forces behind legalization in Belgium came from within the palliative care community. There are a number of key palliative care figures who made it their life’s work to develop and deliver good end of life care for dying patients in Belgium, and are also key and public supporters of legalized euthanasia. Many of these supporters come from the within the Flanders region of Belgium. In general, there was (and is) more resistance/opposition from within palliative care groups in the Francophile regions of Belgium (the south). Some preferred to keep palliative care “pure” from the notion of euthanasia. Most of the people I met with who were publishing and public in their writings/perspective came from within the Flanders groups, so this report will necessarily reflect that bias.

- Medical associations remained silent on legalization, so public palliative care supporter's felt they were essentially out on a limb.
- Palliative care want to set the standard for good practice end of life care, and are best placed to do this in conjunction with PAD. The vision became voluntary euthanasia "embedded" in palliative care. Palliative care groups lobbied for a compulsory second opinion by palliative care physicians enshrined in the law, which was not included in the final version of the legislation because liberalists feared this would control access too much.
- Supporters from within palliative care come from different stances, at each extreme or somewhere in between the following general groups: 1) VE is a procedural intervention provided to a patient who requests it within the parameters of the law, primarily based on respect for patient autonomy and self determination in the matter of death; 2) VE is the end point of good palliative care, where some patients will continue to 'suffer unbearably' despite the highest quality comprehensive palliative interventions. VE is a sad but justifiable recognition of "palliative futility", where there is no reversibility for the patient's current state despite maximal medical and multidisciplinary palliative team intervention, and the patient continues to find their current state of a unacceptable/unbearable quality; 3) VE is a necessary but difficult service provision for patients, which takes a personal and emotional toll on a doctor despite its justifiability for the patient.
- Population based surveys demonstrate: 75% feels that VE is part of good palliative care and 13% disagree; 72% disagree VE impedes the development of good palliative care

4.5.4 Take home messages

- Legalized VE and palliative care have developed in conjunction with one another, and are thought to be synergistic in terms of their development and relationship over time.
- Is anything lost? The main fear expressed is that it promotes a more cavalier attitude toward the taking of life. Complementing this is potentially less compassion in care for the dying. There is also the endorsement of a social construction of human dignity, which is self-perpetuating e.g. independent, self-determining, strong, in control etc.
- This is a “good” in so far as it is seen as a vehicle to respect individuals, and to relieve primarily existential suffering. VE empowers people, giving them agency to do something about a situation over which they have very little control. This control is reinvigorating, allowing them to hold their head high, and create value by determining how they die. There is no ‘loss’, and certainly a gain for those people. There is not sentimental/intrinsic value in “natural dying” *per se*.
- According to some palliative care champions, it is crucial to maintain the transcendence of death itself, even where VE is used. Death should not be ‘procedural’. We must recognize autonomy in a relational sense, and remember the experience of death as a whole person. Similarly, treatment must address the whole person, and requires the input of the whole palliative care multifaceted team. cursory one-sided treatments for pain are not whole person care, and inadequate in terms of palliative intervention.
- Death by euthanasia must be embedded in the medical profession, because it otherwise escapes the togetherness of people who are ill with people who care. It must be performed IN TRUST, inside the covenant of the doctor – patient relationship. It cannot be based on individual autonomy alone, but requires a shared decision-making model. A ‘right’ to VE forces it into the superficial realm, almost commercializing it, whereby the patient is going to the “Dr Shop” so he can provide my procedure based on my individual wishes.
- Care must also be taken not to instrumentalise doctors. This creates superficiality in confining their role to just a technician. It is not cognizant of the relational piece of the experience. Doctors are touched by VE emotionally. There are now support groups operating for doctors who continue to struggle with providing euthanasia.
- Transparency is an important means to facilitate harm minimization, quality assurance, and ethical practice.
- Some very experienced and engaged palliative care physicians felt that we need the option of VE for good palliative care to be possible. We walk along with the patient, trying everything at our disposal to help them live well until they die. Sometimes, we do not succeed, and the patient no longer wants to live. This is the notion of ‘palliative futility’, where it is necessary to surrender as a physician. Potentially VE could be seen as the ultimate gesture of a palliative care physician as a demonstration of love for their patient’s plight. To quote a prominent palliative care physician I interviewed: “It hurts me that you ask VE. Let us try this, or this. And if you still feel this way I will assist you to die.” Control should stay within the relationship, not with the individual patient and not with the individual doctor.

4.6 Luxembourg

In March 2009, Luxembourg passed two laws regarding end of life care identical to those passed in Belgium. One related to the legalization of euthanasia, and the other related to the provision of palliative care at the end of life, including the rights of the individual in terms of advanced directives for treatment choices, and naming of a substitute decision maker in the context of incapacity. A single commission was established to oversee the function of the law, consisting of 3 doctors, 3 judges, 2 representatives for patient rights, and 1 member of health administration. The committee meets 2 monthly depending on the number of cases reported. The panel reviews the paperwork, and checks compliance with the law. Any aberrant cases are referred to the courts, but none have thus far been referred.

The advocates for legalization came primarily from an autonomy-based perspective, to enable patients to decide for themselves whether their life is worth living or otherwise. Advocacy groups were community based and self funded, drafted the legislation, and then lobbied through members of the parliament. The movement was not embedded in the medical community, and physicians were by and large opposed because it was seen as an unnecessary external regulation of medical practice. There was significant fragmentation of opinions, resulting in no concerted or consistent opposition on a political level.

Information relating to Voluntary Euthanasia and palliative care is sparse and difficult to access publically. The reasons for this are as follows:

1. Voluntary euthanasia has only been legal in Luxembourg for 2 years, therefore the numbers are very small, and the processes are in their infancy (total number = 5 the first year, 14 the second year).
2. The commission collects and files the data, but does not yet collate it for public review, or interrogate it given the small numbers.

My experience in Luxembourg was limited and short. According to the interviews I did conduct, the following themes emerged:

- There was varying perspectives prior to legalization, many divided along neighboring national lines in the melting pot that makes up Luxembourg's population. In broad terms, the Dutch were accepting, the French were opposing, and the German groups were very opposed to euthanasia.
- Main vocal opposition was through catholic organizations, which are now more accepting of the legislation, although usually non-participatory
- The main defining and motivating values behind legalization were: 1) Good death as defined by the patient, with preeminence placed on the value of individual autonomy and self determination; 2) The societal value of pluralism and tolerance, particularly where enabling an individuals wish in this circumstance is thought not to harm anyone else in society; 3) Beneficence and Relief of suffering, including psychological suffering; 3) Harm minimization, where it was recognized that this practice in its clandestine form was occurring commonly, sometimes without patient consent. Legalization was a way to institute some type of regulation surrounding the circumstances and review of these practices.
- Weaknesses of the law included: 1) Deaths are certified as their natural causes, not specifically as euthanasia; 2) The criteria are arguably not broad enough, and there is some support for extending access to young people, infants in the first year of life with severe life limiting prognoses, and dementia patients; 3) Access is highly dependent on individual doctors assessments. Doctors who choose not to participate

are not required to refer to sympathetic colleagues who may be supportive of euthanasia.

- Palliative care is still primarily provided by oncologists in hospitals, and by GPs in the community. There are no recognized palliative care specialists by training in Luxembourg.
- Most patients who access VE are in the terminal phase, at home or in hospital.
- On the ground, there is a significant barrier in terms of access, because many GPs/doctors refuse to participate, and patients are left unsure of what to do. This reliance on the relationship with a particular doctor meant that there was little recourse when there is disagreement.

