

I have right to die! A brief review of the evolution of approaches to patients' requests of hastened death.

Borzooyeh Naji, MD, PhD Student in Cognitive Psychology
Institute for Cognitive Science Studies
Borzooyeh.Naji@Gmail.com

Introduction

Death is one of the concepts that has involved the minds of humans since early ages of civilization. Not only our ancestors, but also our ancient cousins, Neanderthals also had their own primitive death rituals!¹

The fear of a painful death has been always a great concern that led some governors to invent torturous methods of execution as preventive strategy to keep the people obedient since ancient era, e.g. crucifixion², burning³, and breaking wheel.³ By increasing of humanitarian concern after renaissance, avoidance of unnecessary pain during procedure of execution led to invention of novel methods such as guillotine.⁴ But there is still a remained question, if we try to preserve a criminal from an excessive pain, why don't we try to do the same for innocent suffering from painful terminal illnesses? But the truth is that "euthanasia" is a concept many centuries older than renaissance.

Euthanasia that is combined from two originally Greek parts, Eu meaning "good" and Thanatos meaning "death", is the term used for intentional effort to end suffering or pain by induction of death.⁵

During ancient Greece, accelerating the death by prescription of hemlock was practiced and approved by great philosophical influencers such as Plato and Socrates. Stressing on restraint of prescription of deadly drugs or advices that may

cause his death to please someone in worldwide famous Oath of Hippocrates, indicates that debates about moral issues of euthanasia has existed since 4th century before Christ.⁶ Reentry of the concept of “euthanasia” to the modern literature goes back to the 17th century when Francis Bacon wrote his book named “Euthanasia Medica”, and 18th century when this term found its way to *Zedlers Universallexikon*, famous German encyclopedia of the time.⁷

During the past 100 years, Euthanasia slowly appeared more in academic literature. Based on the statistics of PubMed search engine, the first 2 articles belong to 1906, with a slight rise during the first decade after the second world war. Another persistent and more significant rise has happened since 1973, until last three years that the keyword of “Euthanasia” leads to approximately 700 articles per year. (Figure no.1)

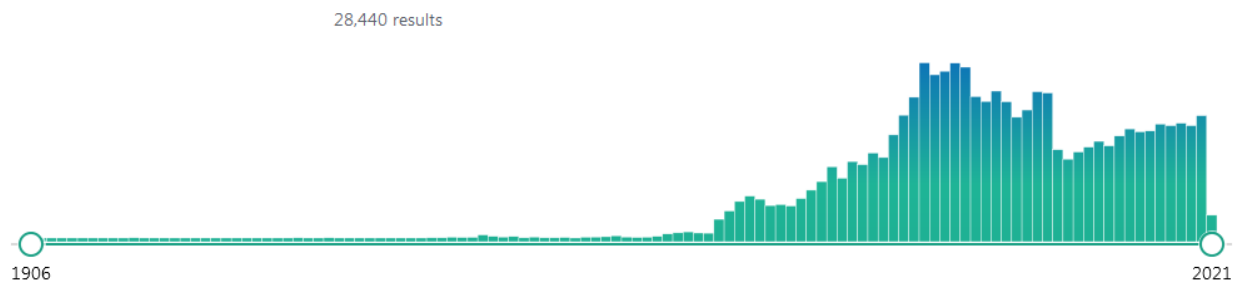


Figure no.1: Growing rate of publications including the keyword of “Euthanasia” according to PubMed search engine

Far from the legal concerns about the accuracy of case selection, clinicians also have their own worries; how can we be sure about the capabilities of applicants for making such a decision? If we consider this act as a humanitarian solution, do we have right to deprive the patient who can't express their desires? Which indicators may prove that such a request is not due to a treatable depression, instead of a reasonable conclusion?

I've made a search in search engines with these keywords: Euthanasia, Decision Making, Decision Making Capacity and Mental Capacity. In the first phase I found 103 articles published since 1988 until 2021. Studying them in order of date will make it possible to follow the trend of changes in legal and clinical aspects, along the time.

