The Ethics of Legalizing Non-Voluntary Euthanasia

Jonas-Sébastien Beaudry[*] **and Anne-Isabelle Cloutier**[**]

Abstract:

This Article serves as a critical introduction to the ethics and law of non-voluntary euthanasia (NVE). It begins by describing the current state of the law and potential arguments to render non-competent patients eligible for NVE. It then surveys the main ethical arguments in favor of and against NVE along four clusters of considerations: suffering, life, vulnerability and justice. This Article also addresses issues that have received less attention within mainstream debates on the topic, namely, policy considerations related to the social dimensions of vulnerability, challenges to moral personhood, and practical barriers to determining the competence of certain patients.

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[*] DPhil, Associate Professor, McGill University.

[**] BCL, JD.

INTRODUCTION

This Article explores the ethical and legal issues raised by non-voluntary euthanasia (NVE). NVE refers to the practice of clinically administering a substance that intentionally causes the death of a legally incompetent patient—that is, a person who is unable to voluntarily request euthanasia or to give (or withhold) informed consent in the end-of-life context.[1]

Depending on the jurisdiction, assisted dying with a clinical component is also called "physician-assisted suicide" (PAS) or "medical assistance in dying" (MAiD). The notion of "assisted suicide" emphasizes the agency of the patient in choosing to end her own life with the aid of a third party.[2] "Euthanasia," meanwhile, refers to the third party act of deliberately ending a patient's life to relieve her suffering.[3] "Medical assistance in dying" seeks to encompass both medically assisted suicide and euthanasia.[4] We have opted for NVE as the term that most accurately describes the patients considered in this article. However, we still use the more general term of MAiD when referring to arguments, scholarship, or laws that apply to assisted dying more generally. Paradigmatic examples of people lacking the capacity to consent to euthanasia because they do not understand the consequence of this choice would be infants, severely intellectually disabled adults, or adults with advanced dementia. The scope of this paper is limited to patients who were never competent, as well as formerly competent patients who left no clear indications of their own end-of-life medical choices.[5]

Outside of Belgium and the Netherlands,[6] NVE has been largely excluded

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[1] JEFF MCMAHAN, THE ETHICS OF KILLING: PROBLEMS AT THE MARGINS OF LIFE 457 (2002) (distinguishing NVE from involuntary euthanasia, as the latter refers to situations "when an individual who is competent to give or withhold consent is killed or allowed to die either contrary to his expressed will or when his consent has not been sought"); PETER SINGER, PRACTICAL ETHICS 179 (2d ed. 1993).

[2] *Final Report of the Expert Panel on MAiD and Mental Illness*, HEALTH CAN. 3 (2022), https://www.canada.ca/content/dam/hc-sc/documents/corporate/about-health-canada/public-engagement/external-advisory-bodies/expert-panel-maid-mental-illness/final-report-expert-panel-maid-mental-illness/final-report-expert-panel-maid-mental-illness.pdf.

[3] *See* Richard J. McMurray et al., *Decisions Near the End of Life*, 267 JAMA 2229, 2229 (1992).

[4] *E.g.*, Loi du 28 mai 2002 relative à l'euthanasie [Euthanasia Act], M.B., June 22, 2002, https://etaamb.openjustice.be/fr/loi-du-28-mai-2002_n2002009590.html; Criminal Code, R.S.C. 1985, c C-241 (Can.).

[5] It excludes patients who left advance directives or for whom previous values and beliefs furnish clear guidance for end-of-life decisions, as well as patients with enough autonomy to express preferences regarding end-of-life decisions. These cases raise additional issues, such as the extent to which one can decide what will happen to one's older self, and how to balance respect for autonomy with other considerations. *See, e.g.*, Ben A. Rich, *Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives*, 6 CAMBRIDGE Q. OF HEALTHCARE ETHICS 138, 138–139 (1997); Stavroula Tsinorema, *The Principle of Autonomy and the Ethics of Advance Directives*, 59 SYNTHESIS PHILOSOPHICA 73, 85–86 (2015).

[6] *See, e.g.*, Marije Brouwer et al., *Should Pediatric Euthanasia Be Legalized?*, 141 PEDIATRICS

from national debates on the legalization of physician-assisted suicide, euthanasia, or medical aid in dying. Judgments rendered on the matter and legislation regulating the practice reflect a belief that the person needs to retain the capacity to autonomously choose to live or die for MAiD to be justifiable. In other words, only competent adults, capable of autonomously requesting physician-assisted suicide and giving free and informed consent to receive it, are eligible.[7]

Although NVE has so far been mostly absent from public policy debates, initiating a conversation on the legalization of NVE is important in anticipation of policy debates that are likely to arise in the not-too-distant future, particularly in jurisdictions where MAiD has already been legalized. Emerging trends in the medical field suggest that substitute decision-makers (SDMs) of incompetent patients who are deemed to be suffering may eventually look to judicial and political institutions to support a right to NVE. SDMs may advocate that continued existence, as lived by their dying or profoundly disabled relatives, is not in these individuals' best interests.[8] For instance, the Canadian Paediatric Society (CPS) reported in 2018 that parents of "never-competent" severely disabled or terminally ill infants and children, "including those too young to make a reasoned decision," are increasingly approaching Canadian health care professionals to discuss MAiD-related issues.[9] Relying on SDMs to decide whether discontinuing life-sustaining treatments is in a patient's best interests creates a decisional protocol that could be transposed to the euthanizing of incompetent patients when it is deemed to be in their best interests. The United Kingdom's Royal College of Paediatric and Child Health's (RCPCH's) clinical and ethical guidelines for deciding on the withdrawing or withholding of life-sustaining care suggest that the child health team must work with parents to determine what is in the child's best interests, and that it may be in the best interests of a child to die "when life is limited in quality."[10] The American Medical Association's (AMA's) opinion on "withhold[ing] or withdraw[ing] life-sustaining interventions" also recognizes the authority of SDMs to decide, within the ethical boundaries of substituted judgement, what the best

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1, 1 (2018).

[7] *Id.*

[8] *See, e.g.*,

[9] *See id.*; *see also* R. v. Cadotte, [2019] QCCS 1987, paras. 5, 9, 13, 33–37, 64 (Can.) (Mr. Cadotte was convicted of manslaughter for suffocating his wife who suffered from advanced early-onset Alzheimers and was permanently in hospital care. Prior to the advanced progression of her disease, his wife had expressed a desire to die rather than be in care,*id.* para. 9, and Mr. Cadotte stated that all he wanted to do was protect her, *id.* para. 64. Although anecdotal and not indicative of a trend, it is reported that Mr. Cadotte had asked his demented wife's healthcare team if they could shorten her suffering by providing her with MAiD. The request was refused because she was not competent and not at a point where her natural death had become reasonably foreseeable. *Id.* paras. 33–37.).

[10] Vic Larcher et al., *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice*, 100 ARCHIVES DISEASE CHILDHOOD s1, s4 (2015).

interests of patients are in end-of-life contexts.[11]

From bioethical and legal stances, arguments in favor of legalizing NVE will likely deploy the same expansionist strategy used to argue in favor of voluntary euthanasia—that is, starting from an existing practice and arguing that logical coherence and concerns of justice require expanding its scope, to treat like cases alike.[12] Once euthanasia is considered a "benefit"—that is, a treatment administered because it is in the patient's best interests—it becomes possible to argue that depriving someone of this benefit is potentially discriminatory.

Such claims could lead jurisdictions where voluntary MAiD is already legal to go beyond the autonomy-based justifications initially put forward to justify the practice. It is therefore important to foster collective reflection on the implications of legalizing NVE, particularly for vulnerable populations. This Article aims to provide a broad and critical survey of the main ethical and legal arguments in favor of and against the practice.

This Article distinguishes itself from existing literature on NVE in its focus and goals. Scholarship on the subject can be described, albeit in a very general way, as belonging to two broad categories.[13] First, there are those texts premised on the "slippery slope" argument, in which scholars debate whether the legalization of voluntary MAiD inevitably leads to the legalization of non-voluntary MAiD.[14]

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[11] CODE OF MEDICAL ETHICS, Op. 5.3 (AM. MED. ASS'N 2001).

[12] This strategy has been used to argue in favor of voluntary euthanasia, by drawing an analogy between this practice and the already accepted practice of withdrawing life-sustaining treatments upon request by the patient. The latter practice was conceptualized as "passive euthanasia" and analogized with "active euthanasia" by arguing that the distinctions between them were not legally or morally relevant. *E.g.*, Michael Tooley, *In Defense of Voluntary Active Euthanasia and Assisted Suicide*, *in* CONTEMPORARY DEBATES IN APPLIED ETHICS 65, 66, 71–80, (Andrew Cohen & Christopher Heath Wellman eds., 2005).

[13] We do not claim to cover the entire literature with this categorization. Rather, the proposed categories reflect general trends identifiable in the literature. However, there are some texts that do not fit in any of the proposed categories.

[14] *See* Michael Stingl, *Voluntary and Non-Voluntary Euthanasia: Is There Really a Slippery Slope?*, *in* THE PRICE OF COMPASSION: ASSISTED SUICIDE AND EUTHANASIA 157 (Michael Stingl ed., 2010) (arguing that the concept of the unbearable suffering of competent patients is a logically clear line that can distinguish voluntary and non-voluntary euthanasia). *See generally* Penney Lewis, *The Empirical Slippery Slope from Voluntary to Non-Voluntary Euthanasia*, 35 J. L. MED. & ETHICS 197 (2007) (discussing the lack of empirical evidence that NVE rates are higher in jurisdictions that legalized VE than those with prohibitions on euthanasia and criticizing slippery-slope arguments as unhelpful to the debate on the legalization of euthanasia generally); Kumar Amarasekara & Mirko Bagaric, *Moving from Voluntary Euthanasia to Non-Voluntary Euthanasia: Equality and Compassion*, 17 RATIO JURIS 398 (2004) (arguing that the legalization of VE is likely to lead to the legalization of NVE and advancing several reasons why NVE is morally impermissible); David Albert Jones, *Is There a Logical Slippery Slope from Voluntary to Non-Voluntary Euthanasia?*, 21 KENNEDY INST. ETHICS J. 379 (2011) (exploring the validity of logical slippery-slope arguments generally before concluding that a refined formulation of a slippery-slope argument that accepting VE implies accepting NVE is logically valid); Robert M. Walker, *Physician-Assisted Suicide: The*

This Article does not intervene in that debate. Instead, we justify our examination of NVE on the basis of the aforementioned possibility that denying euthanasia to people unable to consent to it may be construed as discriminatory, and on evidence from the medical field that SDMs may eventually advocate for the legalization of this practice in jurisdictions where MAiD has already been legalized. The Article does not take a position on whether the SDMs' concerns are the result of a slippery slope related to the legalization of voluntary MAiD. Second, there are texts on the ethics of non-voluntary MAiD that tend to focus on "quality of life" arguments centered on the individual. Some texts address this issue in relation to specific populations, like infants,[15] non-mature children,[16] or mentally ill individuals,[17] while others discuss the subject more broadly.[18] In either case, these articles generally neglect important policy considerations related to vulnerable groups in a society characterized by various forms of oppression. This Article responds to this important omission in the literature on NVE. Finally, we survey a broad array of ethical arguments both for and against legalizing NVE.

Unlike essays that focus on one particular dimension of the goodness/rightness or badness/wrongness of NVE, this Article provides readers with a critical introduction to the ethical landscape that policymakers will have to consider. By targeting an audience of jurists familiar with rights-based claims, we wish to problematize the assumptions that underlie these claims, drawing on philosophical insights.

Legal Slippery Slope, 8 CANCER CONTROL 25 (2001) (surveying pivotal court cases in the US that have defined issues and distinctions in "right-to-die" cases and concluding that the legalization of VE in case law would likely lead to the extension of access to euthanasia to incompetent patients, and therefore NVE).

[15] *See, e.g.*, B.A. Manninen, *A Case for Justified Non-Voluntary Active Euthanasia: Exploring the Ethics of the Groningen Protocol*, 32 J. MED. ETHICS 643, 643–44 (2006); Alexander A. Kon, *Neonatal Euthanasia Is Unsupportable: The Groningen Protocol Should Be Abandoned*, 28 THEORETICAL MED. & BIOETHICS 453, 456–59 (2007).

[16] *See generally* Harprit Kaur Singh, Medical Assistance in Dying (MAID) for Minors in Canada: Considering Children's Voices (Mar. 2018) (M.A. Thesis, McGill University) (ProQuest) (suggesting that the child's voice is a useful tool for assessing unbearable suffering in the context of eligibility for MAiD).

[17] *See generally* Jukka Varelius, *Mental Illness, Lack of Autonomy, and Physician-Assisted Death*, *in* NEW DIRECTIONS IN THE ETHICS OF ASSISTED SUICIDE AND EUTHANASIA 49 (Michael Cholbi & Jukka Varelius eds., 2d ed. 2015) [hereinafter Varelius, *Lack of Autonomy*] (suggesting that the main arguments for physician-assisted death also support physician-assisted death for incompetent psychiatric patients whose illness is incurable and who persistently express the notion that their existence is unbearable); Jukka Varelius, *On the Moral Acceptability of Physician-Assisted Dying for Non-Autonomous Psychiatric Patients*, 30 BIOETHICS 227 (2016) [hereinafter Varelius, *Moral Acceptability*] (arguing restricting physician assisted-suicide to autonomous psychiatric patients on moral grounds is not compatible with the acceptance of end-of-life practices commonly referred to as passive euthanasia for non-autonomous patients).