4.7 Switzerland

4.7.1 Background.

Assisted suicide has been “legal” in Switzerland since the 1940s. Article 115 of the Swiss Federal Criminal Code (StGB) states that:

“Whoever, from selfish motives, induces another person to commit suicide or aids him in it, shall be confined in the penitentiary for not over 5 years, or in the prison, provided that the suicide has either been completed or attempted.”

Thus, Swiss law holds that assisting in a suicide is only illegal where the **motive** of the assistant is selfish. Of note, it is motive rather than intent that is relevant.

Traditionally, assisted death has not been part of accepted medical practice. The Swiss Academy of Medicine until 2003 held that assisted death “was not part of physician activity.” This shifted in 2003, where they then held that doctors could help terminally ill patients to die under strict conditions. Nevertheless, most physicians do not participate in assisted suicide transparently. Non-medical/not for profit organizations developed independently of the medical system in order to facilitate patient’s access to assistance in dying. These organizations rely on a small number of sympathetic doctors (mostly general practitioners) who are comfortable in writing the prescriptions after reviewing the case details. Assisted suicide accounts for 300/0.5% of all deaths in Switzerland (Dignitas had 160 clients in 2011).

4.7.2 Practical Issues

Assisted death is accessible to Swiss nationals and to people from abroad who want to access lethal medicines in a legalized framework. The patient contacts one of these well known organizations with an inquiry regarding the process. The most well know organizations include Dignitas and EXIT International. These organizations are not run from within the healthcare system. They are separate, not for profit and ‘cause-driven’ organizations, run by interested community members with varying backgrounds.

I met with Dignitas, so the following outline applies to that particular organization. For further information, Dignitas outlines their process on their website, which is accessible to the public.⁸⁸ Of the thousands of people who contact the organization for initial information regarding accompanied suicide, 70% do not contact the organization a second time, and only 13% go on to make an appointment for consideration. People need to take out membership with the organization before they can access assisted death or “accompanied suicide”, whereby the cost of membership is 200 SF yearly. The majority of members never actually initiate assisted death proceedings. The security of having the option available to them is enough to alleviate the fear of hopelessness. For those who want to access “the service of accompanied suicide,” the process is as follows.

- They must be a member of the organization, be of sound judgment, and possess a minimum level of physical ability in order to self-administer the medication.
- The member must pay 3000 SF for the application regardless of whether it is approved, to cover administrative costs (AUS\$3430).
- The cooperation of a Swiss doctor is vital, meaning that further prerequisites therefore include diagnosis of a terminal illness, unendurable incapacitating disability, and unbearable and uncontrolled “pain” (or suffering).
- The member must submit a formal request in (preferably typed) writing, comprising of a letter asking for accompanied suicide, stating the reason for the request including

⁸⁸ Please see: <http://www.dignitas.ch>. Accessed 10 July 2013.

the diagnosis and how it affects the patient, a biographical sketch including personal background and family circumstances, and an up to date medical record providing comprehensive information on the case history, diagnosis and treatment.

The organization vets the requests, to sort to those they think are likely to be approved by prescribers. The ideal person to write the prescription is the patients own GP. Where this is refused, or not possible, Dignitas refers the case to one of the few doctors they know who are “sympathetic” to the cause (small group of less than 10). Based on the history, the doctor gives a “provisional green light”, or he/she rejects the request. In the case of the latter, Dignitas will refer to another doctor for consideration. In some circumstances, more information is requested. Definitive agreement is reserved until there is a personal consultation between the Swiss physician and the patient. The main barriers at this encounter are impaired capacity, pressure from a third party, and impression of inconsistency in the request.

The medicine most commonly prescribed is oral Sodium Phenobarbital 10g. It is usually compounded at a particular “well known” pharmacy in Zurich, but not tracked or reported to a central data collection/monitoring agency. The assisted death organizations keep their own extensive records of each case, which are accessible for researchers and policy advisors if requested/appropriate. There is no “veiling” of the process, but it is not tracked or regulated.

When the patient is ready to go ahead, they arrange payment of a further 3000 SF, and are assigned an “accompanying person,” who helps them negotiate the steps and is present at the time of death. The accompanied suicide can happen at home, in nursing homes who are agreeable, or in a specific Dignitas ‘house.’ For those who do not live in Switzerland, this house is made available as their place of death. The patients need to travel to Switzerland a few days before, have a final consultation with the prescribing physician before the medication is dispensed. The physicians charge for their services separately based on their own fee setting, and Dignitas charges an additional contribution of 1000 Swiss Francs for the doctor consultation.

All assisted suicides are video taped in order to support any legal defense that is required to demonstrate altruistic motive. There is an accompanying Dignitas person throughout the process, until the member dies. The death is then reported to the police, the coroner’s office, and the prescribing doctor. Family and friends are interviewed. There is no crime if no selfish motive is established, and the matter is considered resolved. There is a further fee for internationals when they choose to use the Dignitas facilities, and to cover the funeral director, cremation, and cost of dispatching the urn. This is a further 2000 SF. There is also a separated fee to cover the official procedures following a death in Switzerland, amounting to 1500 SF. Total cost of an accompanied suicide is therefore 12600 SF, which equals 14 460 AUD, paid in advance. There is provision for reduction of these costs for people in “modest economic circumstances” which must be discussed and decided in advance. Dignitas is a not for profit organization.

4.7.3 Themes from semi-structured interviews

1. Pre-legalization

a) Position

- There was no “new legislation” debated and passed. However, when the Dignitas tapes were publically released to international controversy, the City of Zurich held a referendum in 2009, asking the populous whether they supported legalized assisted death, and whether they wanted

to allow international travelers to access the law in Switzerland. The overwhelming majority said yes to both (>85%).

b) Values

- Main value is respect for individual autonomy and choice.
- Harm minimization in terms of suicide prevention and prevention of co-morbidities associated with failed suicide attempts. One of the main goals is the prevention of clandestine suicides, and Dignitas claims to result in less suicide overall due to the benefits created by choice and reassurance. Many suicidal patients who contact the organizations are **helped** just by that contact. The openness of discussion creates relationship, and this relationship is highly therapeutic. This openness actually creates value in life in a way that cloaked paradigms cannot achieve.
- Relief of suffering as defined by a combination of both patient experience and medical diagnosis. Doctors are still required to agree and prescribe the medication, and therefore usually require adequate evidence of terminal illness to accept suffering. Approval for euthanasia for a young man who has just broken up with his girlfriend, for example, will not be approved, no matter how intense the existential suffering is claimed to be.
- Respect for pluralism in society was again a significant social value.
- The issue of Swiss nationalism in opposition to German nationalism. According to some of the interviewees, German history, particularly in light of the Nazi era, means that the Germans are very against any form of euthanasia. This is a part of the cultural piece of the Swiss that sets itself up in direct antithesis to the German, and is seen as a way to differentiate themselves from Germany.

c) Concerns

- Not applicable given the long-standing nature of the legal stance. See weaknesses.