Review

In one of the earliest publication about this issue, Gilfix and Raffin made a review on some recent cases of that time about making decision to discontinue extraordinary life support of the patient without consciousness or mentally retarded, and founds the California's legislation of Durable Power of Attorney for Health Care (DPAHC) a great step forward preserving patient's right about terminating his life and physicians from legal liability of their efforts. By such a form, a person indicates who has right to decide for his/her health care issues when he/she is not in a situation to make a decision. By this form, patients may stress on their "right to live", doing whatever to prolong their physiological life, or "right to die", avoidance of extraordinary life support in the lack of hope for recovery.⁸

A solution similar to what mentioned above is also presented by Dennis Brodeur, a hardworking author of articles about medical ethics in 1980s and 1990s. In his article published in 1985, he talks about the policy of discussion about future health care issues including forced feeding with the residents and guiding them to clarify their will when they are competent, in Carmelite Sisters for the Aged and Infirm that is a religious institute for serving the elders.⁹

According to the US laws, the situation could be more complicated. According to The United States District Court District of Colorado, Federal Supplement, in 1987, in the case of a quadri-paralyzed patient who could not speak or swallow and only communicated with moving head and letter board, his doctor and hospital had been sued because of postponing petition for guidance from local court for more than two months since he requested them to remove the feeding gastrostomy tube to accelerate his death. The hospital and doctor challenged that he might have not mental capacity to make refusal decision about his treatment. Whatever the verdict was, the importance of this case is in grabbing attention to this fact that decision making capacity is not always a simple binary situation to be detected easily.¹⁰

Such legal debates that could be found in the Quinn's argument published in 1988 by California Law Review, has always existed in the courts and judiciary systems for decades, but most of all declares the necessity of a well-designed protocol to assess patient's decision making capacity, especially in the cases that are not obviously unconscious but suffer of disorders that may affect mentality.¹¹

Early in 1990s, spotlights turned on a case known as Miss Curzan' case. A 32 years old lady who had passed 7 years in persistent vegetative state after a car accident. It was the first time that a case about "right to die" was presented to a court in the USA, although the first trial did not lead to affirmation of petition. This case was one of the primitive steps toward Patient Self-Determination Act, that provides opportunity for patients to determine their will about their future medical care, including living will and power of attorney. Unfortunately, more details on this issue will take us far from the main topic of this essay.^{12, 13}

Miller and Cugliari published the results of their comprehensive study on long-term care facilities in 1990. One of the important novel issues mentioned in this report was procedure of determination of decision-making capacity among residents.

According to this study, only 12% of these centers have written guidelines for determination of decision-making capacity in 1986, and this ratio had raised up to 48% during just 2 years. This promising growth proves the awareness of this exigency, since 1980s.¹⁴

This recent insight about this necessity evoked new concerns about the accuracy of such standardized and uniformed guidelines to determine patients' decision-making capacity and reflect their wills.^{15 - 17}

These invaluable discussions led to some achievements; as an example, St. Joseph's Hospital and Medical Center in New Jersey established a committee to define an internal institutional policy for approaching to patients' or their surrogates' request of discontinuation of artificially nutrition and hydration, to hasten the death. This committee reached a consensus about ethical, philosophical and medical issues, as a foundation of such a policy. Mitchell from Seton Hall University in New Jersey, admires their efforts and claims that although their policies are not perfect, having an imperfect but certain policy is better than absolute lack of any protocol, that may lead to harassment to patients' rights. Definitely, immature strategies would be the first steps of evolution into the best one.¹⁸

The year 1992 has 2 significant points; firstly, during the first similar legal case out of the USA, Nancy, a young lady in Quebec refused life sustaining treatment, including mechanical ventilation. Quebec Superior Court ruled in favour of her right to decide about receiving or refusing any medical process, due to her intact mental capacity. In a greater step, the court doomed to the permission of ceasing life sustaining treatments in similar conditions.¹⁹

Secondly, again for the first time, this concept was brought up about psychiatric patients. Ganzini et al at Veteran Affairs Medical Center et al. discussed about

challenges around depressed patients' right to benefit of Do-Not-Resuscitate Order. They intelligently proposed that depression may affect the patients' decision-making capacity, while on the other hand, they have right to ask for it, just like any other patient or elder. They believed that psychiatrists can play a critical role to determine patients' mental competence, while their families and family physicians may also aid to clarify their expressed wishes about resuscitation before depressive phase.²⁰

Snyder and Swartz made a practical elicitation based on their comprehensive review of available literature about medical, legal and ethical aspects of termination of life sustaining treatments. They proposed a well sorted assessment guide for physician, that although does not lead to case by case ultimate decisions, provides an efficient framework for evaluation of each instance. This template includes the following steps: 1- Whether it is the case of brain death or not. 2- To determine severity, cause, prognosis and reversibility of the condition. 3- To know the type of treatment that is requested to discontinue. 4- To investigate the futility of therapeutic alternatives and possible interventions. 5- The assessment of patient's capacity for decision making about health care. 6- To gather any evidence indicating patient's own wishes. 7- Participation of family members, surrogate decision makers, and health professionals in the process of decision making. 8- Consideration of available policies, ethical concerns, legislations, and potential conflicts of interest. This conclusive essay that has been published 1993, is important in my review because of its stress on the assessment patient's capacity and its priority.²¹