[18] *See, e.g.*, SINGER, *supra* note 1, at 175–218; MCMAHAN, *supra* note 1, at 424; L.W. SUMNER, PHYSICIAN-ASSISTED DEATH: WHAT EVERYONE NEEDS TO KNOW 157–95 (2017).

We will begin by providing some background on the ethical parameters that structure academic and political discussions of NVE, most notably the principle of respect for autonomy, and the important tensions with this principle raised in the context of NVE. Part 3 examines existing exceptions to the general requirement of autonomy in relation to MAiD. Finally, Parts 4 through 7 move beyond the principle of respect for autonomy in order to grapple with tensions raised in Parts 2 and 3 by examining four clusters of ethically and legally relevant considerations in favor of and against legalizing NVE: suffering, life, vulnerability and justice. Having examined these clusters of ethically and legally relevant considerations, we ultimately conclude that the most persuasive arguments for NVE, those based on beneficence, are insufficient when viewed within a broader liberal conception of commitment to equality and human rights.

While there are different ways of categorizing arguments that justify legalizing MAiD for non-autonomous patients to different extents (or not at all), we suggest that these four concepts encompass all the salient arguments in scholarship on the matter. We prefer to divide arguments thematically instead of by theories of normative ethics (e.g., consequentialism or deontology) or ethical principles (e.g., beneficence or justice) because this approach is more relevant to legal and policy discussions. While this Article provides a comprehensive literature review and takes a critical stand toward the limitations of some mainstream arguments about NVE, it does not flesh out a theory of the permissibility of NVE in ideal or non-ideal circumstances. However, the arguments we present can contribute to the future elaboration of such theoretical proposals. Our critical literature review may notably inform a “principlist” approach, insofar as it holds that the same problem can be looked at through the lens of different ethical principles.[19] It may also inform policymaking considerations, such as the compatibility of legal frameworks with principles found in legal texts, such as human rights conventions.

I. THE ETHICAL PARAMETERS OF NVE

The least controversial reason an individual may choose suicide or euthanasia is that they prefer non-existence over a life of unremitting and severe suffering. Even then, however, individuals will understand and weigh suffering differently in light of not just their immediate pain, but also the values, meanings and roles they ascribe to pain that may annihilate or belittle,[20] all of which requires intensely personal axiological judgments.

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[19] *See e.g.*, TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS (8th ed. 2019).

[20] *See generally* ERIC J. CASSELL, THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE (2d ed. 2004) (detailing Cassell’s seminal conceptualization of suffering).

It is unsurprising, therefore, that judges and legislators in the West have mostly avoided taking a position on the irreducibly controversial question of what makes a life (not) worth living or proposing criteria that the state may use to determine which of its citizens have a life worth living.

Facing unsolvable axiological disagreements, those Western states that have legalized MAiD have largely circumvented such questions by relying on theories of authority instead—that is, by asking *who* should make the decision.[21] Honoring individual autonomy (or dignity, when understood as a state of affairs conditional to autonomy) does not require solving the grave question of when a life is no longer worth living; instead, MAiD legislation carves out a space where individuals may decide this for themselves. From this perspective, the only required procedural protection is to establish that the individuals in question have a sufficient degree of autonomy to make competent decisions. Proponents of this view claim that:

> [a] state may not deny the liberty claimed by the patient-plaintiffs in these cases without providing them an opportunity to demonstrate, in whatever way the state might reasonably think wise and necessary, that the conviction they expressed for an early death is competent, rational, informed, stable and uncoerced.[22]

Several Western legislators have endorsed this view by replacing bans on voluntary MAiD with safeguards meant to ensure that only people able to give free and informed consent to MAiD will access it.[23]

This is not to deny that medical entities have long been in the business of evaluating unavoidably value-laden concepts, like health and quality of life, and of providing guidelines to assess whose life ought to be saved in extreme situations where rationing resources or withholding care becomes necessary.[24] Nonetheless, legislative and judicial bodies that have legalized forms of assisted dying have almost exclusively done so to respect personal autonomy rather than taking a position on the value-laden question of what makes a life worth living.

There are many ways in which policy debates about NVE could go astray. For instance, popular discourses about NVE could pay attention to human suffering,

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[21] In the words of John Arras: "When it comes to matters of life and death, our society prefers procedure to substance. Instead of asking, 'What is the right thing to do?' we ask, 'Who should decide?' Sometimes this preference derives from the sober acknowledgement of a problem's intractability." John D. Arras, *Toward an Ethic of Ambiguity*, 14 HASTINGS CTR. REP. 25, 25 (1984).

[22] Ronald Dworkin et al., *Assisted Suicide: The Philosophers' Brief*, 27 N.Y. REV. BOOKS, Mar. 27, 1997, at 41, 47.

[23] *See, e.g.*, *Canada's Medical Assistance in Dying (MAID) Law*, GOV'T OF CAN. (Mar. 1, 2024), https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html#s2; End of Life Choice Act, 2019 §§ 11–15 (Act No. 67/2019) (N.Z.).

[24] Larcher et al., *supra* note 10, at s4–s5.

but notably through the sentimentalist rhetoric debunked by critiques of the "tragedy model" of disability.[25] This introduction only highlights that a debate on whether the state should legalize NVE cannot proceed by way of simple expansion. It must confront anew all the substantive questions that bioethicists and lawyers have managed to bracket by relying on autonomy (the liberal, proceduralist route). These questions are unfortunately more daunting in the case of incompetent patients because of (i) the epistemic obstacles to knowing how certain people with cognitive impairments experience life and suffering, (ii) their belonging to a historically stigmatized category of people, and (iii) the susceptibility of SDMs to consider factors that are not strictly for the benefit of the persons they represent.

II. EXCEPTIONS TO THE GENERAL REQUIREMENT OF AUTONOMY IN THE CURRENT LAW

A common feature of PAS/MAiD in all jurisdictions where it has been legalized is a requirement for autonomous decision-making. Individuals must retain the capacity to express a voluntary request for MAiD and to consent to it in an informed way.[26] However, although the requirement for autonomous decision-making is the norm, some jurisdictions do permit NVE in specific circumstances. For example, the Netherlands accepts NVE for never-competent severely ill or disabled infants according to the standards set out in the Groningen Protocol.[27] Indeed, some scholars have expressed the concern that NVE may be happening in the Netherlands and in Belgium for patients with psychiatric disorders.[28] This part provides an overview of these instances of NVE[29] both as a experiential foundation

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[25] *See* Jonas-Sébastien Beaudry, *Death as "Benefit" in the Context of Non-Voluntary Euthanasia*, 43 THEORETICAL MED. & BIOETHICS 329, 334, 352 (2022).

[26] *See* Sarah Mroz et al., *Assisted Dying Around the World: A Status Quaestionis*, 10 ANNALS PALLIATIVE MED. 3540, 3540–47 (2021); Trudo Lemmens, *Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice*, 85 SUP. CT. L. REV. 459, 512 (2018) [hereinafter *Charter Scrutiny*]. Note that, with regard to the requirement for capacity in MAiD legislation, Belgium and the Netherlands differ from American states and Canada in that they accept some form of advance request for MAiD.

[27] *See* Eduard Verhagen & Pieter J.J. Sauer, *The Groningen Protocol—Euthanasia in Severely Ill Newborns*, 352 NEW ENG. J. MED. 959, 961 (2005) (describing the Protocol).

[28] *See, e.g.*, Louis Charland, Trudo Lemmens & Kyoko Wada, *Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders*, J. ETHICS MENTAL HEALTH 1, 9 (2016) (citing Scott Y.H. Kim, Raymond G. De Vries & John R. Peteet, *Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014*, 73 JAMA PSYCHIATRY 362, 362–67 (2016)); Lieve Thienpont et al., *Euthanasia Requests, Procedures and Outcomes for 100 Belgian Patients Suffering From Psychiatric Disorders: A Retrospective, Descriptive Study*, 5 BRIT. MED. J. OPEN 1, 2 (2015); Stephan Claes et al., *Euthanasia for Psychiatric Patients: Ethical and Legal Concerns About the Belgian Practice*, 5 BRIT. MED. J. OPEN 1, 1–2 (2015).

[29] Our analysis is focused on systems of Benelux countries for two reasons. First, concerns for nonvoluntary MAiD recently arose from there. Second, Benelux systems are similar to the Canadian

to introduce the ethical and legal concerns implicated by NVE and to ground the practical relevance of our broader consideration of these concerns in the following parts.

A. NVE for Infants in the Netherlands

In 2004, the Groningen Protocol was drafted at the University Hospital of Groningen in collaboration with the district attorney and was published nationwide in 2005.[30] The Dutch Association for Paediatric Care subsequently ratified it. It has been used since as a national guideline for the ethical termination of the lives of severely ill or disabled newborns and for the reporting of physicians' decisions in that regard to authorities.[31] The Protocol is not entrenched in the Dutch legal framework regulating MAiD.[32] As a result, the Protocol does not fully protect physicians from prosecution.[33]

The Protocol provides guidelines for the withholding or withdrawing of life-sustaining treatment and for non-voluntary MAiD. It identifies three groups of newborns: (i) those with no chance of survival, for whom treatment can be withheld or withdrawn;[34] (ii) those "who potentially can survive but whose

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one (although, up to now, Canada has limited MAiD to the end-of-life context). *See* Lemmens, *supra* note 26, at 469.

[30] BRUNO DEBOIS & JACQUES ZEEGERS, EUTHANASIA OF NEWBORNS AND THE GRONINGEN PROTOCOL 3 (European Institute of Bioethics trans., 2015) (2014); Verhagen & Sauer, *supra* note 27, at 961.

[31] DEBOIS & ZEEGERS, *supra* note 30, at 3.

[32] *Id.* However, in 2007, "the Dutch government set up a legal provision that makes it possible for a physician to deliberately end the life of a severely ill newborn without being prosecuted if certain criteria of due care are met. This legal provision has come about in close collaboration with the field of paediatricians and stems from the so-called Groningen protocol." Katja ten Cate et al., *End-of-Life Decisions for Children Under 1 Year of Age in the Netherlands: Decreased Frequency of Administration of Drugs to Deliberately Hasten Death*, 41 J. MED. ETHICS 795, 795 (2015).

[33] *See* DEBOIS & ZEEGERS, *supra* note 30, at 3; SUMNER, *supra* note 18, at 192 ("Following the protocol does not guarantee that the physician will not be prosecuted; however, it was developed on the basis of a survey of twenty-two cases reported to prosecutors over the preceding seven years, in none of which was a prosecution initiated. Needless to say, Dutch criminal law governing non-voluntary euthanasia has not been changed; the protocol relies entirely on the by now familiar device of guidelines for prosecutorial discretion.").

[34] A.A.E. Verhagen & P.J.J. Sauer, *End-of-Life Decisions in Newborns: An Approach from the Netherlands*, 116 PEDIATRICS 736, 736 (2005) ("They are infants with an underlying disease in whom death is inevitable, although in some cases they can be kept alive for a short period of time. Children born with severe lung hypoplasia may serve as an example. In most cases, when the futility of the treatment is apparent, the ventilatory support is removed so that the child can die in the arms of the mother or father"); *see also* Verhagen & Sauer, *supra* note 27, at 959 ("First, there are infants with no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally. These infants have severe underlying disease, such as lung and kidney hypoplasia.").

expected quality of life after the intensive care period is very grim,"[35] for whom treatment can also be withheld or withdrawn if "treatment is not in the best interest of the child";[36] and (iii) those with a "hopeless prognosis"[37] who do not "depend on technology for physiologic stability and whose suffering is severe, sustained, and cannot be alleviated."[38] Infants in this last category can be euthanized when inducing death is deemed more humane than continued existence.[39] According to the two Dutch physicians who developed the Protocol, such end-of-life measures are ethically sound when the following criteria are met: "the parents must agree fully, on the basis of a thorough explanation of the condition and prognosis; a team of physicians, including at least one who is not directly involved in the care of the patient, must agree; and the condition and prognosis must be very well defined."[40] Moreover, after the infant's death, an outside legal body must determine "whether the decision was justified and all necessary procedures have been followed."[41]

Since the Groningen Protocol's publication, the rate of non-voluntary MAiD for infants has been decreasing.[42] This drop in the number of cases is likely related to "both the introduction of legal criteria governing the practice, as well as earlier and improved pre-natal screening."[43]

We introduce the practices of withholding or withdrawing life-sustaining care in this Section because the Groningen Protocol involves such practices alongside

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[35] Verhagen & Sauer, *supra* note 34, at 736 ("Different groups of patients may fall into this category: for instance, infants with severe congenital intracranial abnormalities (eg, holoprosencephaly) or severe acquired neurologic injury (eg, asphyxia or severe intracranial hemorrhages). Children in this category are expected to die when intensive treatment is withdrawn."); *see also* Verhagen & Sauer, *supra* note 27, at 959 ("Infants in the second group have a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim.").

[36] Verhagen & Sauer, *supra* note 34, at 737.

[37] *Id.*

[38] *Id.* at 736–37 ("An example are children who have survived thanks to advanced technology but for whom it becomes clear after completion of intensive treatment that life will be full of suffering without any hope of improvement. In retrospect, one might not have wanted to start treatment for these children if the outcome had been known. Another example are children with serious congenital malformations or diseases that cannot be treated, and as a result of (complications of) this condition, the child will lead a life of sustained suffering that cannot be alleviated (eg, epidermolysis bullosa, type Hallopeau-Siemens). Also in this group are children from group 2 that were expected to die after the intensive care treatment was withdrawn but remained alive with severe suffering.").