2. Legalisation

a) Strengths

- Liberalist, in that it is very accessible, with transparent processes, for all people interested in accessing assisted death.
- The focus on motive rather than intention may be important, in that it removes the ethics of the act from the issues inherent with double effect.
- The decision to end life is always in the hands of the patient in the end.
- Not “detrimental” to the physician patient relationship because it generally lies outside everyday medical practice and relationships.
- System fits into the political system well, and it is longstanding and has therefore been tested in terms of structure and outcomes. Switzerland is a small society, built on close and proximal relationships. Everyone is observing each other, therefore creating some type of internal regulation. This system works well in Switzerland, but may not necessarily in larger communities such as the UK (for example).

c) Weaknesses

- Legally grey, in that it is not clear cut before the act that everyone who participates is legally “safe.” There is still an after-the-fact determination of altruistic motive required. The framework has developed organically, but it is still imprecise and technically open to unexpected outcome.
- Functions outside the medical framework, thus more “procedural” in nature. It is not undertaken from within the “trust” of the therapeutic relationship.

- Issues with “euthanasia tourism” and perceptions of “commercialization” of assisted death, given the costs and payments involved in the process.
- Not regulated from within the medical system, thus relying in individual doctors to grant or refuse based on their own non-standardized judgment.

d) Changes over time

- Increase in the number of internationals accessing the law due to media coverage of the organizations activity.
- Increasing beaurocracy, and more stringent controls over the activities of the assisted death organizations. For example, Dignitas used to stock their own Phenobarbital in the cupboard and dispense from Dignitas head office, but are now no longer able to do that.

e) Patient Drivers

- Fear of the unknown and fear of what will happen to them as they die.
- Sense of control and increased options open to them. Given this is one of the major drivers and values in the modern world, patient choice is seen as a vehicle for increased quality of life.
- Value of functional independence from others.

f) Clinician Factors

- Not openly approved of by medical practitioners, although may have levels of approval and participation outside of the accompanied suicide organizations which have not been captured.
- Doctors are generally divided over these issues. All official bodies are conservative, but prudent in that they do not come out against the practice.
- At a hospital level it is rare, and people are reluctant to perform VE in institutions, and are often in fear of criticism. It is seen as a thing for private spaces – home.
- More that 50% of GPs are in favour. Many encounter it regularly, and want to discuss it in their continuing education seminars as one of the important topics for ongoing education and review.
- It is definitely a procedure of general practice, and not a part of palliative care specialist practice.
- Many doctors have 2 hats in this regard – supporters as citizens and in term of social values of autonomy, but more conservative as doctors. Perhaps because Drs are “naturally paternalistic”, but also because it is difficult to confront a patient who may reject treatment options, yet expects the physician to act outside of their own “conscience/framework and administer a lethal medication”. In 2001, 90% of the population felt they had a “right to die” versus only 10% of doctors who felt that patients had this right.
- Despite VE functioning outside the medical arena, doctors are still expected to act as gate-keepers to accessing this assistance. Most are not supportive of the practice, and those who participate struggle with a sense of isolation, and are not present at the time of the final act.

4) Palliative Care Interface⁸⁹

- Palliative Care is primarily performed by GPs in the community, and VE therefore does not interface formally with specialist services in the hospitals.
- Formal training in palliative care as a specialized practice is limited.
- Comments surrounding Clinician response are relevant here, as most VE is performed in the generalist arena.

⁸⁹ Pereira J, Laurent P et al. The response of a Swiss university hospital’s palliative care consult team to assisted suicide within the institution. *Palliative Medicine* 2008; 22:659-667

4.7.4 Take home messages

- The harm minimization piece is very significant. There is an acceptance that some people will choose to commit suicide and are beyond medical help in swaying their intention. This is something that ought to be accepted, and not fought with tools such as criminal law. However, it was not seen or presented as a *good per se*.
- While patient choice was elevated as a highly ranking value, this harm minimization piece was much more prominent in the Swiss model, which reflected itself in the personal dilemmas faced by those interfacing with people trying to access the service.
- PAD operating largely outside of the medical system creates an unusual anomaly/ conflict. There is a clinical/procedural/mechanistic flavour to the process, which neglects the nuances of human experience. I would argue that this tension is reflected in the people who facilitate PAD. They appeared aware of it, but found it difficult to reconcile with the principled justifications for facilitating access to legal and safe PAD. The principle of individual autonomy is not enough, despite the rhetoric.
- The issue of VE is in fact a 'non resolvable' ethical dilemma, where it is naïve to believe that a single regulation would work and be completely ethically robust in all circumstances. Social context and values are crucial in deciding how a society should legislate around this issue.

5. DISCUSSION AND REFLECTIONS

Given the complicated nature of the topic, and the breadth of the issues involved, it is difficult to be black and white in the take home messages post fellowship. I would have liked to come home with a definitive answer to the question of legalization in Australia, but as one of my interviewees so eloquently and simply stated, this is one of the true “ethical dilemmas” of the modern age: a question of intrinsically competing values, where there will be a number of ethically defensible answers and approaches, and arguably no single “right answer” that fits all situations or communities.⁹⁰ Given the number of great minds and work already engaged in this question, and the fact that the debate still rages, one single “right answer” was an unlikely outcome. In recognizing this limitation, however, I believe some significant contributions can be made to this debate as a consequence of my fellowship as we face this issue going forward.

I would like to take each broad argument individually, and comment on my own reflections as they emerge from the fellowship experience. Then, I will make some specific conclusions and recommendations, and finish off with a way forward, in terms identifying the questions yet to be addressed in managing this ethical dilemma from within an Australian context. Remembering my palliative care “lens”, my comments will be flavoured by my experience thus far in caring for the dying.

Let us revisit the ethics again.

The two main values driving legalized assisted death are respect for individual autonomy and the relief of suffering. I realized through my fellowship that these are in fact intimately related to one another in practice.

The individual wanting access to PAD primarily values two things above other values:

1. **Honouring patient autonomy**, and giving patients control over method and timing of death. These days, the notions of autonomy and control are intimately linked to the idea of dignity in western culture. “Dignity” is essentially married to our sense of self; our identity, our essence; our vitality. In the modern world, these things are often related to our sense of autonomy and independence.
2. **Avoidance of functional incapacity and fear of uncontrolled symptoms or disability.** These are the expected side effects of disease. This too is related intimately to the notion of human dignity. Control of our bodily functions, sense of wellness and functional independence are experienced as essential components of self that will necessarily face challenge with life limiting illness.

Assisted death and voluntary euthanasia allow the individual to take some control of these threats to self, by giving them choice regarding how bearable any challenge may be. This is how “death with dignity” became synonymous with supporters for legalized PAD.

Many of the stories behind those who advocate for legalized assisted death involve a patient/friend/family member who suffered unbearably as they died. The severe neuropathic pain of end stage HIV sufferers in the early days before anti retroviral therapy; the end stage patient in their fifties with metastatic pancreatic cancer and poorly controlled abdominal pain. Counter intuitively, these stories explain partially where antipathy for legalized assisted death comes from within palliative care circles. For a palliative care specialist, these stories both distress and infuriate us. A typical internal reaction would be: “If you had access to good palliative care, your loved one would not be suffering in such a way. They ought not to be dying

⁹⁰ Magnusson RS. The traditional account of ethics and the law at the end of life – and its discontents. *Bioethical Inquiry* 2009; 6:307-324

like that! If people had access to good palliative care, these stories would not exist, and then euthanasia would not be considered necessary.”

The vast majority of patients who have significant physical symptoms due to terminal illness can be managed well, and die comfortably. With or without legalized euthanasia, people should not die with uncontrolled physical symptoms. For those very few who have refractory symptoms, sedative techniques can be used, which have more complex ethical issues for our reflection and discussion (more on this later), but are nevertheless legal and available under current legal and medical structures.