According to the appearance of concerns about influence of psychiatric disorders on decisions, Sullivan and Youngner in 1994 warned that the trend of psychiatric assumptions to link desires of death to depressive mood, may overwhelm patients' wisely made decision to discontinue life sustaining treatments. The authors challenge that depression's impact on decision making capacity is minimal, and not

comparable with some other disorders such as delirium. The concluded that although it is critical to examine all of the demandant for potential depression and efficiently treat them if needed, his/her desire to die should not get neglected.²²

The year 1997 was an outstanding cut of time in the evolution of approaching request of death. In October 27th 1997, Oregon legalized “Physician-Assisted Death” for the first time, leading to Death With Dignity Act (DWDA).²³

This influential step added the right of requesting physicians to participate in the process of suicide, to previously accepted right to refuse life sustaining treatments. Although appreciations as a further step in respecting patients’ wills, a series of reasonable concerns developed according to ambiguities of this act. This act led to publication of guidelines for the physicians involved in these procedures²⁴, but there are still some hesitancies left. For example, Hendin et al complained that in this act physicians are not required to be trained in palliative care, that is necessary to be able to present all of the available palliative alternatives to the patients. By their opinion, not only most of the physicians are not trained enough in this field, but they do not have needed expertise to investigate patients' decision-making capacity also.²⁵

In the same regard, Drickamer et al argued that legalization of physician-assisted suicide has some prerequisites, including physicians’ capability to detect patients’ motivation, assess their mental status and mood, treat depression if detected, offer all of the available palliative alternatives, and investigate whether there is any external pressure leading them to this decision. The physicians should be able to estimate the possibility of cognitive decline during the course of disease, as well as prognosis of the main condition.²⁶

In 1999, a new quandary came into the literature about capacity of making decision about death: dementia. Derse discussed that not all of the patients affected by dementia lack mental competence for decision making. He believed that some patients, such as the patients who are in early stages of Alzheimer's disease, might have enough capacity to decide about continuation or ceasing life-sustaining treatments by their own.²⁷

These concerns about balancing between patients' right and assortment of mental capacity according to deteriorative nature of dementia has lasted so far.²⁸

In the same regard, Low and Ho mentioned that while the best way to preserve patients' autonomy is to anticipate mental decline when they are still capable to make decisions by their own. If patients reached the intermediate stages without determination of their will for health care issues or surrogate decision maker, it necessitates to pass the following step to assess their mental capacity: Assuring that they understand, register, retain, remember and recall the presented information, compare the risks and benefits of their decisions, and are capable to communicate about their decisions with their medical team. They warn that mental capacity may not be fixed and fluctuate between lucidity and confusion, and the assessor is in charge of accurate determination of patients' capacity. Low and Ho also referred to Jonsen's 4-Topic Approach to Resolving Ethical Dilemmas, which had been used in some hospitals. This framework considers Medical Indication and nature of the disease, patients' own preference according to self-determination right, the impact of disorder of current and future quality of life, and contextual features such as social, cultural, ethnical, religious and legal aspects.²⁹

Mondragon et al, in their article about evolution of Advance Euthanasia Directives and Physician Assisted Death in Mexico, stress on 5 steps proposed to determine decision-making capacity by Moberg and Rick, that will be mentioned separately.³⁰

The same team in their later article clarified the distinction between Capacity and Competence, although they are routinely used instead of each other. They described that “Capacity may be defined as a threshold requirement for a person to make an autonomous decision. While capacity refers to a clinical concept determined by a physician or health professional, competency alludes to the ability of an individual to make decisions and is assessed by a legal professional”, according to Moye et al in 2013.³¹ They warn that clinical judgement about capacity surpass the results derived of Standardized capacity assessment instruments.³² Standardized measures are essential for investigation of competency in elder patients, although there isn’t any instrument as the gold standard yet. Some of the tools that can assess the capacity to consent treatment are “MacArthur Competence Assessment Tool”, “Capacity to Consent to Treatment Instrument”, ”Testamentary Capacity Assessment Tool” and “Testamentary Capacity Instrument”, etc.³³

On the other hand, concerns about the impact of depression and hopelessness on the decisions made about end of life remained constant during the first two decades of the century.^{34, 35}

Two cases reported by Leeman in 1999, have elucidated the importance of getting serious depression among demandants. In one of the cases a patient with the diagnosis of depression by consultant psychiatrist was assisted to die, simply because the consultant did not offer him and his wife a trial for treatment of depression. In the other case, a physically disabled lady who attempted twice to obtain right to refuse her life-sustaining treatment, who had history of depression, did not use her right to die, a phenomenon described as “antidepressant effect of the proven right to die”.³⁶

Recently the topic of euthanasia has expanded to include euthanasia for intellectually disabled and autistic people, and minor with capacity of discernment.^{37, 38}

The increasing request of euthanasia due to suffering from psychiatric disorders has evoked controversial discussion about the equal right for psychiatric patients to benefit from this alternative. But still the critical point that overshadows all of the other aspects, is decision making capacity.^{39, 40}

Juristic and clinical approaches for resolution of this critical ambiguity differed. While legislators were doing their best to accurately define the concepts, clinicians were trying to find the best instruments and guidelines; both influential and invaluable to preserve human's rights to live and to die.