[39] Verhagen & Sauer, *supra* note 27, at 960.

[40] *Id.*

[41] *Id.*

[42] ten Cate et al., *supra* note 32, at 796.

[43] *The State of Knowledge on Medical Assistance in Dying for Mature Minors: The Expert Panel Working Group on MAID for Mature Minors*, COUNCIL OF CANADIAN ACADS. 112 (2018) [hereinafter *The State of Knowledge on Medical Assistance in Dying for Mature Minors*] (citing ten Cate et al., *supra* note 32, at 796), https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-for-Mature-Minors.pdf.

the practice of active euthanasia. Withholding or withdrawing treatments in a way that passively terminates an infant's life are legal practices in Europe and the United States for children with very poor prognostics falling within Group 1 or 2.[44] However, infants may not die immediately, especially those belonging to Groups 2 or 3. Only in the Netherlands could doctors legally hasten their death through euthanasia.[45] The Groningen Protocol illustrates the conceptual and circumstantial proximity between so-called "passive" and "active" euthanasia. Some of the arguments we consider could apply equally in favor of or against both "passive" and "active" terminations of life, but the two practices are factually and legally different, and the question of whether and to what extent they are morally different is a controversial topic in bioethics. Given the focus of this Article on NVE, which is active euthanasia, we will not discuss of the similarities and differences between active and passive euthanasia.

B. (Non)Voluntary Euthanasia for Mental Health Patients in the Netherlands and in Belgium

Trudo Lemmens suggests that NVE for mental health patients may already be happening in the Netherlands and Belgium under the guise of voluntary euthanasia.[46] His concerns are based on a detailed analysis of two recent Belgian[47] and Dutch[48] studies, which raise concerns regarding diligent respect of the capacity assessment requirement.[49] While the Belgian study barely discusses the issue of

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[44] Hilde Lindemann & Marian Verkerk, *Ending the Life of a Newborn: The Groningen Protocol,* 38 HASTINGS CTR. REP. 42, 43–44 (2008); Verhagen & Sauer, *supra* note 27, at 960.

[45] *See The State of Knowledge on Medical Assistance in Dying for Mature Minors*, *supra* note 43, at 111–13. "The Netherlands and Belgium are currently the only two jurisdictions where euthanasia and assisted suicide (EAS) is permitted for minors." *Id. at* 111. In Belgium, "[r]epeated requests must come directly from the patient who must exhibit the capacity to fully understand their request and its consequences," *id.* at 113, meaning infants, who necessarily lack capacity, are excluded from eligibility.

[46] Trudo Lemmens, *The Conflict Between Open-Ended Access to Physician-Assisted Dying and the Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime for the Canadian Post-*Carter *Era*, *in* LES GRANDS CONFLITS EN DROIT DE LA SANTÉ 261, 299–302 (Catherine Régis, Lara Khoury & Robert P. Kouri eds., 2016). Lemmens raises concerns about the Belgian study's classification of all patients who received MAiD as competent, "without further discussion of the inherent challenges in determining competency to request aid in dying" in mental health patients. *Id.* at 300. Lemmens also notes that the Dutch study by Kim, De Vries & Peteet confirms the concerns relating to competency assessments of psychiatry patients. *Id.* at 299 n.97.. If competency cannot be or was not correctly assessed and established, there is a serious risk that NVE has necessarily occurred.

[47] *See generally* Thienpont et al., *supra* note 28 (surveying a group of 100 outpatients who requested euthanasia for reasons related to mental health).

[48] *See generally* Kim, De Vries & Peteet, *supra* note 28 (surveying reports of psychiatric euthanasia and assisted suicide cases occurring between 2001 and 2014).

[49] *See* Lemmens, *supra* note 46, at 299–302; Lemmens, *supra* note 26, at 488–92, 511–18;

capacity assessment and does not acknowledge its inherent complexity and variability with mental health patients,[50] the Dutch study identifies alarming features of the practice, such as "relatively frequent disagreement among evaluating physicians with respect to the capacity of patients asking for euthanasia and the irremediable nature of the condition,"[51] "lack of details in the case reports about how capacity was assessed,"[52] no independent psychiatric review of the capacity assessment,[53] and excessive deference to physicians' judgment calls on the part of authorities charged with reviewing their decisions.[54]

Such trivialization of capacity assessments for patients whose capacity to choose death is often not clear-cut prompts Lemmens to doubt the voluntariness of all euthanasia of mentally ill patients in these countries. This fear seems to be reasonably well-founded, particularly when one considers that psychiatrists—the physicians arguably best trained in capacity assessments—often have a low estimation of their own ability to conduct such assessments.[55] Although highly subjective and variable, the "current standard of care in the area is still the individual clinical judgment of the attending physician."[56] This is the case even though physicians often "lack a good grasp of the concept and often have limited appreciation of the inherent difficulties in capacity assessment."[57] This fear is all the more reasonable when one considers the extent of the subjectivity and variability of capacity assessments in the context of MAiD for mental health patients expressing a desire to die. Indeed, Linda Ganzini and her colleagues have documented how the beliefs and values of the health care professionals in charge of assessing capacity influence their findings in the context of MAiD.[58] The ones who "are firmly committed to MAiD are more likely to judge that patients have

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Charland, Lemmens & Wada, *supra* note 28, at 9.

[50] *See* Thienpont et al., *supra* note 28, 2, 4–5; Charland, Lemmens & Wada, *supra* note 28, at 9. For other authors who consider these findings alarming, see Claes et al., *supra* note 28, at 1–2. For a response to Claes et al., see generally Lieve Thienpont & Monica Verhofstadt, *A Commentary on "Euthanasia for Psychiatric Patients: Ethical and Legal Concerns about the Belgian Practice" from Claes et al.*, 5 BRIT. MED. J. OPEN (2016) (responding to four points raised by Claes et al. about the number of verifications performed by a single psychiatrist, the 38 euthanasia requests that were withdrawn, the notion of mental health issues as a transient state, and the vagueness of the term "unbearable suffering").

[51] Lemmens, *Charter Scrutiny*, *supra* note 26, at 491–92 (citing Kim, De Vries & Peteet, *supra* note 28).

[52] *Id.*

[53] Charland, Lemmens & Wada, *supra* note 28, at 9 (citing Kim, De Vries & Peteet, *supra* note 28).

[54] *Id.*

[55] Lemmens, *Charter Scrutiny*, *supra* note 26, at 516.

[56] Charland, Lemmens & Wada, *supra* note 28, at 4.

[57] Lemmens, *Charter Scrutiny*, *supra* note 26, at 516.

[58] Linda Ganzini et al., *Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists*, 157 AM. J. PSYCHIATRY 595, 600 (2000).

capacity to opt for MAiD, even when they suffer from depression and other mental health conditions."[59]

The concerns raised in relation to the trivialization of capacity assessments, the impact of medical provider's pre-existing beliefs, as well as the conceptual and circumstantial overlap between passive and active euthanasia demonstrated in NVE of infants are issues that will continue to arise in the context of expanded MAiD in other jurisdictions. They will also re-emerge as we move into discussing the four conceptual clusters of legal and ethical concerns in relation to NVE in the following four parts.

III. THE MORAL IMPORTANCE OF SUFFERING AS GROUNDS FOR LEGALIZING NVE

This Part examines ethical arguments in favor of and against legalizing NVE on the basis of beneficence. First, the main points of the argument from beneficence will be summarized within the context of non-voluntary MAiD. Next, two categories of objections to the argument from beneficence, principled and circumstantial, will be discussed. Finally, we conclude that while a defeasible duty of beneficence to sometimes provide NVE exists, it can never obtain in practice for several reasons, including epistemic barriers to adequately assessing unbearable suffering and the risks that operationalizing NVE will lead to its overapplication.

A. The Argument From Beneficence in Favor of Non-Voluntary MAiD

The conception of the value of life most often associated with a defense of non-voluntary MAiD holds that quality of life should be valued above quantity,[60] a position best captured by the notions of "quality of life" and "quality adjusted life years."[61] This view makes room for the possibility of a life having a negative value, i.e., being worse than death. The more negatively valued a life is, the stronger the justification for ending it.[62]

Arguments supporting the credibility of NVE on the basis of beneficence have

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[59] Lemmens, *Charter Scrutiny*, *supra* note 26, at 516 (citing Ganzini et al., *supra* note 58, at 600).

[60] We explore how the value of life is perceived through different ethical paradigms in the next Part. However, it is necessary to present one of these views here, since it underlies arguments about NVE based on beneficence.

[61] John Harris, *QALYfying the Value of Life*, 13 J. MED. ETHICS 117, 117–18 (1987).

[62] *Id.* at 117 ("The essence of a QALY is that it takes a year of healthy life expectancy to be worth one, but regards a year of unhealthy life expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the 'quality adjusted' bit is all about). If being dead is worth zero, it is, in principle, possible for a QALY to be negative, i.e. for the quality of someone's life to be judged worse than being dead.").

focused on the importance of pain or suffering. It could seem vicious, wrong, and unfair to deprive non-competent people of a humane end to their suffering. Some therefore argue that non-voluntary MAiD should be legalized for incompetent patients because their suffering is as deserving of compassion as the suffering of competent persons.[63] It follows from the equal moral significance of their suffering that they are equally owed support in actively hastening a death considered to be in their own best interests.

This position relies on the fact that it seems "counter-intuitive" to consider grave suffering to be of less importance simply because it is experienced by incompetent patients, like older adults with dementia, young children, or schizophrenics in the grip of delusions and hallucinations.[64] We must recognize that incompetent patients can suffer as horribly and sometimes "far more horribly than anyone who accepts voluntary euthanasia."[65] Further, the fact that incompetent patients' distress can result from an irrational understanding of reality does not alter the equal moral significance that should be given to their suffering. Indeed, it is precisely because some incompetent patients lack insight into their illness that they suffer intolerably. It is impossible for such people "to step back from the suffering and the reality filled with it."[66] Their distress is at least as significant as that of competent individuals. Just like competent individuals can have no control over their intolerable and enduring physical and/or psychological suffering, incompetent patients too have no power over their intolerable and enduring mental suffering.[67]

From this perspective, although MAiD has been traditionally justified in the name of autonomy and well-being through the relief of intolerable and enduring suffering,[68] the administration of a substance intentionally hastening death can be justified in the absence of autonomous decision-making.[69] In such circumstances,

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[63] *See, e.g.*, Singh, *supra* note 16, at 32; Varelius, *Lack of Autonomy*, *supra* note 17, at 63–64; Varelius, *Moral Acceptability*, *supra* note 17, at 231–32; Bryson Brown, *Robert Latimer's Choice*, *in* THE PRICE OF COMPASSION: ASSISTED SUICIDE AND EUTHANASIA 161, 161–82 (Michael Stingl ed., 2010); NORMAN CANTOR, MAKING MEDICAL DECISIONS FOR THE PROFOUNDLY MENTALLY DISABLED 106 (2005); Len Doyal, *The Futility of Opposing the Legalisation of Non-Voluntary and Voluntary Euthanasia*, *in* FIRST DO NO HARM: LAW, ETHICS, AND HEALTHCARE 461, 473–75 (Sheila McLean ed., 2006); *see also* Amarasekara & Bagaric, *supra* note 14, at 405 (predicting that certain groups will argue that NVE should be legalized for incompetent patients because their suffering is as deserving of compassion as the suffering of competent persons).

[64] *See, e.g.*, Varelius, *Lack of Autonomy*, *supra* note 17, at 63; Singh, *supra* note 16, at 31–32.

[65] Brown, *supra* note 63, at 182.

[66] Varelius, *Moral Acceptability*, *supra* note 17, at 232 (applying *mutatis mutandis* to all incompetent patients with irrational suffering).

[67] *Id.* at 231–32.

[68] *See* SUMNER, *supra* note 18, at 38–42; Varelius, *Lack of Autonomy*, *supra* note 17, at 61.