One of the key fellowship messages is that experience of assisted death in legalized countries has shown that it is **not** severe intractable physical suffering that it primarily allays. It is existential suffering, where a small number of people are trying to control for the suffering that comes with dying as a threat to their sense of self.⁹¹ This is particularly prominent where an individual’s sense of self is intimately related to their individual autonomy, capacity for self-determination, and physical independence from others. This type of suffering is also integral to death and dying. In most cases of expected death, dying involves a reduction in autonomy and independence, a decrease in one’s functional capacity and ability to do the usual things of life, and an increasing reliance on others for one’s fundamental care needs. People who access assisted death in these jurisdictions by and large see death as an affront to their essential idea of themselves, as it relates to these values. PAD is thus largely an attempt to access some type of control over the degradation that dying brings to this notion of self. For these people, a ‘good death’ requires some defense against this corruption of self.

Incidentally, this adoption of ‘death with dignity’ by the advocates for assisted death is also a bone of contention within palliative care circles. Surely it is everybody’s goal to facilitate death with dignity? This does not necessarily require access to assisted death practices and euthanasia. The notion of dignity for advocates of legalized assisted death is often one that intimately ties up with individual control and sense of independent self in the modern world. This is not a morally neutral claim. It elevates the values of individual autonomy and functional independence over other notions of human dignity, such as ones that rely on more communal values (e.g. human interdependence, self growth and surrender, relational notions of self, the value of human life per se regardless of extrinsic measures of quality or usefulness etc).

There are many ways to consider human dignity⁹², and this debate is far too complex to be well enunciated here, but it is worth briefly exploring. Take, for example, the important patient driver of functional independence. I understand this value on personal level, but it strikes me that this is very utility-based notion of human or self worth. A person feels that their life is only worthwhile while they can contribute, or at least not hinder others by their need for help or physical dependence. One could argue that in needing help and allowing oneself to be cared for at the end of life, there could be some circularity in a person’s journey of self, rather than presuming a fixed and linear view of personal dignity. There is a significant communal question here too: is there a value in people depending on one another, and relying on one another? After all, this is one of the defining features of community. How important is this to us, in the face of competing values?

⁹¹ Hudson PL, Kristjanson LJ, Ashby M et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. *Palliative Medicine* 2006; 20:693-701

⁹² Cohen-Almagor R. Language and reality at the end of life. *The Journal of Law, Medicine and Ethics* 2000; 28 (3):267-278

The other main argument in favour of legalization is:

3. Harm minimization in that overt life-ending practice is happening in a clandestine fashion as a covert part of medical practice, regardless of its illegality. Restructuring the law to regulate and define acceptable parameters around these practices is seen as a gain in terms of the current 'norm' of frequent "under the table" assisted deaths. This so called 'clandestine euthanasia' is where agreement to facilitate death is hidden and physician specific, as well as unmonitored and potentially done badly in a technical sense.⁹³ There is also clandestine "life ending" actions which are done without the explicit request of the patient. That is, medical interventions which **intend and cause** death, not via respect for autonomy at the express permission of the patient, but based on assessment of "best interests" as defined by doctor +/- next of kin or substitute decision maker.

While this is a very important argument, I think there are some misconceptions I see around this notion of "harm minimization."

a) Issues with the data

In the current best available data, assisted death and euthanasia, along with withdrawal or withholding of life sustaining treatments, lay on the same spectrum of clinical decision-making because they share the common outcome of "hastening death" by intention. These studies provide excellent population wide data, collected at varying intervals longitudinally over the last 13 years, and are therefore very useful in monitoring trends in light of legalization. However, there are a number of methodological limitations worth keeping in mind, mainly related to the fact that the data is captured retrospectively, based on random samples of death certificates, and reliant on physician recollection and self reporting in terms of what they intended to do, as well as their opinion on whether it hastened death.

Apart from the obvious issues with recollection based retrospective data collection, the studies also indicate that many physicians are confused about what they do, and whether they are causing death, thereby potentially biasing the data to reflect these confusions. For example, many of the things we traditionally thought hastened death, such as the proportional titration of opioids to relieve symptoms, are now known to not actually hasten death based on more recent data.^{94 95 96 97} Many doctors, however, still believe that they do, and would therefore report their actions in this way. There are also significant issues with definition, and physician convergence of their actions and intentions, despite good methodological attempts to delineate practice. The data relies heavily on physician knowledge of end of life decision-making and practices, the quality or level of which is variable and often outdated.

The other interesting piece to this for me is that there are these significant numbers of 'clandestine' end-of-life practices reported in the literature,^{98 99} and yet, as a doctor who deals

⁹³ Nuland SB. Physician assisted suicide and euthanasia in practice. *NEJM* 2000; 342:583-584

⁹⁴ Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *The Lancet Oncology* 2003; 4:312-318

⁹⁵ Good PD, Ravenscroft PJ, Cavenagh J. The effects of opioids and sedatives on survival in an Australian inpatient palliative care population. *Internal Medical Journal* 2005; 35: 512-517

⁹⁶ George R, Regnard C. Lethal opioids or dangerous prescribers? *Palliative Medicine* 2007; 21: 77-80

⁹⁷ Philp MR, Poolman M, Martin NP, Makin MK. Opioid use in the last days of life: what is good practice? *European Journal of Palliative Care* 2009; 16(3): 110-115

⁹⁸ Kuhse H, Singer P et al. End of life decisions in Australian medical practice. *Med J Austr* 1997; 166:191-96

only with the dying, I simply do not see these practices in the context of specialist palliative care. In Australia, we do a lot of training to specialize in care of the dying, with a minimum of 7 full time equivalent years of clinical practice training, at least 3 of which purely dealing with patients who are dying. We are thus on par with the UK in terms of specialist training, but arguably receive more training than any of the palliative care trainees in the jurisdictions I visited. One would think that with such high rates of clandestine euthanasia, I would have seen or come in contact with at least one. I can honestly say that I have not, and I am at a loss to understand how this could be so. I can only presume it is related to the fact that the data thus far captures generalist across-the-board medical practices. Perhaps it is not reflective of specialist palliative care practices in Australia, where we can more readily assume that the full spectrum of palliative care capacity is likely to be accessed by the patient. What is the specialist palliative care experience of these issues? We do not know. This is a crucial piece of information for us to understand before we can really appreciate the role of this harm minimization argument. What is the experience and perspective on euthanasia and assisted death in the context of best practice palliative care?

b) Problems with the conceptual framework

As a palliative care specialist and bioethicist, I believe that **intention and causation** of death are **both** relevant issues in this debate.^{100 101 102} That is to say, the medical intervention in question must intend to hasten death, and it must cause death to occur. This medical **agency** is an important ethical piece. Withdrawal or withholding of treatment is action intended to allow death to take place; PAS/VE are causative and intended actions to specifically cause death. In the former, death is happening despite, or at least without, our best efforts; in the latter, death will happen **due to our own agency**, even in the case where it is already happening but more slowly, such as in the case of the terminally ill.

Traditional thinking around this distinction has been blurred due to the belief that some of what we do in end of life care was ethically acceptable even where it was thought to hasten or bring about death, though this was not our primary intention.¹⁰³ For example, the use of opioids with the intention of pain relief was thought to inadvertently but knowingly bring about death by reducing respiratory drive. Ethical thinking thus relied in the past on the notion of 'double effect' to justify treatments that could potentially hasten death.¹⁰⁴ A thorough exploration of this as an ethical issue is beyond the scope of this paper, but essentially the notion of double effect requires **only intention** on behalf of the agent to be morally problematic. It became popular to accept that the moral significance of intention alone was justifiable, in order that we might relieve suffering in a terminal patient, even in the knowledge that our decisions might bring about death 'sooner' than the disease itself.