Oregon's legislature, as one of the pioneer states of the US about the legal issues around this topic, defines capable and capacity in as below:

*"Capable" means that in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.*⁴¹

*'Capacity' means an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision.*⁴²

By the way, considering the necessity of applicable instruments, even the lawyers tried to present some candidate as screening tools. For example, Martyn and Bourguignon in their review about legal issues, have suggested Mac Arthur Tool based on trust of Werth, Benjamin, and Farrenkopf, great investigators who have presented the most comprehensive guideline for the assessment of mental capacity in demandants of death so far, and its potency to assess four main domains of capacity including choice, understanding, appreciation, and reasoning. They also reminded the wise warning of Burt and Youngner about dehumanization of the process of evaluation by insertion of instruments.⁴³⁻⁴⁵

Conclusion

The number of countries that legislated euthanasia and physician assisted suicide is growing.⁴⁶ This fact necessitates the existence of standardized protocols, guidelines and instruments. Although the legal and ethical issues differ widely around the world, based on the cultural, religious, and even political contexts, the experiences of the communities that have passed this way earlier would be advantageous.

About the instruments that may be useful in the assessment of decision-making capacity among elders, Moberg et al suggest 3 rating scales in addition to other ways and tools for the evaluation of other aspects of competency. These three tools include: MacArthur Competence Assessment Tool (MacCAT-T), Capacity to Consent to Treatment Instrument (CCTI), And Hopemont Capacity Assessment Interview (HCAI).⁴⁷

The efficiency of Mac Arthur Assessment Tool has been stressed by Werth, Benjamin and Farrenkopf in their well-known article and proposed guideline in 2000. They have properly expressed that the main question in the assessment of

mental capacity of a person is what should be evaluated, and complained that the Legislature and specially the Death with Dignity Act Guidebook did not provide a *substantive direction for how to assess the capacity*. They discuss that according to the law and clinical opinions such an assessment should include these four abilities: to reach and communicate a decision, understand relevant information, apply the given information, and manipulate them rationally, considering the potential depression, effects of medications and mental consequences of the underlying disease. Hence, they have suggested some other instruments in their guideline including Mini-Mental State Examination, Neurobehavioral Cognitive Status Exam, Wechsler Adult Intelligence Scale III, Beck Depression Inventory and/or Hamilton Rating Scale for Depression, Beck Hopelessness Scale, Geriatric Depression Scale (for elders), Brief Psychiatric Rating Scale and Schedule of Attitudes toward Hastened Death.⁴⁸ Their invaluable practical guideline is attached as the Appendix A.

As an end to this essay, the point mentioned in the Belgian guideline created by Gastmans, Van Neste and Schotsmans following a multistep process of review, consultation and brainstorm, is appropriate. According to this guideline, a request for euthanasia is firstly a message from the patient about his/her feelings about the situation that he/she is locked in, pain, deteriorative process, and exhaustion. Hence, such a request is not a trigger to pull, but an opportunity for discussion, and active listening to patient, while assuring that his/her wish is respected and autonomy preserved. It is critical to know patients' motivations; they may simply need more care or feel burdensome on their families. Their mental competence and knowledge about their request and the process of euthanasia, and the palliative alternatives available but not applied yet, should be assessed. How much they overestimate the fearfulness of their prognosis and underestimate their own potency to fight with the

illness. The family members may participate in the discussions, and all of them should know that where they can pose their questions. Eventually if the request persisted, a second independent physician may reassess the whole process as an expert, before performance of the action.