[69] *Contra* Cees M.P.M. Hertogh, *Unbearable Suffering and Advanced Dementia: The Moral Problems of Advance Directives for Euthanasia, in* PHYSICIAN-ASSISTED DEATH IN PERSPECTIVE: ASSESSING THE DUTCH EXPERIENCE 215, 224–25 (Stuart J. Younger & Gerrit K. Kimsma eds., 2012)

a duty of beneficence is the only justification for MAiD. Beneficence connotes "acts of mercy" and requires, in the health care context, actions done to benefit others. This means actions undertaken to "produce a positive balance of goods over inflicted harms."[70] It involves the minimization or suppression of existing harms in order to favor goods or benefits.[71] Incompetent patients who cannot "exercise autonomy have a right to beneficence from those entrusted to decide on their behalf."[72] In the context of MAiD, beneficence would therefore require health care professionals to alleviate the enduring and intolerable suffering of their incompetent patients. The assumption at work in this argument is that there are circumstances where "a person's suffering can be so severe and unremitting that it outweighs the benefits—the pleasures and satisfactions—of further existence."[73] When other reasonable means of relieving suffering are not available or successful, administering a substance causing death can be an appropriate way to alleviate a nonautonomous patient's suffering.[74]

B. Principled Objections to NVE on the Basis of Beneficence

Arguments against legalizing NVE may deny that there is a defensible duty of beneficence to actively end a life that is worse than death. For instance, one may argue that killing someone who is unable to express a desire to die can never count as a benefit to that person. We can call these kinds of objections *principled* (or radical) because they disallow the euthanasia of non-competent people in all cases for reasons that attack some fundamental premises underlying the permissibility of non-voluntary MAiD. Alternatively, arguments against legalizing NVE may concede that NVE is not inherently unjustifiable, but instead propose a number of reasons to override a duty to end life. We can call these *circumstantial* objections. In the case where X is non-autonomous, these reasons generally relate to epistemic

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(arguing that beneficence and mercifulness cannot exist without responsive receptiveness of a competent individual). "Put metaphorically, the Samaritan can only be helpful if the wounded and robbed traveler to Jericho is ready to accept his assistance, not if the traveler rejects him, feels threatened by him, or does not understand him. Only the responsiveness of the other makes the Samaritan into a merciful giver, and this responsiveness cannot be replaced by a distant request on a piece of paper. What this assistance wants is consenting reciprocity at the moment it is given." *Id.*

[70] Tom Beauchamp, *The Principle of Beneficence in Applied Ethics*, STAN. ENCYC. PHIL. (Feb. 11, 2019), https://plato.stanford.edu/entries/principle-beneficence.

[71] *Id.*

[72] Rebecca Dresser, *Dworkin on Dementia: Elegant Theory, Questionable Policy*, 25 HASTINGS CTR. REP. 32, 32–33 (1995).

[73] CANTOR, *supra* note 63, at 106.

[74] *See, e.g.*, Singh, *supra* note 16, at 28; Brown, *supra* note 63, at 176; Varelius *Lack of Autonomy*, *supra* note 17, at 60, 63–64; Varelius, *Moral Acceptability*, *supra* note 17, at 232–33. *Contra* Francesca Giglio & Antonio G. Spagnolo, *Pediatric Euthanasia in Belgium: Some Ethical Considerations*, 12 J. MED. & PERSON 146 (2014)(arguing that to consider death beneficial is perverse, because without life, it is impossible to enjoy any benefit).

difficulties, that is, difficulties that relate to the nature of knowledge and limits related to its acquisition. These difficulties have two main sources: 1) inherent difficulties in assessing pain and suffering in other people, amplified by cognitive differences in the case of non-autonomous persons, and 2) conscious or unconscious considerations motivated by irrelevant interests or prejudices. We assess the plausibility of such principled and circumstantial objections in the next subsections.

1. Euthanasia Does Not Eliminate Suffering

Some critics of euthanasia have pointed out that to end a person's life does not, strictly speaking, "relieve" or "diminish" their suffering: rather, it eliminates the sufferer.[75] From this perspective, the practice may still appeal to a consequentialist because there would be less "units" of suffering remaining in the world. It might, by contrast, be less appealing to other ethicists keen to act benevolently, but who conceptualize the value of an action eliminating or diminishing suffering as being dependent upon the value of the person whom the said action benefits—in this case, no one.

According to this critique, in order for the beneficence argument to make sense, it must assume that, though there will be no one to benefit post-mortem, the living individual ultimately benefits from ceasing to exist. The rationality of a beneficence-based choice to euthanize would not be based on comparing the individual in question's state of being sick and alive, on the one hand, or dead, on the other. Instead, it would be based on a comparison between the suffering individual having "a shorter life, whose duration is truncated by suicide [euthanasia], versus the longer life an individual would be most likely to have if they forego suicide [NVE does not occur]."[76]

2. Certain Incompetent Patients Cannot Suffer

Another principled objection against euthanizing incompetent patients in order to make their suffering stop is that they cannot suffer. Some critics of the Groningen Protocol made this point by referring to the nature of "quality of life" and "suffering." Regarding "quality of life," which they define as the satisfaction one gains from "engag[ing] in life tasks," they observe that incompetent patients such as infants would not have the "cognitive and physical capacity to identify and engage in life tasks and to develop values on the basis of which they can determine

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[75] *See* Scott Kim, *Lives Not Worth Living in Modern Euthanasia Regimes*, 16 J. POL'Y & PRAC. INTELL. DISABILITIES 134, 135 (2019); Brouwer et al., *supra* note 6, at 2.

[76] Michael Cholbi, *Suicide*, STAN. ENCYC. PHIL. (Nov. 9, 2021) § 3.7, https://plato.stanford.edu/entries/suicide.

whether those life tasks are satisfying."[77] With respect to suffering, they define it as "a complex psychosocial phenomenon in which an individual experiences the loss, to different degrees, of the ability to realize intentions, desires, and hopes for the future."[78] In contrast, pain would be "a physiologic phenomenon: the awareness of reports of tissue damage or threat of tissue damage in the central nervous system."[79] It follows that some incompetent patients cannot "suffer" or experience a poor "quality of life," at least as those terms are commonly understood, even if they can literally perceive pain.

While this objection may justify the conclusion that some people cannot experience certain kinds of suffering, it neither negates nor confirms the view that NVE should be legalized. Whether we qualify their experiences as ones of "pain," "physical suffering" or "suffering," incompetent patients can experience a painful, negative state of affairs that is real. To justify the denial of relief on these grounds risks not only over-intellectualizing the concept of suffering, but also misrepresenting what suffering/pain and death mean to non-competent people experientially, if not intellectually. Even if one believes, like Cassell, that young infants or profoundly demented adults lack the capacities required for personhood and suffering, one should not deny that they can be in terrible pain and that this pain calls for relief.[80] However, the fact that non-competent patients can experience a pain that ought to be alleviated does not tell us whether this relief should take the form of pain-management care or euthanasia.

3. *The Extent of Incompetent Patients' Suffering is Unknowable*

A similar radical objection to legalizing non-voluntary MAiD on grounds of beneficence is based on the notions of pain and suffering and their ineliminable subjectivity.

Numerous scholars highlight that assessments of another person's suffering and quality of life are deeply subjective.[81] In this regard, the Canadian Society of

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77 Frank A. Chervenak et al., *Why the Groningen Protocol Should Be Rejected,* 36 HASTINGS CTR. REP. 30, 30–31 (2006).

[80] *Id.* at 31.

79 *Id.* at 30–31.

80 ERIC J. CASSELL, THE NATURE OF HEALING: THE MODERN PRACTICE OF MEDICINE 221 (2012).

81 *See, e.g., The State of Knowledge on Advance Requests for Medical Assistance in Dying: The Expert Panel Working Group on Advance Requests for MAID*, COUNCIL OF CANADIAN ACADS. 72 (2018) [hereinafter *The State of Knowledge on Advance Requests for Medical Assistance in Dying*], https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf; Chervenak et al., *supra* note 77, at 31; Chris Gastmans & Jan De Lepeleire, *Living to the Bitter End? A Personalist Approach to Euthanasia in Persons with Severe Dementia*, 24 BIOETHICS 78, 82 (2010); CANTOR, *supra* note 63, at 106; Singh, *supra* note 16, at 21; Julian Savulescu, *Autonomy, Interests, Justice and Active Medical Euthanasia*, *in* NEW DIRECTIONS IN THE ETHICS OF ASSISTED SUICIDE AND EUTHANASIA 31, 40–42 (Michael Cholbi & Jukka Varelius

Palliative Care Physicians declared that "we have no objective means of confirming whether an incapable person's suffering is 'intolerable' to the point that he or she would want MAiD."[82] This subjectivity is accentuated by common communication issues with incompetent patients in the end-of-life context. For example, dementia patients gradually lose the ability to communicate their suffering to their physician as their condition worsens. Once in an advanced stage of dementia, while "there will sometimes be very reliable evidence of physical pain,"[83] it is not possible to know with certainty whether the person is experiencing intolerable suffering.[84] Similar concerns have been raised with never-competent minors: there will always be some "ambiguity or uncertainty in the understanding of a child's suffering experience through their voice."[85] This objection may be buttressed by distinguishing pain from suffering, as we noted in the previous Section, since suffering can be understood as even more unavoidably subjective than pain.[86]

The point here is not that incompetent patients cannot suffer, but rather, that their pain/suffering is unknowable without the subjective input of another party. A way to go about overcoming this barrier would be to develop technologies[87] capable of detecting the kind of pain that would produce a relatively constant desire for suicide in unavoidably suffering patients. However, this option may not be viable in the short-term, and the utility of such tools may ultimately be limited. This is because such technology would not only have to indicate that a non-competent patient's brain is registering "pain" (e.g., an experience of tissue-damaging stimuli) but also be able to convey how this awareness is subjectively experienced qua pain/suffering. Since not all patients experiencing extreme suffering—even tremendous, unending suffering—want to die, the technology

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eds., 2015).

[82] *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 145.

[83] Jocelyn Downie & Georgia Lloyd-Smith, *Assisted Dying for Individuals with Dementia: Challenges for Translating Ethical Positions into Law*, *in* NEW DIRECTIONS IN THE ETHICS OF ASSISTED SUICIDE AND EUTHANASIA 97, 115 (Michael Cholbi & Jukka Varelius eds., 2015).

[84] *Id.* at 106, 115.

[85] Singh, *supra* note 16, at 68.

[86] Chervenak et al., *supra* note 77, at 31; *see also* Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, 306 NEW ENG. J. MED. 639, 639 (1982) (defining suffering as a threat to the "intactness of the person as a complex social and psychological entity"). Some also define pain as having a subjective, existentially personal rather than objectively factual or medical quality. *See, e.g.*, ANNE CASE & ANGUS DEATON, DEATHS OF DESPAIR AND THE FUTURE OF CAPITALISM 84 (2020) ("The long-held understanding of pain as a signal to the brain to deal with an injury has been discarded and replaced by the recognition that the mind is involved in *all* pain and that social distress or empathetic distress can engender pain in the same way as the distress from a physical injury.").

[87] *E.g.*, Jennifer A. Chandler et al., *Brain Computer Interfaces and Communication Disabilities: Ethical, Legal, and Social Aspects of Decoding Speech from the Brain*, 16 FRONTIERS HUM. NEUROSCIENCE 1, 2 (2022).

would have to be able to convey whether non-existence would be a preferable state of affairs for each particular patient. This level of subjective insight remains far beyond the reach of existing technologies.

The claim of complete unknowability of pain—beyond the obvious fact that we cannot know for sure, or experience exactly, what pain means to someone else––is unconvincing. It is much less controversial to say that pain is opaque, or that it is epistemically difficult to access the pain of others. Of course, we cannot (barring futuristic technologies) step into someone else's body and experience their subjective awareness of the world. Nonetheless, medicine and public affairs proceed in spite of these obvious limitations, on the basis that human beings have enough capacities to experience pain and suffering in common for assumptions and communication not to be pointless. That said, the pain and suffering of incompetent patients remains relatively less knowable. Both the projection of one's own evaluative framework onto someone else and forms of communication are much less reliable in the case of many incompetent patients. Still, as noted above, we have developed measurements to evaluate the physical pain of non-competent people.

Given the relative opacity of incompetent patients' suffering, it would be very difficult, perhaps impossible, to determine whether pain has reached a level such that death would be a net benefit.[88] This potentially leaves policymakers, families, and doctors in a situation where they truly do not know whether a life should be continued or not, such that they may do harm whichever route they choose. One may argue that this epistemic obstacle justifies a certain humility that would weigh against euthanasia. However, if the choice is strictly between death and terrible unending pain, relying on epistemic humility to justify refusing taking any action goes farther than protecting us from the risk of unduly ending a life: it also exposes us to the risk of unduly continuing it.[89]

While the radical objections do not seem particularly conclusive on their own, their premises emphasize that it will be difficult to justify non-voluntary MAiD *on the basis of a beneficent response to suffering* when any sort of palliative care can attenuate pain.

Other objections have to do with the precision of such measurements, and

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[88] Beaudry, *supra* note 25, at 335–37, 351.

[89] *Cf.* Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 240 (1989) ("While the predominant danger of the orthodox approach is undertreatment, it also poses a risk that unjustified overtreatment will occur whenever the courts impose a strict standard for inferring the patient's choice if competent.");David Orentlicher, *The Supreme Court and Terminal Sedation: Rejecting Assisted Suicide, Embracing Euthanasia*, 24 HASTINGS CONST. L.Q. 947, 960 (1997) ("With respect to euthanasia, terminal sedation poses the same risks of abuse while serving fewer purposes of right-to-die law. Compared with assisted suicide, terminal sedation poses even greater risks of abuse and serves fewer purposes of right-to-die law.").

whether they can be carried out with sufficient objectivity by the relevant SDMs. We now turn to these circumstantial considerations.

C. Circumstantial Objections to NVE on the Basis of Beneficence

Whether an individual's suffering is so intolerable that it calls for actively ending life is currently assessed in a subjective manner by patients themselves in all jurisdictions where physician-assisted suicide has been legalized.[90] This subjective assessment implies that the state need not officially endorse controversial value-laden views on whether and when certain individuals are better off not existing. Should non-voluntary MAiD be legalized, third parties would have to decide whether someone's suffering calls for euthanasia. In all likelihood, for newborns and non-mature minors, that responsibility would lie with their legal guardians, who are by default their parents.[91] For adults, the SDM would be a family member, a friend, or a court-appointed guardian, depending on the circumstances and jurisdiction.[92] Medical professionals are also likely candidates to be made alternative SDMs.[93] In every case, the subjectivity inherent to third-party assessments of suffering includes a variety of risks. The SDM's response to suffering may not be properly benevolent if it is clouded by irrelevant considerations, and the SDM's evaluation of quality of life may not be beneficent if it encompasses irrelevant axiological assumptions.[94]

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[90] We use physician-assisted suicide here in favour of MAiD to signify the inclusion of jurisdictions that have not legalized euthanasia as well as those which have. *See e.g.,* End of Life Choice Act, *supra* note 23, §§ 13-15; *Canada's Medical Assistance in Dying (MAID) Law*, *supra* note 23; *The State of Knowledge on Medical Assistance in Dying for Mature Minors*, *supra* note 43, at 112–13.