⁹⁹ Douglas CD, Kerridge IH et al. The intention to hasten death: a survey of attitudes and practices of surgeons in Australia. *MJA* 2001; 175: 511-517

¹⁰⁰ Ashby M. Death causation in palliative medicine. In Freckelton and Mendelson ed. *Causation in law, medicine and science* 2002. Dartmouth publishing, Hampshire England 2002 pp229-249.

¹⁰¹ Ashby M. Of life and death: The Canadian and Australian Senates on Palliative Care and Euthanasia. *Journal of Law and Medicine* 1997; 5:40-51

¹⁰² Hun RW. Intention, the law, and clinical decision-making in terminal care. *MJA* 2001; 175:501-503

¹⁰³ Thomson CJH. '...Death a necessary end, will come when it will come'. *Internal Medical Journal* 2011; 41:439-440

¹⁰⁴ White BP, Willmott L, Ashby M. Palliative care, double effect and the law in Australia. *Internal Medical Journal* 2011: 485-491

It is a small step, therefore, that the question of assisted death is raised. Double effect holds that intention is paramount. If we can knowingly give drugs which hasten death in order to relieve suffering, even where that is not our primary intention, why should we not give drugs specifically intended to hasten death, where again our primary intention is to relieve suffering?

The reality of 'intention' in end of life decision-making is that at times our decisions specifically intend to allow death to happen imminently, rather than prolonging the dying process by ongoing attempts to slow it down. That is to say, sometimes we think that an imminent and rapid death is in the best interests of our patients, and make decisions (with the patient where possible) in accordance with that principle.

The notion of intending to 'hasten death' being the sole ethical predictor can therefore be misleading and confusing in this debate. The truth is that death is not always a "bad" to be avoided at all costs. Eventually, patients start irreversibly dying, regardless of how many interventions are instituted in an attempt to slow death down a little. We can believe that a quick death would be in the best interest of a patient. In some circumstances, we remove treatments that are prolonging the dying process. In others, we choose to forgo life-prolonging treatments, again because they are seen to only prolong the dying process. We may hope that death comes quickly if we perceive that the patient is suffering, because it is our goal to minimize suffering, and therefore make medical decisions in accordance with this. We can also hope that death comes quickly when there is no "good" to be found in prolonging biological life and the patient is understood to be irreversibly dying. Thus, in such circumstances, our goal again is to remove all unnecessary or unwanted impediments to death, in order to allow it to happen as quickly and as smoothly as possible.

Intention is therefore relevant, but not sufficient alone to validate the ethics of PAD. Assisted death and euthanasia also involve agency in causing death. **Both intention and causation are contingent.** This agency is of crucial importance. Condoning or endorsing the deliberate and causative taking of life is a huge moral shift for our society. The communal values at stake are fundamental to our social fabric. Legalisation of PAD condones the deliberate taking of human life in specific circumstances. What circumstances are weighty enough to justify this communal shift? Based on my fellowship experience in other communities, these circumstances are related to the relief of primarily existential suffering of an individual as they face death or a life they feel is not worth living. This existential suffering is bound inextricably to the need for individual control and independence, which is essentially the elevation of individual autonomy as the overriding value of our social structure. The question for us is whether we are that society, and/or whether we want to be that community?

This brings us to the main cons in the legalization debate:

5. Significant moral shift in terms of communal normative value (or interest) in not taking the life of other human beings.

This is not a religious issue regarding sanctity of life, as is often touted in the literature and very commonly held by advocates in the jurisdictions I visited. This is a significant moral shift in terms of communal values in Australia. The current legal norm and societal structure holds life itself as a value of the highest order. It should be actively sacrificed only where there is significant and acceptable pay off to the community at large. Most competing arguments in favour of PAS/VE are based on individual gain; or at least based on society **valuing** individual gain over community. Is this enough for us to trade the communal gains made by valuing life in and of itself? A high level of ethical validation is required to end life, since it is a grave and irreversible act. Significant

thought needs to go into the components of this ethical validation in the debate as it moves forward.

6. Damage to the doctors role and healer, and to the doctor patient relationship

This is a much-touted argument, and one that lies very close to the heart of palliative care doctors in particular. We are already the “death doctors” to our patients, which frequently ties us up with “the enemy” as they fight the progression of their disease. To many, our involvement initially heralds something of fear and destruction: the loss of hope, abandonment by the acute medical system, the increasingly powerful pull toward facing their own mortality. Fear of medications is common, and there is often a long discussion establishing that we are actually involved to help them live well until they die, and it is not our plan to “just drug them up” and leave them to waste away. We spend a lot of time early on in our patient relationships reassuring people that our goals align with theirs, and this usually means maximizing quality of life for as long as possible, and preparing for death. It is an understandable fear that the involvement of palliative care doctors in assisted death practices may make this establishment of trust more difficult in some circumstances.

While I recognize and understand this fear, I do not believe it has been validated by the experiences of doctors and patients in jurisdictions where assisted death is legalized. There has been no erosion of trust, and not one clinician I spoke to felt that it had damaged the trust inherent in the doctor patient relationship. Indeed, the individual cases of physician assisted death tended to arise out of that trust, helping doctors shift their thinking to encompass assisted death, where it may have traditionally conflicted with their sense of moral responsibility. Many opponents to legalization who feared this effect felt that this fear had eased since legalization, and there were many stories of “that one patient” with whom the trust and relationship were strong enough for the clinician to consider assisted death in that particular circumstance, despite their previous opposition. It was highly reassuring when PAS/VE arose out of this trust, rather than externally via a notion of pure patient “right” to access assistance in dying.

It is also important to note that the role of the physician is not just defined by tradition or current fact. It has a normative component. The question is not whether we always have or currently do, but whether we ought to in the future. This a decision to be made by physicians and by the people they care for, and is therefore subject to self-definition as it moves forward within relationship.

7. **Potential risk to vulnerable groups and the slippery slope.** This slippery slope has many incarnations, but essentially it states if PAS/VE is legalized in any society, then the potential exists for:
 - a. Pressure on vulnerable persons;
 - b. Widening of the clinical criteria to include other groups in society;
 - c. An increase in the incidence of non-voluntary and involuntary medicalised ‘killing’;
 - d. Progressive devaluation of life, and for ‘killing’ to become accepted in society;

These complications are possible and potential consequences of crossing the traditional ‘absolute value of life’ frontier. However, to date, data collected in jurisdictions where PAS/VE is legal has not yet demonstrated any validity to these fears. Given the short time span, this data is certainly not conclusive, but important nonetheless. It shows no evidence of a) or c). Some may argue that there has been some evidence of b) in the lowlands of Europe, and d) will only be known with time. Cultural shifts happen slowly, and we may therefore fail to see trends developing until much further down the track.