Making the related decision, even for the competent patients, is based on interpersonal negotiations and family members, physician, nurses and other health care team members may participate. This approach is not against patients' autonomy, but to accurate clarification of the inner tenor behind their requests of euthanasia.⁴⁹

This quote by Callahan and White seems to be the best end for this essay:

Thus, the determination of decision-making capacity in this context is inevitably a matter of individual case-by-case evaluation that will vary from physician to physician and patient to patient.... Variable capacity, limited capacity, fluctuating capacity, diminished capacity, and even depression and some forms of mental illness are not presently grounds for the automatic invalidation of a patient's consent to or refusal of treatment, but are left to the discretionary judgment of the treating physicians.⁵⁰

Summary points:

- The patients' autonomous right to refuse life sustaining treatments, and physician assisted death is respected according to Legislature in some countries.
- The number of countries that permit euthanasia is growing. Accordingly sharing the related experiences is worthy and facilitating.
- Although the determination of surrogate decision maker is an appropriate solution for the predicted situations of incapability, still determination of mental competence and decision-making capacity is critical, even for the selection of attorney for health care decisions.
- Request of euthanasia might be derived of other factors such as exhaustion, feeling of being a burdensome, or lack of correct knowledge about available palliative alternatives, etc. rather than inner desire to die. Hence, open discussion about the request, participating members of family and health care team is required.
- Although some standardized scales have been introduced to be applied for the assessment of decision-making capacity in demandants, the eventual opinion about competency should be based on clinical judgement.
 - o Even demented people with mild to moderate severity and intellectually disabled patients could be considered as competent enough for making such a decision, under certain conditions.
 - o Depressive disorders should be considered and treated if detected. Sometimes depressed patient can justify their mood induced wills by apparently rational reasons.

- The best experienced tool in the assessment decision-making capacity and mental competence in related cases is the MacArthur Competence Assessment Tool.
- Altered mental competence might be due to delirious state, medications, or any other transient cause. These temporary conditions should not lead to neglecting patients' will by misdiagnosis of lack of mental capacity.
- Well designed guidelines are available based on the ethical, legal and medical experiences from different communities. They can be used as templates to create domestic guidelines and protocols.
 - The guideline by Werth, Benjamin and Farrenkopf is one of the best instances.

References

1. Richard Gray. Cave fires and rhino skull used in Neanderthal burial rituals. *New Scientist*. 28 September 2016.
2. Byard, Roger W. (March 5, 2016). "Forensic and historical aspects of crucifixion". *Forensic Science, Medicine, and Pathology*. 12 (2): 206–208.
3. Bohnert, Michael (2004). "Morphological Findings in Burned Bodies". *Forensic Pathology Reviews*. 1. Humana Press. pp. 3–27
4. Executive Producer Don Cambou. (2001). *Modern Marvels: Death Devices*. A&E Television Networks.
5. Voluntary Euthanasia (Stanford Encyclopedia of Philosophy). Plato.stanford.edu. Metaphysics Research Lab, Stanford University. 2018. Retrieved 7 May 2019
6. Hippocrates of Cos (1923). "The Oath". *Loeb Classical Library*. 147: 298–299. 1923. Retrieved 6 October 2015.
7. Zedlers Universallexikon, Vol. 08, p. 1150, published 1732–54.
8. Gilfix M, Raffin TA. Withholding or withdrawing extraordinary life support. Optimizing rights and limiting liability. *West J Med*. 1984 Sep;141(3):387-94.
9. D. Brodeur, "Feeding Policy Protects Patients' Rights, Decisions," *Health Progress*. 66 (une 1985): 38-43.
10. U.S. District Court, D. Colorado. *Ross v. Hilltop Rehabilitation Hospital*. *Fed Suppl*. 1987 Dec 31;676:1528-44.
11. Quinn KP. The best interests of incompetent patients: the capacity for interpersonal relationships as a standard for decisionmaking. *Calif Law Rev*. 1988 Jul;76(4):897-937.
12. Lewin T. Nancy Cruzan dies, outlived by a debate over the right to die. *N Y Times Web*. 1990 Dec 27:A1, A15.
13. Kelley K. The Patient Self-Determination Act. A matter of life and death. *Physician Assist*. 1995 Mar;19(3):49, 53-6, 59-60 passim.
14. Miller T, Cugliari AM. Withdrawing and withholding treatment: policies in long-term care facilities. *Gerontologist*. 1990 Aug;30(4):462-8.
15. Wicclair MR. Patient decision-making capacity and risk. *Bioethics*. 1991 Apr;5(2):91-104.
16. Brock DW. Decision making competence and risk. *Bioethics*. 1991 Apr;5(2):105-12.
17. Wicclair MR. A response to Brock and Skene. *Bioethics*. 1991 Apr;5(2):118-22.
18. Mitchell JJ. From ethical dilemma to hospital policy. The withholding or withdrawing of artificially provided nutrition and hydration. *Health Prog*. 1991 Nov;72(9):22-6; discussion 27-30.
19. Canada. Quebec. Superior Court. *Nancy B. v. Hôtel-Dieu de Québec*. *Dom Law Rep*. 1992 Jan 6;86:385-95.
20. Ganzini L, Lee MA, Heintz RT, Bloom JD. Do-not-resuscitate orders for depressed psychiatric inpatients. *Hosp Community Psychiatry*. 1992 Sep;43(9):915-9.