[91] *See* Kevin W. Coughlin, *Medical Decision-Making in Paediatrics: Infancy to Adolescence*, 23 PAEDIATRICS & CHILD HEALTH 138, 139 (2018).

[92] *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 45 (citing MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY: ADVANCING SUBSTANTIVE EQUALITY FOR PERSONS WITH DISABILITIES THROUGH LAW, POLICY AND PRACTICE 44 (2010)). The SDM may also be someone appointed in an advance directive. However, we do not consider such circumstances in the present paper.

[93] *See, e.g.*, Jeff Perring, *Practical Realities of Decision-Making Relating to End of Life Care*, *in* A GOOD DEATH? LAW AND ETHICS IN PRACTICE 151, 155–56 (Lynn Hagger & Simon Woods eds., Routledge 2016) (2013).

[94] Irrelevant axiological assumptions may include ableist and agist assumptions, stereotypes and prejudices, for example, the belief in a diminished societal and/or self-assessed value of the life of the elderly or persons with disabilities. For a discussion of these types of considerations, see Mary Lay Schuster et al., *Determining "Best Interests" in End-of-Life Decisions for the Developmentally Disabled: Minnesota State Guardians and Wards*, 34 DISABILITY STUD. Q. (2014) (finding that decisions made by Minnesota State Guardians as substitute decision-makers are made within a framework that includes non-problematized ableist assumptions); Laverne Jacobs & Trudo Lemmens, *The Latest Medical Assistance in Dying Decision Needs to Be Appealed: Here's Why*, THE CONVERSATION (Oct. 9, 2019), http://theconversation.com/the-latest-medical-assistance-in-

1. SDMs' Emotions, Perceptions and Values

One circumstantial objection is derived from the inherent subjectivity involved in assessing another person's suffering and overall quality of life and the related risk that SDMs' emotions, perceptions, and values might influence their assessment of whether it is in a person's best interests to end their life.[95] As explained by Gastmans and Lepeleire, for persons with dementia (but it applies *mutatis mutandis*[96] to all individuals under study in this article), "there is a real risk that their close relatives will project their personal fears and concerns onto the person suffering from dementia. If relatives impose the disvalue they attach, in terms of their own life plans, to the states they observe in the person with dementia, they may well be imposing on the person a meaning to quality of life that does not fit with the patient's current lived experiences."[97] It is often pointed out in support of such concerns that people with dementia and individuals with disabilities tend to rate their own quality of life higher than one might expect.[98]

For example, a person with dementia may adapt to her new environment and

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[95] See Gastmans & Lepeleire, *supra* note 81, at 82; *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 148.

[96] The Latin phrase is translated directly as "with the necessary changes" or "all necessary changes having been made." It designates that the main points of an argument are broadly applicable in a different but similar context, taking into consideration all necessary adjustments needed to move from one context to another. In this case, it indicates that Gastman's & Lapeliere's arguments about SDMs' ability to assess the quality of life of dementia patients are broadly applicable to SDMs for other types of patients, assuming distinctions between these cases have been accounted for.

[97] Gastmans & Lepeleire, *supra* note 81, at 82.

[98] *See, e.g.*, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 148 (citing Trevor Buckley et al., *Predictors of Quality of Life Ratings for Persons with Dementia Simultaneously Reported by Patients and their Caregivers: The Cache County (Utah) Study*, 24 INT'L PSYCHOGERIATRICS 1094, 1099 (2012)); Kristiina Hongisto et al., *Self-Rated and Caregiver-Rated Quality of Life in Alzheimer Disease with a Focus on Evolving Patient Ability to Respond to Questionnaires: 5-Year Prospective ALSOVA Cohort Study*, 23 AM. J. GERIATRIC PSYCHIATRY 1280, 1286 (2015); Gina Bravo, Modou Sene & Marcel Arcand, *Surrogate Inaccuracy in Predicting Older Adults' Desire for Life-Sustaining Interventions in the Event of Decisional Incapacity: Is It Due in Part to Erroneous Quality-of-Life Assessments?*, 29 INT'L PSYCHOGERIATRICS 1061, 1066 (2017); *see also* Chervenak et al., *supra* note 77, at 31 (citing Jon E. Tyson & Saroj Saigal, *Outcomes for Extremely Low-Birth-Weight Infants: Disappointing News*, 294 JAMA 371 (2005)) (stating that "the self-reported quality of life of children with handicaps does not differ from that of children without disabilities"); Heather O. Dickinson et al., *Self-Reported Quality of Life of 8–12-Year-Old Children with Cerebral Palsy: A Cross-Sectional European Study*, 369 LANCET 2171 (2007) (finding self-reported quality of life assessments of children with cerebral palsy did not differ significantly from those of children in the control group). *But see* Govert den Hartogh, *The Authority of Advance Directives*, *in* JUSTICE, LUCK & RESPONSIBILITY IN HEALTH CARE: PHILOSOPHICAL BACKGROUND AND ETHICAL IMPLICATIONS FOR END-OF-LIFE CARE 167 (Yvonne Denier, Chris Gastmans & Antoon Vandevelde eds., 2013) (contesting the validity of such research because demented patients lose the capacity to assess their quality of life).

appear to enjoy participating in social activities at her nursing home. Her bouts of anxiety and depressive symptoms can be attenuated with comforting words by the staff and easily controlled when her antidepressant dose is adjusted. She may not show signs of recognizing her children, but she is unaware of her illness and her decline. Her children are extremely saddened that their mother no longer recognizes them and are troubled to see her caring about things as trivial as cartoons. Although she appears to be living, overall, a pleasant life that is mostly free from suffering, there is a risk that her children—because of their emotions as well as ableist and ageist values, stereotypes, and prejudices—will give disproportionate weight to the few episodes of suffering she experiences and conclude that she is better off dead than alive.

Is this risk equally alarming for never-competent patients as for formerly competent ones? For some, the answer is yes. Devaluing the quality of a human life because of ableist, ageist, or "disease-ist" values and perceptions or negative feelings and emotions is seriously reprehensible in all cases.[99] However, according to others, like Norman Cantor, the answer is no: the risk is more alarming for never-competent individuals than for formerly competent ones. This is because, for formerly competent persons who left no clear indications of their own end-of-life medical choices, it is common for SDMs to draw "guidance from a projection of what most people would want done for themselves in the circumstances of the particular case."[100] For such formerly competent individuals, it is generally assumed that they "want their interests furthered and to have those interests defined according to majority preferences—absent personal indications to the contrary."[101] Such an approach seeks to "honor a form of self-determination by implementing the now incompetent patient's likely, albeit putative, wishes."[102] Thus, following this logic, if ableist and ageist stereotypes as well as a hypercognitive perspective (the perspective that cognition is integral to an individual's identity and consequently their externally and internally constructed societal/moral value, including the dignity of their existence) inform generally what constitutes a life worth living[103] and if hypercognitive perspectives motivate a majority of

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[99] *See generally* Schuster et al., *supra* note 94 (finding that decisions made by Minesota State Guardians as substitute decision-makers are made within a framework that includes non-problematized ableist assumptions); Jacobs & Lemmens, *supra* note 94 (arguing that the *Truchon* decision overturning certain access criteria for medical assistance in dying should be appealed, partially due to a failure to consider how expanded access to MAiD risks reinforcing or normalizing problematic ableist and agist assumptions).

[100] CANTOR, *supra* note 63, at 103.

[101] *Id.* at 104.

[102] *Id.*

[103] *See* Gastmans & Lepeleire, *supra* note 81, at 80, 84; Jonas Beaudry, *MAiD Monitoring and the Carter Compromise*, VULNERABLE PERSONS STANDARD (Mar. 26, 2018), http://www.vps-npv.ca/blog/2018/3/26/maid-monitoring-and-the-carter-compromise ("[T]he notion that the lives of old, sick or disabled people are 'less worth living' is one of the most damaging and longstanding

competent individuals in a given society to express a desire for MAiD should they become demented, then consequently their children can only approximate what they surmise their parent's wish would have been. In other words, if ableist or ageist assumptions inform decisions made by autonomous people, why not apply this prejudiced lens to an understanding of their suffering and best interests when they are old and disabled by impairments or illnesses?

Objection to this line of thought may challenge the assumption that the fully competent person writing a living will to decide when her older, sicker self ought to die has strong moral or legal claims to make life and death choices for her older self. For instance, if that claim is based on an identity between younger and older selves, one may object that the older self is a quite different person from the younger one. Giving a younger, more intelligent and cognitively apt self a right to decide whether their older, cognitively impaired self must die would become as questionable as giving anyone a right of life and death over anyone else than themselves.[104] Policies granting such power to the former self would seem prima facie ableist and ageist, all the more so if research indicates that the older self is overall experiencing an acceptable level of contentment. The younger self may feel that this ending to their previously more productive and richer life is an unfitting or even degrading end to their lives. Intuitions on this issue hinge on controversial conceptions of identity, autonomy, and dignity.[105]

It is, however, different for never-competent individuals. Severely cognitively disabled individuals "have never had the capacity for autonomy—have never had the ability to issue instructions concerning end-of-life treatment (or other serious medical matters) or to form values and preferences that would guide surrogate decision makers."[106] It is thus nonsensical to attribute to them majoritarian values, because compared to individuals who "once had the perspective of a competent person," their "values are either nonexistent or opaque."[107] What needs to guide SDMs is a never-competent patient's best interests, understood from their point of view as a severely cognitively disabled human.[108] Here, the question is whether this individual would be better off dead than alive in the circumstances that they are facing, not whether their SDMs would want to live in those circumstances.[109]

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ableist and ageist belief in our productivity-obsessed culture.").

[104] *See e.g.,* Rich, *supra* note 5, at 139.

[105] On identity, see generally Helga Kuhse & Peter Singer, *The Quality/Quantity-of-Life Distinction and Its Moral Importance for Nurses*, 26 INT'L J. NURSING STUD. 203 (1989). On autonomy and beneficence, see generally RONALD DWORKIN, LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM (1st ed. 1994) [hereinafter DWORKIN, LIFE'S DOMINION]; Dresser, *supra* note 72.

[106] CANTOR, *supra* note 63, at 104.

[107] *Id.*

[108] *Id.* at 107.

[109] *Id.* at 106.

In such an exercise, there is a real risk that SDMs transpose or project their feelings, values, and personal perception of a life worth living onto the individual,[110] which is a seriously alarming prospect in the case of never-competent individuals.[111]

While some argue that the risk created by the inherent subjectivity of third-party assessment of suffering and quality of life renders non-voluntary MAiD unethical,[112] others advocate instead for greater scrutiny of end-of-life substitute decision-making.[113] Susan Martyn, for example, calls for "caring interpreters" to determine what incompetent patients "find meaningful in life"[114] and "how that person experiences life."[115] Such an approach allows for sensitivity to "noncognitive notions of well-being" that are grounded in "emotional and relational well-being."[116] It allows for a better understanding of incompetent patients' lived experiences and thus for a more accurate assessment of what constitutes their best interests.

Finally, in the context of newborns and young children, the subjectivity of third-party assessments of suffering and the related risk of SDMs imposing their own values, perceptions, emotions, and feelings is not seen as a risk at all by some scholars. For example, Lindemann and Verkerk argue that for parents to impose their values and vision of a life worth living onto their severely disabled or sick child is desirable.[117] Indeed, parents are "major contributors to the long process of shaping their children's selves, enveloping their children with their own 'thick' normative framework and in that way giving them some rich and comprehensive notion of what matters in life."[118] Parents "so directly mark the child in its first few years when children are at their most receptive, parents provide a window into the values and settled preferences, the particular outlook on life, that might well characterize the child when grown."[119] Thus, in assessing suffering and their

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[110] *Id.* at 108–09.

[111] *Id.* at 109 (noting that this line of reasoning applies equally to disabled newborns or infants). For a different view on the ethical considerations surrounding end-of-life decisions for disabled infants, see generally HELGA KUHSE & PETER SINGER, SHOULD THE BABY LIVE?: THE PROBLEM OF HANDICAPPED INFANTS (1985), at 184-189; Lindemann & Verkerk, *supra* note 44, at 46–50.

[112] *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 145 (explaining that the Canadian Association for Community Living holds such a view).

[113] CANTOR, *supra* note 63, at 108.

[114] *Id.* at 109 (citing Susan R. Martyn, *Substituted Judgment, Best Interests, and the Need for Best Respect*, 3 CAMBRIDGE Q. HEALTHCARE ETHICS 195, 201 (1994)).

[115] Susan R. Martyn, *Substituted Judgment, Best Interests, and the Need for Best Respect*, 3 CAMBRIDGE Q. HEALTHCARE ETHICS 195, 199 (1994).