Nevertheless, it is highly reassuring to review the data and find no evidence of increased risk to vulnerable groups, and no sustained increase in the incidence of life ending medical interventions without the explicit request or consent of the individual patient.¹⁰⁵ There has been some widening of the acceptable clinical criteria to include groups in society who do not have an already terminal diagnosis, particularly in the Netherlands and Belgium. This ‘widening’ is in fact consistent with the original structure and rationale of the legal framework in those countries. That is to say, it prioritizes the relief of suffering rather than the primacy of individual autonomy, and recognizes that suffering is defined primarily by the individual and is therefore not determined by prognosis or diagnosis of life limiting illness. Some members of those communities do not see this “expansion” as the first rung of a slippery slope, but rather an unfolding of the spirit of the law as it applies in a practical sense within the countries cultural landscape. In either case, it is notable, and requires further monitoring and analysis.

8. The nature of suffering, and whether the avoidance of suffering is truly a good.

The notion of ‘unbearable suffering’ is highly problematic, because suffering is essentially an individual’s experience. Some individuals can “bear” more than others, and an amazing number of others actually “bear” much more suffering than they ever believed themselves to be capable of. Sometimes, what individuals perceive as potentially unbearable suffering turns out to be not that bad after all, and sometimes it even turns out to be enriching. I see this every day in my work looking after people who are dying. In light of the high ethical bar required to justify community acceptance of legalized PAD, the question then becomes: what does society require as a minimum defensible level of suffering to justify the legally sanctioned ending of one persons life by the direct and deliberate agency of another member of the community?

Do they have to be dying anyway? If so, why? Terminal illness has a clear line toward suffering, but there are many other arguably unbearable suffering states. What of the weight of severe existential suffering, or the unbearable suffering of a patient with severe mental illness, wholly and consistently refractory to medical treatments? Do we define suffering truly through each individual’s self-suffering assessment, which is the argument often put forward by those who feel that assisted death should be a ‘right’ for patients to access, based on their right to self determination? Arguments for PAD based solely on individual autonomy and relief of suffering as defined by the patient necessarily open the scope of PAD to enable patients without terminal illness to access assistance. It is only social and communal values that limit these individual assessments, and thus must be the primary informant on how we choose to manage this issue going forward.

More controversially, could there be some intrinsic benefit to accepting suffering in some circumstances? Let’s take childbirth as an example. There is significant pain and significant risk to both mother and child associated with vaginal childbirth. Pain is generally considered to be needless suffering. We now have the means to avoid that suffering through the option of epidural pain relief for everyone. For those where pain control is not sufficient to relieve their suffering, particularly suffering related to fear of pelvic floor instability in older age for example, or the very few where epidural pain relief may not work, we have the option of bypassing vaginal birth all together and booking everybody who requests it in for an elective caesarian section. Birth could thus become wholly medicalised; controlled and geared toward minimizing suffering and pain in whatever cause, as defined by the individual. The individual may gain in terms of

¹⁰⁵ Battin MP, van der Heide A, Ganzini L et al. Legal physician assisted dying in Oregon and in the Netherlands: evidence concerning the impact on patients in vulnerable groups. *J Med Ethics* 2007; 33:591-597

measurable suffering, but is this truly a gain? Would something not be lost by this in terms our experience of humanness? Childbirth is very different to death in that the individual also gains through suffering with a 'reward' at the end of the difficult road, whereas the individual in facing death may not. But what of the communal gain? Is that worth at least considering? It is hard to face death; to let go of life; to surrender control; and to experience the intense pain of loss. Is there some intrinsic value in suffering through death for humans?¹⁰⁶ What does it give us? For some: knowledge, depth, understanding; unavoidable challenge of spirit; of 'virtue'; of capacity; of courage in adversity. For others: the loss of a recognizable sense of self, unbearable existential pain, and hopelessness. What is 'worth' preserving on a community level, even at the expense of the individual?

This is a difficult issue, and one with which I am not sure where I stand. In the absence of legalized assisted death, this argument essentially holds that an individual in society must suffer what they as individuals deem to be 'unbearable', for the good of some generalized social value, or some notion of human character that is deemed to be worthwhile. Who is one to enforce another's suffering, where it is in their power to remove it? Nonetheless, I do believe that a community may choose as a collective what is important to value. The issue of immunization is good example of this ethical conflict and is therefore relevant here. The risks and actual complications are borne by each individual, but are sacrificed for the communal good.

¹⁰⁶ Kellehe A. The changing face of dying in Australia. *MJA* 2001; 175: 508-514

6. CONCLUSIONS AND RECOMMENDATIONS

- I am not currently in favour of legalization of PAD in Australia. I believe we need more accurate data, and more rigorous engagement in the ethical issues and values at play as they apply to our community in Australia. These will help inform our decision-making in this very important and fundamental communal decision.

- I cannot yet conclude that PAD is a “good” per se. Aside from the usual criticisms, there is one wholly invalidated, but very poignant issue that plagues me: a fundamental belief that death ought to be somehow part of our sense of self, of our humanness and our understanding of our selves beyond individualism. That the adjustment, acceptance and surrender I see so often as people approach death ought to somehow stay a part of how we chose to experience dying. This surrender does not equate to or result in hopelessness. In fact, it is the hopelessness inherent in euthanasia that I struggle with. The patient feels hopeless for any further goodness to be found in life. The physician feels hopeless for them, in that there are no further interventions that are seen as potentially helpful in relieving their suffering. PAD stems from a mutual acceptance of futility: of life; of medical care; of relationship. There is a certain nihilism that does not ring true to me, undoubtedly related to my work. The whole principle of palliative care is to help people live well until they die. Some people may then respond with: “how can you live well if you are incontinent/exhausted/immobile/demented/paralyzed on one side/deaf and dumb/on painkillers/dying imminently /locked in etc?” The answer is that many people do, a significant number of who truly believed that they could not.¹⁰⁷ Hope is sustained in the palliative setting by shifting the goal posts. Small hopes can be infinitely more powerful than big ones, and sometimes throw the bigger picture into sharper definition. The bigger picture being the one beyond individualism; to family; to community; even to humanness in the broadest sense. Witnessing this is one of the wonderful privileges of end of life medicine.

- While recognizing this personal conflict, I am fully aware that not everyone finds this journey to death expanding or fulfilling. Some people suffer intractably in life, and some in death. PAD may be a necessary ‘sacrifice’ in values that we make in our overriding goal to relieve suffering. This suffering, in the context of PAD, is understood to be primarily existential, and intricately connected to individual autonomy, self-determination and physical independence rather than unrelieved physical suffering in the most part. The decision to value these things over values, such as our interest in not taking life, is a communal one, and not one to be made on the case of an individual preference. It represents a significant social shift in values. What does society require as a minimum defensible level of “suffering” to justify and endorse taking life/causing death?

- There are some legal practices in our society that may not be ‘goods’ per se, but may nevertheless be defensible ethically. Abortion is the example I think here. Few hold that abortion itself is “a good”, but many (including myself) hold that it should be legally available within our society, primarily as a harm minimization tool. I heard this parallel a number of times through my fellowship experience, in terms of the emotional experience of physicians participating in assisted death, and intend to explore it more thoroughly from a philosophical standpoint.