21. Snyder JW, Swartz MS. Deciding to terminate treatment: a practical guide for physicians. *J Crit Care*. 1993 Sep;8(3):177-85.
22. Sullivan MD, Youngner SJ. Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry*. 1994 Jul;151(7):971-8.
23. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon--the first year's experience. *N Engl J Med*. 1999 Feb 18;340(7):577-83.
24. Miles SH. The Oregon Death with Dignity Act: A Guidebook for Health Care Providers, edited by Kathleen Haley and Melinda Lee. *JAMA*. 1998 Jul 22-29;280(4):387-8.
25. Hendin H, Foley K, White M. Physician-assisted suicide: reflections on Oregon's first case. *Issues Law Med*. 1998 Winter;14(3):243-70.
26. Drickamer MA, Lee MA, Ganzini L. Practical issues in physician-assisted suicide. *Ann Intern Med*. 1997 Jan 15;126(2):146-51.
27. Derse AR. Making decisions about life-sustaining medical treatment in patients with dementia. The problem of patient decision-making capacity. *Theor Med Bioeth*. 1999 Jan;20(1):55-67.
28. Cipriani G, Di Fiorino M. Euthanasia and other end of life in patients suffering from dementia. *Leg Med (Tokyo)*. 2019 Sep;40:54-59.
29. Low, J. A., & Ho, E. (2017). Managing Ethical Dilemmas in End-Stage Neurodegenerative Diseases. *Geriatrics (Basel, Switzerland)*, 2(1), 8.
30. Mondragón JD, Salame-Khoury L, Kraus-Weisman AS, De Deyn PP. Bioethical implications of end-of-life decision-making in patients with dementia: a tale of two societies. *Monash Bioeth Rev*. 2020 May;38(1):49-67.
31. Moye, J., Marson, D. C., & Edelstein, B. (2013). Assessment of capacity in an aging society. *The American psychologist*, 68(3), 158–171.
32. Moye J, Marson DC. Assessment of decision-making capacity in older adults: an emerging area of practice and research. *J Gerontol B Psychol Sci Soc Sci*. 2007 Jan;62(1):P3-P11.
33. Mondragón, J. D., Salame, L., Kraus, A., & De Deyn, P. P. (2019). Clinical Considerations in Physician-Assisted Death for Probable Alzheimer's Disease: Decision-Making Capacity, Anosognosia, and Suffering. *Dementia and geriatric cognitive disorders extra*, 9(2), 217–226.
34. Menon AS, Campbell D, Ruskin P, Hebel JR. Depression, hopelessness, and the desire for life-saving treatments among elderly medically ill veterans. *Am J Geriatr Psychiatry*. 2000 Fall;8(4):333-42.
35. Montanari Vergallo G, Gulino M, Bersani G, Rinaldi R. Euthanasia and physician-assisted suicide for patients with depression: thought-provoking remarks. *Riv Psichiatri*. 2020 Mar-Apr;55(2):119-128.
36. Leeman CP. Depression and the right to die. *Gen Hosp Psychiatry*. 1999 Mar-Apr;21(2):112-5.
37. Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine

- relevant euthanasia cases in the Netherlands (2012-2016). *BMC Med Ethics*. 2018 Mar 5;19(1):17.
38. Van Assche K, Raus K, Vanderhaegen B, Sterckx S. 'Capacity for Discernment' and Euthanasia on Minors in Belgium. *Med Law Rev*. 2019 May 1;27(2):242-266.
 39. Nicolini ME, Kim SYH, Churchill ME, Gastmans C. Should euthanasia and assisted suicide for psychiatric disorders be permitted? A systematic review of reasons. *Psychol Med*. 2020 Jun;50(8):1241-1256.
 40. Calati R, Olié E, Dassa D, Gramaglia C, Guillaume S, Madeddu F, Courtet P. Euthanasia and assisted suicide in psychiatric patients: A systematic review of the literature. *J Psychiatr Res*. 2021 Mar;135:153-173.
 41. Or. Rev. Stat. Sec.127.800 (3) (1999).
 42. 1993 Oregon Law Ch. 767 (S.B. 286). Sec. 1 (3) of the Uniform Health-Care Decisions
 43. Misguided Guidelines, 6 *PSYCHOL. PUB. POL'Y & L.* 382 (2000)
 44. Youngner SJ. Bureaucratizing suicide. *Psychol Public Policy Law*. 2000 Jun;6(2):402-7.
 45. Martyn SR, Bourguignon HJ. Physicians' decisions about patient capacity: the Trojan horse of physician-assisted suicide. *Psychol Public Policy Law*. 2000 Jun;6(2):388-401.
 46. James Ashford. *The Week*. Countries where euthanasia is legal Assisted dying is allowed in a growing number of countries - but not the UK. 28 Aug 2019.
 47. Moberg PJ, Rick JH. Decision-making capacity and competency in the elderly: a clinical and neuropsychological perspective. *Neuro Rehabilitation*. 2008;23(5):403-13.
 48. Werth JL, Benjamin GA, Farrenkopf T. Requests for physician-assisted death: guidelines for assessing mental capacity and impaired judgment. *Psychol Public Policy Law*. 2000 Jun;6(2):348-72.
 49. Gastmans C, Van Neste F, Schotsmans P. Facing requests for euthanasia: a clinical practice guideline. *J Med Ethics*. 2004 Apr;30(2):212-7.
 50. Callahan D, White M. The legalization of physician-assisted suicide: creating a regulatory Potemkin village. *Univ Richmond Law Rev*. 1996 Jan;30(1):1-83.