[116] Stephen G. Post, *Dementia in Our Midst: The Moral Community*, 4 CAMBRIDGE Q. HEALTHCARE ETHICS 142, 143–44 (1995).

[117] Lindemann & Verkerk, *supra* note 44, at 49–50.

[118] *Id.* at 49.

[119] *Id.*

child's current and future quality of life, parents can and should rely on their personal value structure.

While it is true that parents are generally given a wide berth of discretion in raising their children in light of their own value system, there are limits to analogizing child-rearing to making life and death choices, since the state typically interferes with parental discretion when it is used in a way that risks seriously injuring the best interests of the child.[120] Moreover, the importance of giving parents the freedom to imprint their value system onto their child must be weighed against the importance of a number of parental virtues that would support constraining this freedom, such as welcoming or accepting one's child's differences or uniqueness and being committed to fulfilling the particular needs of that child.[121] While some parents may be exceptionally well-attuned to their child's best interests, [122]others may make the decision to end their child's life in reaction to their own emotional state, or before having developed a full "understanding of the reality of caring for a disabled child."[123]

2. SDMs' Personal and Utilitarian Interests

Another circumstantial objection is that SDMs' personal and utilitarian interests risk conflicting with the person's best interests, thereby distorting their assessment. Providing care for non-competent patients can be financially, emotionally, and physically burdensome, and some people therefore fear that SDMs may have an interest in ceasing to provide care.[124] For example, in the context of individuals with dementia, caregivers face both the physical burden of

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[120] For example, child welfare legislation in Canada typically allows for a court order that dispenses for the need for parental consent to medical treatment, where that consent is denied or cannot be obtained. *See e.g.*, Medical Consent of Minors Act, S.N.B. 1976, c. M-6.1, s 4 (Can.); Child and Family Services Act, R.S.O. 1990, c. C-11, s 62(3) (Can.).

[121] Rosalind McDougall, *Impairment, Flourishing, and the Moral Nature of Parenthood*, *in* DISABILITY AND DISADVANTAGE 352, 354–64 (Kimberley Brownlee & Adam Cureton eds., 2009). On acceptance and approbation in the context of gene editing, see generally HUMAN FLOURISHING IN AN AGE OF GENE EDITING (Erik Parens & Josephine Johnston eds., 2019). On familial welcome in the context of prenatal testing, see generally Adrienne Asch & David Wasserman*, Where Is the Sin in Synecdoche?: Prenatal Testing and the Parental-Child Relationship*, *in* QUALITY OF LIFE AND HUMAN DIFFERENCE: GENETIC TESTING, HEALTH CARE, AND DISABILITY 172 (David Wasserman, Jerome Bickenbach & Robert Wachbroit eds., 2005).

[122] *See* Sabine Vanacker, *The Story of Isabel*, *in* A GOOD DEATH?: LAW AND ETHICS IN PRACTICE 167, 167–76 (Lynn Hagger & Simon Woods eds., 2013).

[123] *See* Perring, *supra* note 93, at 160.

[124] *See The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 146; Giulia Cuman & Chris Gastmans, *Minors and Euthanasia: A Systematic Review of Argument-Based Ethics Literature*, 176 EUR. J. PEDIATRICS 837, 842 (2017); CANTOR, *supra* note 63 at 136; Chervenak et al., *supra* note 77, at 31; A.B. Jotkowitz & S. Glick, *The Groningen Protocol: Another Perspective*, 32 J. MED. ETHICS 157, 157 (2006).

performing a range of caregiving responsibilities and the mental stress of being in an altered relationship with a loved one (e.g., various forms of grief or guilt).[125] Similarly, some have pointed out that disabled children can strain their family's financial resources and induce burnouts, usually on the part of their mothers who carry an unequal share of the burden of care.[126] Therefore, some worry that SDMs' assessment of suffering and quality of life may be distorted by self-interested and utilitarian considerations, such as the financial and emotional costs of care.[127] This poses a risk for non-voluntary MAiD to be administered to individuals in circumstances where it is not obvious that death rather than continued existence is in their best interests.

For some, in the context of never-competent severely disabled or ill children, the critique that parents may want "to wiggle out from under the responsibility" of looking after their child is both "unmotivated and mean-spirited."[128] For others, this concern is ill-founded. For example, Peter Singer sees no problem in prioritizing the interests of SDMs over those of nonautonomous, non-rational and non-self-aware beings: as we will see in the next Part, Singer considers the lives of severely cognitively impaired people to be of lesser value and, thus, their interests to remain alive may in some cases be of lesser importance than various important interests of SDMs.[129] Finally, scholars like Cantor weigh the risks of prioritizing SDMs' interests over those of incompetent patients according to whether the individual in question is either a formerly or never-competent individual. According to this view, third parties' interests in being discharged from the burden of care can be rightly considered in the case of formerly competent individuals, but not for never-competent ones. In the context of formerly competent persons who left no clear indications of their own end-of-life medical choices, taking into consideration the putative wish of these individuals not to burden their loved ones can be reasonable if, in a given population, there is a shared belief that "most people have such strong solicitude for their immediate families

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[125] Chris Gastmans, *Euthanasia in Persons with Severe Dementia, in* EUTHANASIA AND ASSISTED SUICIDE: LESSONS FROM BELGIUM 202, 205 (David Albert Jones, Chris Gastmans & Calum MacKellar eds., 2017).

[126] SUMNER, *supra* note 18, at 121–22 (citing KUHSE & SINGER, *supra* note 111, at 146).

[127] Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. STATE U. L. REV. 893, 905 (2017) (citing Mary Crossley, *Medical Futility and Disability Discrimination,* 81 IOWA L. REV. 179 (1995)).

[128] Lindemann & Verkerk, *supra* note 44, at 49 (highlighting that "parental conflicts of interest arise routinely, yet responsibility for the care of the young continues to be assigned to their progenitors. . . . To create public policy on the assumption that parents are likely to sacrifice their desperately ill child's interests to their own would be to overturn deep-seated, widely shared understandings about who is responsible for the care of the young. Concern about conflict of interest in parents' making end-of-life decisions of any kind for their children needs to be specific and substantial, not general and notional.").

[129] *See, e.g.*, SINGER, *supra* note 1, at 160.

that they would want such interests to be considered."[130] In the context of never-competent patients, it is, however, more difficult to ascribe "an altruistic wish to have the interests of loved ones considered"[131] in end-of-life decisions because they never possessed the capacity to weigh third-party interests against their own well-being. They were never capable of deliberating "about the positives and negatives of self-sacrifice."[132] Attributing to them a desire for self-sacrifice may be nothing but a "convenient fiction."[133]

D. A Defeasible Duty of Beneficence to Sometimes Provide NVE Exists, but Never Obtains in Practice

In conclusion, the most compelling beneficence argument in favor of NVE is that the suffering of non-competent patients matters. Arguments that seek to deny this relatively obvious claim appear unconvincing. The crux of the ethical disagreement is not whether non-competent people can suffer intolerably or could potentially benefit from euthanasia. On the contrary, the claim that NVE may be the most *beneficent* course of action in specific circumstances is relatively intuitively plausible.

We nonetheless have three main reasons for rejecting the view that legalizing NVE is justified on the basis of beneficence, all things being equal. First, in the vast majority of cases considered as candidates for NVE, the suffering of non-competent patients is not so severe that it would typically be considered intolerable.[134] Second, even in the exceptionally rare cases where there are grounds to believe that death may be in a patient's best interests, the subjectivity of the experience of suffering, communicational challenges with non-autonomous people, and the morally irrelevant emotions, interests, and considerations of the SDM render the accuracy of this assessment questionable.

However, the theoretical possibility of inflicting a life worse than death on a patient unable to wish for euthanasia will remain, unless there are other ways of controlling pain. The thorniest ethical disagreement about NVE is *how* one ought to respond to the suffering of non-competent patients in light of this epistemic

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[130] CANTOR, *supra* note 63, at 141.

[131] *Id.*

[132] *Id.*

[133] *Id.*

[134] In the pediatric context, see generally Chervenak et al., *supra* note 77. In the context of dementia, see generally Dresser, *supra* note 72. On the much-discussed under-evaluation of the quality-of-life of people with disabilities, see generally Stephen M. Campbell & Joseph A. Stramondo, *The Complicated Relationship of Disability and Well-Being*, 27 KENNEDY INST. ETHICS J. 151 (2017). Even proponents of the Groningen Protocol emphasize the exceptional character of this norm. *E.g.*, Lindemann & Verkerk, *supra* note 44, at 48; *see also* Manninen, *supra* note 15, at 650 (expressing concerns that the assessments of unbearable suffering reaches a "grey area very quickly," creating the potential for euthanasia of infants who may have survived).

opacity, not with *whether* this suffering matters or even whether it may, in theory, call for NVE in some exceptional circumstances and under conditions attenuating documented risks.

The third reason for rejecting non-voluntary MAiD on the basis of beneficence is that pain management treatments are generally sufficient to alleviate suffering that would otherwise be extreme. This is not true in the same way for autonomous patients who may, for example, suffer from being forced to receive pain-management treatment against their will. Incompetent patients offer no such autonomous resistance to receiving pain-management treatments. Of course, patients may show frustration and displeasure at experiencing certain treatments (no one enjoys dialysis, with or without dementia). The challenge lies in understanding their pain/suffering and responding to it[135] with "comfort-only care,"[136] rather than projecting ableist suicidal ideations onto moderate restlessness or resisting behaviors that are not so much a resistance to any particular course of *treatment* as they are a resistance to or an expression of displeasure at the specific *steps* taken to achieve said treatment. Life-saving treatments should not be interrupted, nor should patients be euthanized, when the patient is unable to understand the consequences of receiving a given treatment or not. Alternative ways of delivering life-sustaining treatments can be considered when possible to minimize this displeasure. Note here the distinction between situations where a patient with limited intellectual capacities still has enough residual autonomy to reject the *treatment*, as opposed to simply pushing back the hand administering it because it is experienced as an unpleasant stimulus. Our concern in this Part is rather with the questionable imputation of residual autonomy—and of a wish to die—to patients who never expressed an understanding that their life was threatened in any way, and whose resistance may just as well point to the fact that they personally dislike a nurse administering a treatment.

One final objection to legalizing NVE on the basis of beneficence is a pragmatic one: it is risky policymaking to create a rule that has a broad and ambiguous scope of application (such as the Groningen Protocol) where it only applies to a few excessively rare cases. It is even more dangerous when the risks it raises (over-application of the rule because of systemic ableist, ageist, diseasist assumptions) are, by contrast, insidious and widespread.

While pain management will always or almost always suffice to respond to the kind of grave physical suffering we have been considering here, one may object that it may still not be available for socioeconomic reasons, and that in certain contexts (e.g., low-income countries with extremely poor access to health care), NVE may well be the most beneficent available solution in many cases.

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[135] CASSELL, *supra* note 80, at 219–30.

[136] ARTHUR J. DYCK, LIFE'S WORTH: THE CASE AGAINST ASSISTED SUICIDE (2002) at 31.

The weight of this objection will vary on a case-by-case basis, since it must be assessed along with the circumstantial risks that we have explored in this Part. Incidentally, those risks would in fact direct those professing to take the ethical principle of beneficence seriously to invest more into research on the suffering of non-competent patients. That said, even if (i) such research would reveal that NVE is the most beneficent course of action in certain exceptional circumstances, and (ii) even assuming, counterfactually, that all aforementioned risks could be controlled and that beneficence would require ending a patient's life in this situation (where no pain management care is available), the desirability of legalizing NVE would still need to be assessed globally, in light of considerations of morality and justice weighing against the legalization of NVE, that we will explore below.

IV. VALUING LIFE

Of course, all the aforementioned risks become irrelevant if the lives of non-competent people are judged as not worth living in the first place. If, for instance, incompetent patients are not the kinds of beings who can enjoy a continued existence or who can benefit from a right to life, or if one assumes that ending their lives is either morally neutral or much less wrong than ending the life of a more cognitively able person, euthanizing them would be either morally neutral or more easily justified. We turn now to such arguments. First, we discuss how, like the principle of beneficence, the value of life can be understood through different ethical paradigms, potentially leading to contradictory outcomes: legalizing or banning NVE. We then introduce various ways in which the value of life of those which limited cognitive ability has been evaluated, before turning to critiques of these valuations in the literature.

A. Valuing All Human Lives

On the one hand, arguments for a blanket prohibition on—or strict limits on access to—MAiD have often revolved around the principle of the sanctity of human life.[137] Sanctity of life is a principle rooted in the idea that "[a]ll human beings possess, in virtue of their common humanity, an inherent, inalienable, and ineliminable dignity."[138] This dignity renders all human lives intrinsically valuable, independently of the subjective negative assessment of the value of one's life due,

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[137] *See* Nathalie Burlone & Rebecca Grace Richmond, *Between Morality and Rationality: Framing End-of-Life Care Policy through Narratives*, 51 POL'Y SCI. 313, 323–25 (2018); Carter v. Canada (A.G.), [2015] 1 S.C.R. 5 (Can.), para. 2.