- On a community level, ‘unbearable suffering’ cannot be understood as defined by the individual alone. If the value of human life continues to be an important value to uphold, even in the

¹⁰⁷ Bruno MA, Berheim JL et al. A survey on self assessed well being in a cohort of chronic locked in syndrome patients: a happy majority, miserable minority. *BMJ Open* 2011; doi:10.1136/bmjopen-2010-000039

context of legalized PAD in Australia, then there will need to be some type of gatekeeper system to guard against the expansion of practice beyond community accepted boundaries. The legal system in the USA relied on the diagnosed medical condition and its accurate prognosis to limit the practice, and defined communally accepted 'minimum clinical requirements' to their suffering in order to limit the practice of PAD. In the European low lands, physicians are the gatekeepers, in that they must assess the validity of a patient's claim to intractable and untreatable suffering, and are not required to fulfill a patient's request for VE solely based on the patient's assessment of a life not worth continued living. Doctors are required to assess what suffering is reversible with good "care" (or medical intervention in both the narrow and broad sense). Some would argue that the broadest sense is necessary in this context, such as where a palliative care multidisciplinary team should be required to input into whole person care, in order to fully assess whether the person suffering is truly refractory to 'treatment'. The problem with this model is that it is therefore doctors who have to say, "you are not suffering enough to justify me taking your life." This is highly dependent on each individual doctor's perspective, and raises significant ethical issues in terms of access and justice. Could there be a socially determined definition outlining the 'acceptable parameters' of suffering? If so, is it likely to capture that individual existential piece of suffering that primarily drives the push for legalized PAD?

- Euthanasia is not just about who we are, but arguably also about whom we want to be. In the USA, I repeatedly heard that the community value piece was in fact the driving determination behind legalization. People in the Pacific North west states valued autonomy and control over all other values, and that the primacy of this value led to the legislation in the first place. Further, many people felt the health system was already so fraught with access issues and depersonalization that PAD was about giving a struggling community some sort of control over health decisions at the end of life. Thus, there was an overall individual benefit without perceived significant community cost. Can the same be said for our community in Australia?

- The long-term effect of the communal values shift that is represented by legalizing PAD can only be fully understood over time. This does not mean we balk at any change because we cannot know for sure what effect it will have on our societies. It means we must actively choose our future as a community. What values do we want to espouse and encourage? What values do we believe we should elevate above others?

- In the lowland European countries, euthanasia is by and large a part of the therapeutic relationship between patient and doctor, and thus driven primarily by the relief of suffering rather than the honouring of autonomy. This value taking primacy increases the relative "agency" of the doctor in the act of assisted death, and therefore increases the ethical complexities involved in legislative change. However, there are significant strengths to be found in keeping any notions of assisted death within the complex of relationship and caring for one another.¹⁰⁸ Euthanasia ought not to be seen as a technical procedure in isolation. Death is ultimately more complicated, both for patient and physician, and should be recognized as such.

- A lot of data relies on outdated concepts in the context of developments in palliative care. Most of the broad international studies continue to treat euthanasia as one end of the spectrum of medical decisions and actions that hasten death. There are a few assumptions and misconceptions that fundamentally change the nature of this debate. Namely: 1) The proportional titration of opioids to symptoms in end of life care does not shorten life;^{109 110 111 112}

¹⁰⁸ Wood Mak YY, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliative Medicine* 2005; 19: 343-350

¹⁰⁹ Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *The Lancet Oncology* 2003; 4:312-318

2) Many doctors continue to think it does, and also sometimes converge the notions of 'palliative sedation' with opioid use, which is inaccurate and inappropriate; 3) Most of the data collected around PAD is gathered via physician self reporting, and therefore reflects these misconceptions and biases; 4) There is a significant amount of confusion and inconsistency surrounding the notion of palliative sedation that needs further exploration and investigation. We need a re-evaluation of the data in light of these problems, and then apply these reframed outcomes to the Australian context. We also need better local empirical data on these issues, specifically from within palliative care circles, to ensure we capture experience and perspective where the best available palliative care is being practiced.

- **However**, legalized assisted death not the 'evil incarnate' that it is often painted to be in anti-euthanasia panels and discussions. That is to say, it is not as bad in practice as it may be feared to be in principle. Legalisation enables a small number of individuals to control what they can of their own dying, without necessarily resulting in a slippery slope effect in terms of risk to vulnerable groups, or increased incidence of life ending acts without consent. The potential for a cultural slippery slope cannot yet be seen or measured, but it remains a theoretical possibility that can only be understood over time. This means that the issue of legalizing PAD in and Australian context requires our community to choose what is important for us to elevate among competing values, in order to define our own future going forward.

- There are a number of significant advantages that legalizing PAD may have: 1) given the high rates of reported clandestine PAD, the 'no tolerance' stance is apparently not working well in a generalist sense, and likely putting both patients and doctors at risk; 2) removing assisted death from the criminal arena may help to put death and dying discussions on the table, which in turn could lead to better end of life care for everyone. Legalized PAD may encourage people to engage help from doctors to review their treatment options, and enforce a more thorough assessment of the patients suffering as well as the options available to relieve them; 3) It forces us to crystallize our overriding values in making end of life decisions more broadly.

- There is significant variability around the world in terms of training in specialist palliative care, and there are widely varying practices despite similar terminology. It is also difficult to comment of the comparative quality of palliative care services in each jurisdiction as compared to Australia. Australian palliative care is highly developed, and physicians receive a significant amount of training to specialize in palliative medical practice; proportionally more than in formal training programmes anywhere in Europe or the U.S.A. However, there was a high level of satisfaction for the services available in each jurisdiction according to my interviews, and no evidence in Europe that legalized euthanasia is related to underdevelopment in palliative care services.¹¹³

- While palliative care may currently define itself in direct contradiction to PAD, I do not believe this *has* to be the way going forward. From my fellowship experience, I conclude that even where patients are given access to good palliative care services, they may still experience 'unbearable suffering' in an existential sense, and may therefore want access to assisted death. This does not

¹¹⁰ Good PD, Ravenscroft PJ, Cavenagh J. The effects of opioids and sedatives on survival in an Australian inpatient palliative care population. *Internal Medical Journal* 2005; 35: 512-517

¹¹¹ George R, Regnard C. Lethal opioids or dangerous prescribers? *Palliative Medicine* 2007; 21: 77-80

¹¹² Philp MR, Poolman M, Martin NP, Makin MK. Opioid use in the last days of life: what is good practice? *European Journal of Palliative Care* 2009; 16(3): 110-115

¹¹³ Chambaere K, Centeno C et al. for the European Association for Palliative Care (EAPC). *Palliative Care Development in Countries with a Euthanasia Law: Report for the Commission on Assisted Dying Briefing Papers Submitted October 4th 2011.*

mean palliative care *ought* to provide assistance in death, but my fellowship experience demonstrated that PAD *could* function well within a palliative care framework. This is another area requiring significant further investigation and work.

- It is possible that I have not yet had enough experience in end of life care to meet my “one patient” who changes my perspective on these issues. I met a number of inspiring clinicians and palliative care specialists on my fellowship, whose reflections and perspective have led me to question my own level of expertise and knowledge in this area. Each of these wise and reflective clinicians practiced assisted death and euthanasia in the context of their palliative care practice, encompassing the notion that PAD (for them) is occasionally the best, and perhaps only, available option to care well for the person in front of them. They saw the option of PAD as one means at their disposal to treat suffering in their patients, and achieve a ‘good death’ as defined by the people they cared for. One particularly inspiring interview ended with him reflecting the question back to me: “what do you do for those patients who experience true ‘palliative futility’ and continue to request PAD where PAD is not legal?”