Appendix A:

The Guidelines⁴⁸

1. Review the person's previous and current medical and psychological records with the attending physician and nurses and associated mental health personnel; consult with previous providers.
 - a. Mental health issues would include psychotic symptoms, clinical depression, suicidal behavior, personality disorders, substance abuse, post-traumatic stress disorder (PTSD).
 - b. Medical/mental health issues include organic/cognitive deficits, traumatic head injury history, dementia, delirium, side effects of medications.
 - c. Medical issues include reviewing the diagnosis and prognosis to determine if the requirements of the Act (i.e., the person has been diagnosed as terminally ill with 6 months or less to live) have been satisfied.
 - d. The person's advance directives include a review of the living will, durable power of attorney for health care (if present) — to look for inconsistencies between these documents and the request for assisted death.
 - e. Other treatment options include a review of the extent to which alternatives to the present course of treatment and to assisted death have been discussed and tried by the client; if apparently viable alternatives have not been tried, find out why.

2. Use appropriate objective assessment instruments. For example
 - a. MacArthur Treatment Tool that would also include evaluating the person on all four aspects of capacity: Choice, Understanding, Appreciation, and Reasoning;
 - b. Mini-Mental State Examination;
 - c. Neurobehavioral Cognitive Status Exam;
 - d. WAIS-III;
 - e. Beck Depression Inventory and/or Hamilton Rating Scale for Depression;
 - f. Beck Hopelessness Scale;
 - g. Geriatric Depression Scale, if appropriate;

- h. Brief Psychiatric Rating Scale;
- i. Schedule of Attitudes toward Hastened Death.

3. Conduct a clinical interview including the following components.

a. Understanding of his or her medical situation

Self-report of physical pain—what has been tried to alleviate it

Self-report of suffering

Attitudes toward current and expected situation

Perception of diagnosis and prognosis

Recent changes in functioning

Self-report of emotional, cognitive, and perceptual functioning

Expectations for the future

Experiences with death

b. Ability to give informed consent

Understanding of procedures

Understanding and appreciation of consequences (risk and benefits)— including the possibility of not dying

Understanding of alternatives, including palliative care

Understanding and appreciation of the consequences (risks and benefits) of alternatives

Memory of the discussion

Application of the above information to his or her own situation instead of in the abstract (e.g., use his or her own values and experiences along with his or her actual physical condition and prognosis to come to a decision)

If necessary, inquire about why apparently viable alternatives

have not been tried

Ambivalence or stability in decisions made

c. Perceived quality of life

Pain/comfort/suffering

Physical functioning

Interpersonal functioning

Coping strategies and abilities

d. Stated and implied reasons for requesting physician-assisted death:

Is this a request for help and/or better care or palliative care to relieve suffering or communicating some other concerns?

Is this a request for someone else to decide at the end of life?

Are there relevant cultural, spiritual, or religious issues?

Is there ambiguity, ambivalence, anxiety, depression, hopelessness, helplessness, or rigid thinking that can be addressed and alleviated?

Does she or he have fears of pain, death and dying, or being a burden?

Are there feelings of guilt, self-punishment, or the perceived need for atonement present?

Are there actual or perceived losses she or he has experienced?

If so, how might these be affecting the decision-making?

What is the extent of the person's psychological, physical, social, existential, and spiritual suffering?

Are there concerns about loss of control?

Are there feelings of rage and/or revenge?

What is the extent of personal and social system resources?

Are there financial pressures?