[138] *See* JOHN KEOWN, THE LAW AND ETHICS OF MEDICINE: ESSAYS ON THE INVIOLABILITY OF HUMAN LIFE 5 (2012).

for instance, to illness, cognitive impairment, or dependence on others.[139] A prohibition on *intentionally* taking away a life follows from this view, as such an action, in implying a negative assessment of someone's life value, would be contrary to the sanctity of life principle.[140]

The sanctity of human life principle remains, for some, the "ultimate discussion stopper"[141] when debating the ethics of MAiD or the possibility of its expansion.[142] Following this principle, a critic of the legalization of NVE might maintain that allowing SDMs to request the administration of a fatal substance to end the life of incompetent patients violates "the precept that all human life is intrinsically valuable" and "[undermines] the status, morale, and well-being" of incompetent patients through stigmatizing behaviors.[143] Further, it might be said that such devaluation of incompetent patients' lives risks becoming a self-fulfilling prophecy: "the negative valuation leads to indifferent care; indifferent care leads to a poor quality of day-to-day experiences; and the poor quality of experiences provides grounds for the negative valuation."[144] Finally, some might suggest that a

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[139] *Id.* at 5–6. For an overview of the concept of the sanctity of life, see SUMNER, *supra* note 18, at 48–54.

[140] *See* KEOWN, *supra* note 138, at 6 ("Although the value of human life is not absolute, the prohibition on taking it is."); Helga Kuhse, *Sanctity of Life, Voluntary Euthanasia and the Dutch Experience: Some Implications for Public Policy*, *in* SANCTITY OF LIFE AND HUMAN DIGNITY 19, 19 (Kurt Bayertz ed., 1996). *But see* DWORKIN, LIFE'S DOMINION, *supra* note 105, at 179, 218 (explaining that belief in the sanctity of human life is not necessarily incompatible with the legalization of assisted dying; it is important for each life to go well, and when a life is not going well, and never will, deliberately bringing it to an end might be legitimate).

[141] Stephen Wear, *Sanctity of Life and Human Dignity at the Bedside*, *in* SANCTITY OF LIFE AND HUMAN DIGNITY 57, 60 (Kurt Bayertz ed., 1996).

[142] *See, e.g.*, André Schutten, *Lethal Discrimination: A Case Against Legalizing Assisted Suicide in Canada*, 73 SUP. CT. L. REV. 143, para. 115 (2016).

[143] Norman L. Cantor, *Déjà Vu All Over Again: The False Dichotomy Between Sanctity of Life and Quality of Life* 8 (Rutgers L. Sch. (Newark) Faculty Papers No. 22, 2005) https://law.bepress.com/cgi/viewcontent.cgi?article=1023&context=rutgersnewarklwps; *see also The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 146 (arguing that allowing MAiD could convey the message that our "society tacitly approves of the notion that life with a decline in mental capacity is not worth living, contributing to the stigma associated with such a decline");*The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition: The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition*, COUNCIL OF CANADIAN ACADS. 29, 48 (2018) [hereinafter *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*], https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-Where-a-Mental-Disorder-is-the-Sole-Underlying-Medical-Condition.pdf (arguing that allowing MAiD "more broadly may be seen as perpetuating an ideology that devalues people with mental disorders by suggesting that their lives may not be worth living").

[144] *Dementia: Ethical Issues*, NUFFIELD COUNCIL ON BIOETHICS 26 (2009), https://www.nuffieldbioethics.org/assets/pdfs/Dementia-report-for-web.pdf. Although this risk is highlighted in the context of patients with dementia, it can apply *mutatis mutandis* to any vulnerable and stigmatized population (e.g., the disabled, the sick, the mentally ill).

blanket prohibition on NVE should be maintained to prevent a further "weakening [of] the social perception of the value of human life,"[145] which has already been eroded by the legalization of voluntary MAiD.

On the other hand, scholars advocating in favor of NVE are likely to consider these fears ill-founded or simply irrelevant. These proponents argue that allowing MAiD for incompetent patients who are suffering will not stigmatize vulnerable populations as a whole, nor will it compromise the value a society accords to human life. For example, writing about mental illnesses rendering a patient incompetent, Jukka Varelius maintains that advocating that some people with severe cognitive impairments would be better off dead "does not entail that the lives of the severely mentally ill have no value or that human life has no significant worth."[146] This is because his specific claim "concerns only the cases of the severely mentally ill who have a persistent wish to die because of their continuing unbearable and incurable suffering."[147] Such an argument "does not entail that their lives have no value, but that the value of their lives can be outweighed by the worth of relieving their distress and enabling them to avoid the kind of existence they would most plausibly autonomously eschew."[148] From this view, any argument to the effect that NVE for individuals suffering intolerably will affect the value we collectively place on incompetent patients' lives and on human life in general is likely to be labelled as false and alarmist.

Scholars likely to find these fears irrelevant generally include those who believe that human beings under a certain threshold of cognitive functioning should not enjoy the full moral status ascribed to personhood.[149] For them, such concerns are irrelevant because there is nothing inherently valuable or sacred about the life of any human being. These scholars question the inherent and invariable dignity ascribed to all human beings by virtue of their membership in the human species and independently of their quality of life.[150] They consider the reasoning justifying the unique value of all human beings to be rationally flawed and conclude that such a belief is not only a matter of faith but is also speciesist.[151]

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[145] Cuman & Gastmans, *supra* note 124, at 844 (citing Giglio & Spagnolo, *supra* note 74).

[146] Varelius, *Lack of Autonomy*, *supra* note 17, at 62.

[147] *Id.*

[148] *Id.*

[149] KEOWN, *supra* note 138, at 5.

[150] *See, e.g.,* Universal Declaration of Human Rights, G.A. Res. 217 (III) A, preamble, U.N. Doc. A/RES/217(III) (Dec. 10, 1948). Although the inherent dignity of all human beings is not explicitly mentioned in the Canadian Charter, the Supreme Court has repeatedly indicated that it is an underlying value of all guaranteed rights and freedoms. *See, e.g.*, Charter of Human Rights and Freedoms, C.Q.L.R., c C-12, arts. 1, 4, 10, (Can. Que.); Canadian Charter of Rights and Freedoms, s. 7, Part I of the Constitution Act, 1982, *being* Schedule B to the Canada Act, 1982, c 11 (U.K.); Blencoe v. British Columbia (Human Rights Commission), 2000 SCC 44, para. 78 (Can.); Hill v. Church of Scientology of Toronto, [1995] 2 S.C.R. 1130, para. 120 (Can.).

[151] Emily Jackson, *Secularism, Sanctity and the Wrongness of Killing*, 3 BIOSOCIETIES 125,

From their perspective, under a certain quality threshold, prolonged life is less valuable than death, and intentionally ending one's life is ethically sound.[152] Thus, even if the legalization of MAiD can stigmatize vulnerable populations, they maintain that there is nothing fundamentally alarming about this result. Conveying the message that some lives are of lesser value constitutes, for them, a fair reflection of reality. We turn now to illustrations of this position.

B. Limited Cognitive Abilities and the Value of a Life

For some, what matters in assessing the ethics of the practice of MAiD is not death or suffering "but loss of psychological continuity and connectedness."[153] According to Julian Savulescu, "when a human organism does not have mental states, it is not wrong to kill it."[154] Following this view, NVE for advanced demented patients or people with severe cognitive impairments is justified because their lives are of "little or no value."[155] For others, like Peter Singer and Jeff McMahan, NVE of an incompetent patient can be justified when the individual lacks intrinsic capacities essential for personhood.[156] The essential capacities entitling one to personhood—and thus to full moral status—may vary depending on the scholars, but they generally relate to a minimal level of cognitive functioning (e.g., capacity for rational thinking, practical reasoning, self-awareness, etc.).[157] Such scholars reject the widely shared view—entrenched in most, if not all, Western countries' legal frameworks—that membership in the human species guarantees full and equal moral status to all independently living beings.[158] For them, the moral worth of the lives of severely cognitively impaired individuals is akin to that of other (non-human) animals.[159] Once an individual falls

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125, 133 (2008).

[152] *Id.* at 125, 139–40 (citing MCMAHAN, *supra* note 1, at 98).

[153] Savulescu, *supra* note 81, at 44.

[154] *Id.* (citing Walter Sinnott-Armstrong & Franklin G. Miller, *What Makes Killing Wrong?* 39 J. MED. ETHICS 3 (2013)).

[155] *Id.*

[156] MCMAHAN, *supra* note 1, at 486; SINGER, *supra* note 1, at 87.

[157] *See, e.g.*, SINGER, *supra* note 1, at 87; MCMAHAN, *supra* note 1, at 203–32; *see also* Eva F. Kittay, The Moral Significance of Being Human, Presidential Address Delivered at the One Hundred Thirteenth Eastern Division Meeting of the American Philosophical Association in Baltimore, MD (Jan. 6, 2017), *in* 91 PROC. & ADDRESSES AM. PHIL. ASS'N, at 22, 26 (2017) [hereinafter Kittay, Being Human] (discussing how the moral significance of being human, while often attributed to possession of supposedly intrinsic properties to humanity like cognition, should be justified through humans real and potential relations to other human beings).

[158] *See, e.g.*, G.A. Res. 217, *supra* note 150, preamble; Charter of Human Rights and Freedoms, *supra* note 150, arts. 1, 4, 10; G.A. Res. 61/106 Convention on the Rights of Persons with Disabilities (Dec. 12, 2006), arts. 1, 5, 12; Canadian Charter of Rights and Freedoms, *supra* note 150; Blenco v. British Columbia*, supra* note 150, at para. 78; Hill v. Church of Scientology of Toronto, *supra* note 150, at para. 120.

[159] *See, e.g.*, Eva Feder Kittay, *The Personal Is Philosophical Is Political: A Philosopher and*

below the threshold of minimal cognitive abilities required for personhood, both his death and his killing are more easily justifiable because they do not carry the same moral significance as the death and the killing of a "person."[160]

C. Valuing Lives in Spite of Limited Cognitive Abilities

The view that one's value of life depends on cognitive ability has been criticized for numerous reasons, notably for conceiving personhood in an incomplete and hypercognitive fashion[161] and for making abhorrent comparisons between severely cognitively impaired individuals and animals.[162] In response to such arguments, scholars such as Eva F. Kittay and Agnieszka Jaworska have offered alternate bases for rationalizing the conferral of equal moral status to human beings with limited intrinsic capacities. These scholars fall broadly under the category of care ethicists.

Kittay proposes to confer personhood to all human beings based on "relational properties," rather than intrinsic ones.[163] Relational properties are "properties that

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Mother of a Cognitively Disabled Person Sends Notes from the Battlefield, *in* COGNITIVE DISABILITY AND ITS CHALLENGE TO MORAL PHILOSOPHY 393, 394–95 (Eva F. Kittay & Licia Carlson eds., 2010) (discussing the arguments raised by MCMAHAN, *supra* note 1).

[160] *See, e.g.*, SINGER, *supra* note 1, at 87, 90 and 182; KUHSE & SINGER, *supra* note 111, at 133; Peter Singer, *Speciesism and Moral Status*, *in* COGNITIVE DISABILITY AND ITS CHALLENGE TO MORAL PHILOSOPHY 330 (Eva F. Kittay & Licia Carlson eds., 2010), at 338–40; MCMAHAN, *supra* note 1, at 204–09; Jeff McMahan, *Radical Cognitive Limitation*, *in* DISABILITY AND DISADVANTAGE 240 (Kimberley Brownlee & Adam Cureton eds., 2009), at 243–59; Jackson, *supra*, note 151, at 125.

[161] *See, e.g.*, CHARLES A. FOSTER & JONATHAN HERRING, IDENTITY, PERSONHOOD AND THE LAW 39 (2017); *Dementia: Ethical Issues*, *supra* note 144, at 32.

[162] For a discussion of the use of animal comparisons in rhetoric justifying the marginalization, abuse, and killing of severely cognitively impaired human beings, see Alice Crary, *The Horrific History of Comparisons Between Cognitive Disability and Animality (and How to Move Past It)*, *in* ANIMALADIES: GENDER, ANIMALS, AND MADNESS 117 (Lori Gruen & Fiona Probyn-Rapsey eds., 2018) at 117–33; Peter Singer, *A Response to Alice Crary's "Horrific History,"* 2 ZEITSCHRIFT FÜR ETHIK UND MORALPHILOSOPHIE [Z.E.M.O.] 135 (2019) (Ger.) [hereinafter Singer, *Response to Alice Crary*], at 135–37; Eva Feder Kittay, *Comments on Alice Crary's The Horrific History of Comparisons Between Cognitive Disability and Animality (and How to Move Past It) and Peter Singer's Response to Crary*, 2 ZEITSCHRIFT FÜR ETHIK UND MORALPHILOSOPHIE [Z.E.M.O.] 127 (2019), at 127–32; Alice Crary, *Animals, Cognitive Disability and Getting the World in Focus in Ethics and Social Thought: A Reply to Eva Feder Kittay and Peter Singer*, 2 ZEITSCHRIFT FÜR ETHIK UND MORALPHILOSOPHIE [Z.E.M.O.] 139 (2019), at 139–46; *see also* Kittay, *supra* note 159, at 396–97 (discussing how arguments like Jeff McMahan's use of comparisons between the philosophical treatment those with severe intellectual disabilities and animals in MCMAHAN, *supra* note 1, at 221–22, have a devastating impact on the loved ones and individuals within the disability community, who are historically marginalized from the field of philosophy).