- In Australia, our answer to this question in the context of intractable suffering is palliative sedation.¹¹⁴ The term ‘palliative sedation’ is incorrectly used and inconsistently applied throughout literature, but it refers in this report to the practice of deep sedation at the end of life in order to control refractory symptoms. True palliative sedation is rarely required, and where it *is* required, it is almost always during the last few hours to days of life. Recent evidence suggests that the practice of palliative sedation does not hasten death.¹¹⁵ However, if we sedate someone to the point of unconsciousness for more than 2 weeks in order to manage otherwise intractable suffering/symptoms, we may theoretically hasten death.¹¹⁶ We practice palliative sedation based on the recognition that relief of suffering is our primary responsibility and value. The absolute numbers of those where palliative sedation potentially hastens death are unknown, but on the basis of my palliative care experience, I would wager those numbers are in fact extremely small. I have not seen sedation for more than two weeks in my palliative care practice thus far. Nevertheless, in principle, the issues around palliative sedation are hugely important in our engagement with the PAD debate, our analysis of overriding communal and medical values, and our understanding of physician ‘agency’ in hastening death. I believe this is the true remaining grey zone in palliative care practice that relies on the double effect defense ethically.¹¹⁷ Palliative sedation is therefore an area of important further research and reflection in terms of how it relates to PAD.

¹¹⁴ Kirk TW, Mahon MM. National Hospice and Palliative Care Organization (NHPCO) Position statement and commentary on the use of palliative sedation in terminally ill patients. *Journal of Pain and symptom management* 2010; 39(5):914-922

¹¹⁵ Maltoni M, Pittureri C et al. Palliative Sedation therapy does not hasten death: results from a prospective multicenter study. *Annals of Oncology* 2009; 20:1163-1169

¹¹⁶ Reitens JA, van der Heide A et al. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. *Ann Intern Med* 2004; 141: 178-185

¹¹⁷ Broeckaert B, Leuven KU. Palliative sedation, physician assisted suicide, and euthanasia: “same same, but different”? *The American J Bioethics* 2011; 11(6): 62-64

7. THE WAY FORWARD

In order to address this issue appropriately going forward, we need:

- Data collection which reflects current best practice end-of-life care in Australia
- Revised ethical reflection and analysis of end-of-life decision making
- High-level public debate aimed at raising awareness of the issues, with some communal engagement in the values we would like our society to reflect in the future.

Along with my commitment to engage with the debate wherever possible on a community and policy level, I intend to direct my academic and research skills to add some empiric data and analysis to the pool of already extensive literature to inform the debate as it progresses. The specific questions raised for follow up and investigation from my fellowship experience include:

1. Collection of accurate empirical data in the Australian context surrounding:

- Experience and perspective on this issue from within specialist palliative care groups
- Incidence in Australia for both patient request for PAD, and episodes of patient requested PAD, from within the context of best practice palliative care.
- Incidence of (and rationale behind) life ending acts without explicit patient request, including the capture of significant factors and values leading to these decisions.

2. Revision of the ethical framework that is commonly used currently to understand end of life decision making, particularly:

- Reducing reliance on the principle of double effect.
- Understanding the notion that intention and agency are both contingent in unpacking the ethics of physician assisted death.

3. What are the defining values for us as a community, and how do they weigh against each other in the PAD debate?

4. A comprehensive review and critique of the methodology and data that currently inform this debate, in light of significant developments in our understanding of best practice palliative and end-of-life care.

5. What is valuable on a community or human level in the experience of death, and how does this relate to PAD? Specifically, what defines dignity in death *on a communal level*, and what is the significance of interdependence and human reliance on one another at the end-of-life?

6. What defines gold-standard end-of-life care, and how can it be achieved prior to (or in conjunction with) any notion of legalized PAD?

7. If PAD were legalized in Australia, what would the model look like in an ideal world, as led by the values that guide our decision making as a community?

8. What parallels can be drawn with the issues of abortion and immunization, and how do these help inform our thoughts in the legalization debate?

9. How should PAD interface with palliative care in Australia: incorporate, oppose or take a neutral stance?

10. 'Palliative sedation': definition, incidence, indications, method used, goals identified/intention, efficacy (in achieving stated goal), duration, and any potential relationship with 'hastened death'.

APPENDIX 1

SEMI-STRUCTURED INTERVIEW OUTLINE

Objective: Explore the interface between legalised physician assisted suicide/voluntary euthanasia and palliative care

1. General context and demographics
 - a. Churchill fellowship is essentially an information gathering exercise, understanding how the legislation actually functions within end of life care, and how it interacts with palliative care services
 - b. I have some general questions outlined, but am very happy to for the discussion to take its own course based on your thoughts and expertise.
 - c. Primary outcome is a report to the Churchill Trust and obligation to disseminated the findings to better the Australian community and inform the debate going forward
 - d. With your permission I'd like to record the interview only for my records and reflection. The recording will not be for public access or release
 - e. Let me know if there's any specific part of the conversation you'd like to me to keep completely de-identified or confidential, so I can make sure this is reflected in the final report
 - f. Could we start by just outlining your role, and how you came to be involved in this area of expertise?
 - g. How does the legislation interface with your work? I.e. direct or indirect/frequently or rarely/clinician or researcher
2. Pre legislation perspectives
 - a. POSITION: What was your position/perspective on this issue prior to legalisation?
 - b. VALUES: What were the main values informing or underpinning that perspective? (list if helpful)
 - c. CONCERNS: Did you have any PARTICULAR major concerns or fears about legalisation?
3. Legalisation
 - a. STRENGTHS AND WEAKNESSES: Do you have any comments about the strengths and weaknesses of the legislation itself?
 - b. FUNCTION: On a practical level, how does legalisation function within end of life health care?
 - i. Setting
 - ii. Who initiates
 - iii. Always hospice/pall care as well? If not why not?
 - c. CHANGES OVER TIME: Has the experience of legalisation changed your ideas on primary driving values/ fears we discussed earlier?
 - d. PATIENT DRIVERS: What do you think primarily drives patient requests?
 - e. PHYSICIAN ROLE/RESPONSE: How have clinicians/physicians coped with the introduction of assisted death?
 - i. What effect if any has it had on the physician/patient relationship and/or how doctors are viewed in general?

4. Palliative Care

- a. STRUCTURE AND ACCESS: Could we talk a little about palliative care services in this jurisdiction:
 - i. how is it structured/accessed
 - ii. Is it comprehensive? – Inpatient/consult/community
- b. ROLE PRE: What was the palliative care community's role in the lead up to legalisation?
- c. ROLE POST: What role, if any, does palliative care have in assisted death requests?
- d. EFFECT ON SERVICES: What sort of effect has assisted death had on palliative care services in this jurisdiction?

5. Specific questions arising from interview process

- i. Is this legislation a "good"? All other things being perfect, do you think this is a "good" addition to the social fabric?
- ii. Could you comment on the perception that the practice is 'veiled' or secretive rather than transparent?
- iii. The word dignity has become synonymous with the pro assisted death lobby, Could you comment or reflect on this notion? How is dignity defined? Is the alternative (i.e. best supportive care) a non-dignified option?
- iv. What of the issue of justice in terms of access? Is this a significant problem?
- v. Is anything lost in people not experiencing those last days of life?
- vi. The acceptance of assisted death formalises a positive individual choice that life of a certain quality is not worth living for that individual. Is any alternative assessment of that nature valid? E.g. substitute decision maker such as spouse in the end stage dementia patient or parent in terminally ill child perceived to be suffering
- vii. Could you comment on the concern that legalising this practice might result in insurance companies not funding potentially life-prolonging treatments, or appropriate palliative care/comfort measures based on the financial reality that assisted death is cheaper for the health cost?