Is the person wanting the medically ill part of the self to die but wanting the healthy part to live on or does the person experience himself or herself as already dead?

e. The decision-making process

How does hastened death fit into the person's value structure?

How long has the desire for assisted death existed and what led to it?

Has the person considered the potential impact on significant others, both living and yet-to-be-born?

Has the person consulted with others (if not, why?), possibly including significant others, family; palliative care specialists/Hospice professionals; disability rights advocates; spiritual advisors; and an attorney (to put affairs in order)?

f. Mental status

Orientation to person, place, and time

Judgment

Verbal reasoning

Delirium

Dementia

Influence of medication

If verbal limitations, can use nonverbal IQ test items

g. The presence of a mood disorder

Differentiate between clinical depression and adjustment disorder

Differentiate between clinically significant symptoms and situationally appropriate sadness

Differentiate between mood disorders and grief/mourning

Assess for bipolar disorder

Assess the impact of despair and guilt

Assess the impact of hopelessness

Assess for the possibility that the person's clinical depression may not make the person incapable

Review the client's fears

Determine if there is PTSD impacting the decision-making

h. General functioning

Life pattern, history

Spiritual, existential, moral value and belief systems

Financial situation and planning

Grief and trauma cycle/process functioning

i. Interpersonal functioning

Coercion by significant others

Pressure from health care system

Undue influence of internalized negative attitudes

j. The presence of internal or external coercion

Is there subtle or overt coercion to hasten death by others?

Is there pressure from society at large (e.g., due to ableism, ageism, elitism, racism, sexism, being uninsured)?

Is the person experiencing internalized stigmata (e.g., selfhatred due to a disability or sexual orientation)?

How might the context in which the assessment is taking place affect the decision and how the person is acting in the evaluation?

4. If possible and consented to by the person, significant others should be consulted about the dying person's perceptions:

Current functioning

Recent changes in physical, mental, or emotional health

Mental health and substance abuse history

Typical pattern of adjusting to loss, change, and illness

Personality style

Reasons for requesting hastened death and their reactions to these reasons

5. Provide a written report for both the attending and consulting physicians.

The report should thoroughly document whether the psychologist or psychiatrist believes the dying person is experiencing one or more conditions that are impairing his or her judgment regarding the decision to request assisted death under the Act. If no impairment is detected, the report should describe the evaluation process and results, highlighting how concerns about the person's judgment and/or the possibility of coercion or undue influence were assessed and eliminated as points of concern, suggesting treatment for conditions that were present but did not impair judgment, and recommending appropriate avenues for helping significant others of the dying person. Other needs detected, but not impairing judgment, should be outlined as necessary, including referrals to spiritual, legal, and other medical specialists.

However, if the evaluator does believe the person has impaired judgment, then the reasons for such a determination, and the process used to detect the condition(s) precipitating the impairment, should be detailed. In addition, a course of action designed to ameliorate or eliminate the influence(s) that are causing the impairment should be thoroughly described. One of the interventions may be individual counseling"; other possibilities include family or group counseling and psychotropic medications. It is recommended that the professional doing the evaluation does not provide the treatment interventions. After the treating clinician believes that the person is no longer experiencing impaired judgment, the dying individual should be referred back to the original psychologist or psychiatrist for a new assessment, if the individual wishes to pursue this course. This process should continue until the evaluator determines that the person requesting assisted death either no longer has impaired judgment or will never be without impairment, rendering the dying person unable to use the Act. In any event, the evaluator should not allow the assisted death to proceed until he or she is convinced that the person is not experiencing impaired judgment.

Appendix B

MacArthur Competence Assessment Tool (MacCAT-T)⁴⁸

The MacCAT-T is perhaps one of the most widely used structured interview scales in the competency literature.

This measure was developed to meet the need for a practical tool that would help obtain and organize information about patients' decision-making abilities. Briefly, the MacCAT-T is a structured interview that takes approximately 15-20 minutes to complete. The core of this test is based on the four areas of decisional capacity related to generally applied legal standards for competence and consent to treatment and research. The four areas assessed include: 1) Understanding relevant information, 2) Appreciation of the implication of the information for one's own situation, 3) Reasoning with the information in a decisional process, and 4) Evidencing a choice. The MacCAT-T interview covers the following specific domains: 1) Understanding of disorder, 2) Appreciation of disorder, 3) Understanding of treatment risks/discomforts, 4) Appreciation of treatment, 5) Alternative treatments, 6) Reasoning, and 7) Expressing a choice. Although a total score is not used, the MacCAT-T does yield four general subscales (i.e., Understanding, Appreciation, Reasoning, Expressing a Choice). The MacCAT-T has been widely used in competence studies in Alzheimer's disease (AD) and has generally been shown to have good predictive validity.