[163] Kittay, Being Human, *supra* note 157, at 26; *see also* Eva Feder Kittay, *At the Margins of Moral Personhood*, 116 ETHICS 100, 149 (2005) ("group membership (a relational concept) is the wrong sortal for moral consideration, whereas the intrinsic properties of an individual, such as certain psychological capacities, are the right sortals.").

we have only in virtue of the relationships we are in with other human beings."[164] Kittay defines humans as all beings that are the "offspring[s] of a human mother and a human father."[165] This definition is, of course, not only biological but also relational,[166] and the moral status enjoyed by all humans is based on the relational aspect of this definition. According to Kittay,

> [the] relational property of being human binds all humans, as all humans stand in this relation. The relation is morally and conceptually prior to any intrinsic properties. We have moral obligations to other human beings for the simple reason that we find ourselves in relation to them. We cannot be the sorts of creatures we are except by being in relationship to other human beings.[167]

As a result, by virtue of their relational nature, all human beings stand in morally significant relations to each other "prior to knowing anything of the morally salient traits of the other human being."[168] Thus, concluding that the lives of non-competent people are neither worth living nor worth preserving is a serious moral wrong.

Jaworska, for her part, argues that the "emotional capacity to care is a sufficient condition" for conferring the full moral status ascribed to personhood.[169] Consequently, we should not interfere with severely cognitively impaired individuals' interests as dictated by their caring about certain things, as not respecting what they care about undermines the inviolability to which they are entitled as persons, and therefore constitutes a significant moral wrong.[170] In the context of NVE, this means that individuals who enjoy personhood (and thus full moral status) because of their capacity to care should not be euthanized when it goes against their interests as caring beings. It would therefore be wrong to end the

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[164] Kittay, Being Human, *supra* note 157, at 26.

[165] *Id.* at 36.

[166] *Id.*

[167] *Id.*

[168] *Id.* at 38–39. It is, however, different for animals, according to Kittay. Although we can also confer a special moral status on animals, "the main route to our moral obligations to animals is not through relations but through knowledge of the intrinsic traits a particular animal or species of animal. When an animal exhibits what we take to be morally significant traits, behaviours, or relationships, we ought to respond in a morally responsible fashion. Being human is a sufficient condition for the stringent moral obligations we have to humans, but it needn't be a necessary condition." *Id.*

[169] Agnieszka Jaworska, *Caring and Full Moral Standing Redux*, *in* COGNITIVE DISABILITY AND ITS CHALLENGE TO MORAL PHILOSOPHY 369, 369 (Eva F. Kittay & Licia Carlson eds., 2010).

[170] *Id.*; Agnieszka Jaworska, *Caring and Full Moral Standing*, 117 ETHICS 460, 460 (2007); Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value*, 28 PHIL. & PUB. AFFS. 105, 125–37 (1999).

life of people with cognitive impairments who would retain the capacity to care for certain things, be it listening to music, watching cartoons, or participating even passively in social activities.[171]

These relational accounts of personhood assert broad conditions for personhood beyond high intellectual capacities. However, they do not morally prohibit euthanasia in all cases. Having a duty to "hold [someone] in personhood," to use Lindemann's expression, is distinct from having a duty to "hold [them] in [their] life."[172] However, even if the pro-euthanasia beneficence argument is still theoretically available to theorists like Kittay or Jaworska, it would reflect a way to care for the incompetent patient rather than deny their personhood. This would notably imply that the value of an incompetent patient's life benefits from equally robust protection as that of a competent person, and cannot be more easily traded off (e.g., for less suffering, or reduced costs for others).

Moreover, epistemic limitations would incite care ethicists like Kittay to prudence and "epistemic modesty,"[173] which includes reducing the reach of certain unavoidably opaque or ambivalent decisions to an urgent minimum. Responding to immediate, observable, excruciating physical pain may fall within the category of "urgent minimum." Ending the life of those who are unable to communicate whether or not they enjoy their life on the assumption that they probably do not benefit from existence is problematic, since it is either questionably speculative[174] or questionably eugenicist.[175]

In summary, the perspective adopted in terms of the appropriate valuation of life for individuals with limited cognitive functioning intersects a great deal with positioning on the ethics of NVE, both in terms of the possibility of an increased devaluation of the life of certain persons, and how the interests of individuals with limited cognitive functioning are assessed and acted upon in the context of suffering.

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[171] *But see* Thomas R.V. Nys, *The Wreckage of Our Flesh: Dementia, Autonomy and Personhood*, *in* JUSTICE, LUCK & RESPONSIBILITY IN HEALTH CARE: PHILOSOPHICAL BACKGROUND AND ETHICAL IMPLICATIONS FOR END-OF-LIFE CARE 189, 197–99 (Yvonne Denier, Chris Gastmans & Antoon Vandevelde eds., 2013) (contending that Jaworska's view neglects the importance of assessing the value of what we are left caring about once severely demented).

[172] HILDE LINDEMANN, HOLDING AND LETTING GO: THE SOCIAL PRACTICE OF PERSONAL IDENTITIES 22–30 (2014).

[173] Kittay, *supra* note 162, at 617.

[174] Beaudry, *supra* note 25, at 335–41.

[175] Since we refer to eugenics in this paper as problematic, we must also note that there are contemporary defenses of eugenic practices. However, the practices that are defended do not include euthanasia, which is the topic of this paper. They include other kinds of technologies, such as human enhancement. *See* NICHOLAS AGAR, LIBERAL EUGENICS: IN DEFENCE OF HUMAN ENHANCEMENT, at vi (2004) (defending a version of eugenics that is primarily concerned with "the protection and extension of reproductive freedom" rather than the strict regulation of reproductive freedom typically associated with 20th-century eugenics).

V. VULNERABILITY

In recent legal debates, the protection of vulnerable individuals has become a central argument against the legalization of MAiD. Vulnerability can be understood at both individual and social levels. This part will address each of these levels in turn, outlining the specific ways in which NVE has significant implications for each level of vulnerability.

A. Individual Vulnerability

Those opposing NVE are likely to argue that incompetent patients are too vulnerable for NVE to be legalized. Contrary to competent individuals, they are generally not "able to stand up for themselves."[176] Thus, abuses of MAiD laws will be "much more likely in the cases of patients who are incapable of autonomously deciding about ending their lives than in cases of competent patients."[177] A total ban on NVE would not affect those who have the capacity for autonomous decision-making in the end-of-life context and would protect the most vulnerable citizens. This vulnerability-based argument was sometimes rejected in the context of voluntary MAiD on the basis that it insulted people with disabilities or illnesses, by depicting them as less than autonomous and in need of protection against their will.[178] However, this objection does not hold for incompetent patients for whom a certain degree of paternalism and care is morally required.

As a counterargument, some may invoke the ethical principle of justice according to which "like cases should be treated alike," and the possibility of implementing safeguards.[179] Even though incompetent patients are more vulnerable, their situation is morally equivalent to that of competent individuals because they too can experience intolerable suffering. Because they ought to be treated equally, some may argue that it is "unfair not to extend eligibility for MAiD to them."[180] Such basic principles of justice cannot be outweighed by incompetent patients' vulnerability. Not only is the risk of abuse already part and parcel of our medical system, but appropriate safeguards can also be implemented to protect

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[176] Varelius, *Lack of Autonomy*, *supra* note 17, at 62; *see also* Singh, *supra* note 16, at 30 (exploring the vulnerability counterargument in the context of expanding MAiD to minors).

[177] Varelius, *Lack of Autonomy*, *supra* note 17, at 62.

[178] *See, e.g.*, Joan Brydan, *MAID Litigant Says Disability Doesn't Make Her Vulnerable to Pressure to End Her Life,* CTV NEWS, (Dec. 16, 2020, 4:28 AM), https://www.ctvnews.ca/canada/maid-litigant-says-disability-doesn-t-make-her-vulnerable-to-pressure-to-end-her-life-1.5233205.

[179] TOM BEAUCHAMP, STANDING ON PRINCIPLES: COLLECTED ESSAYS 41 (2010).

[180] Singh, *supra* note 16, at 30–31.The argument is made with reference to minors but is applicable *mutatis mutandis* to all incompetent patients. This "additional justification invokes the principle of justice by proposing an argument in the form, *if X is available to Y, and Y=Z in some morally relevant way, then X ought to be available to Z*.") *Id.*

incompetent patients from such abuse, as is already the case for other important medical decisions, like invasive surgery or organ donation.[181]

To rebut this counterargument, one may argue that it puts too much faith in the efficacy of safeguards and in the ability of policymakers to formulate their content. Unlike safeguards for voluntary MAiD, safeguards for NVE would have to handle unsolvable disagreements between deeply controversial value judgments. In the context of voluntary MAiD, safeguards mostly consist of a series of steps to ensure free and informed consent, whether or not the patient has internalized ableism. We cannot similarly rely on the principle of respect for autonomy in the case of incompetent patients to solve the hard question of when a life could or should be ended. As we saw, the risks of abuse are higher and more insidious in the case of incompetent patients: they notably include the risk that SDMs would not make decisions in the beneficiary's best interests or would entertain a notion of "best interests" skewed by ableism.[182] Limiting the impact of far-reaching ableist assumptions is no small feat. The very limited ways in which current MAiD safeguards address ableist oppression[183] do not bode well for the likelihood that they would succeed in the case of NVE.

Not only would these safeguards have to address new and harder to curtail dimensions of abuse, but they would also need to propose generalizable protective criteria. It is hard to imagine what these criteria would be or how they would operate in practice. In the case of voluntary MAiD, to secure conditions of uncoerced consent is a potentially achievable and monitorable criterion (whether states will actually carry out effective monitoring is a different question, but it is at least feasible in theory). Curtailing SDMs' ableism and self-interest, and making more room for the idea that a life with severe disabilities may still be worth living, is a much less clear-cut goal. Procedural solutions like requiring two medical practitioners to sign off on the request for NVE, or compelling SDMs to provide reasons for their decision or take a number of days to reflect on it (i.e., voluntary MAiD safeguards) will not resolve deep social disagreements about the value of life. Moreover, such "proceduralist" criteria would multiply foci for potential ableist judgments. The advantage of relying on an autonomous decision-maker to choose death or not is that it circumvents difficult, potentially unsolvable disagreements about the value of life and the morality of euthanasia.

In sum, the individual vulnerability of incompetent patients cannot be addressed by autonomy-protecting measures elaborated for voluntary MAiD and is unavoidably connected to social dimensions of vulnerability, to which we now

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[181] *Id.* at 31; Brown, *supra* note 63, at 185; Varelius, *Lack of Autonomy*, *supra* note 17, at 63; Manninen, *supra* note 15, at 649.

[182] *See supra* Section III.C.

[183] *See* Jonas-Sébastien Beaudry, *Somatic Oppression and Relational Autonomy: Revisiting Medical Aid in Dying Through a Feminist Lens*, 53 UBC L. REV. 241, 270 (2020).

turn.

B. Collective Vulnerability

Incompetent patients may also be vulnerable due to their membership in a historically marginalized group.[184] The SDMs of members of such vulnerable populations (e.g., people who are disabled, sick, mentally ill, or of older age) risk opting for MAiD because of societal failures to provide incompetent patients with the social, economic, and medical means to live a worthy existence.[185] Lack of "rewarding activities that could help improve their daily life,"[186] inhumane treatment in nursing homes,[187] "chronically difficult circumstances (e.g., poverty, homelessness, unemployment),"[188] limited access to "adequate and culturally appropriate mental healthcare"[189] and limited access to palliative care[190] are but a few of the factors that can negatively affect the quality of life of members of one or more of the groups identified above.

For some scholars, these factors provide reasonable grounds to question the immutability or permanency of certain negative quality of life assessments because they could be changed through proper policies and resource allocation decisions.[191]

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[184] This risk is often mentioned in the context of voluntary MAiD, but it applies equally to nonvoluntary MAiD.

[185] *See, e.g.*, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 56–57, 142, 145, 147; Jonas-Sébastien Beaudry, *What's Missing from the Conversation About Assisted Death*, POL'Y OPTIONS (Oct. 16, 2019), https://policyoptions.irpp.org/magazines/october-2019/whats-missing-from-the-conversation-about-assisted-death; Anita Ho & Joshua S. Norman, *Social Determinants of Mental Health and Physician Aid-in-Dying: The Real Moral Crisis*, 19 AM. J. BIOETHICS 52, 52–53 (2019); Jacobs & Lemmens, *supra* note 94; Lemmens, *supra* note 26, at 501.

[186] Beaudry, *supra* note 185.

[187] Jacobs & Lemmens, *supra* note 94 (citing Charlie Fidelman, *Saying Goodbye to Archie Rolland, Who Chose to Die: 'It Is Unbearable,'* MONTREAL GAZETTE (Oct. 21, 2016), https://montrealgazette.com/news/local-news/saying-goodbye-to-archie-rolland).

[188] *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*, *supra* note 143, at 161.

[189] *See id.* at 172–73 (explaining that although accessing mental health care is a challenge across Canada, it is particularly difficult for Indigenous peoples and in rural areas); *see also* Ryan Tanner, *An Ethical-Legal Analysis of Medical Assistance in Dying for Those with Mental Illness*, 56 ALBERTA L. REV. 149, 164 (2018) (discussing how "in a substantial number of cases, a contributor to the suffering of mental illness is the failure of the healthcare system to appropriately respond to mental illness in the first place" (citing Mark Henick, *Why People with Mental Illness Shouldn't Have Access to Medically Assisted Death*, GLOBE & MAIL (May 8, 2016), https://www.theglobeandmail.com/life/health-and-fitness/healthlwhy-people-with-mental-illness-shouldnt-have-acce ss-to-medically-assisted-death/ article29912867.

[190] *See The State of Knowledge on Medical Assistance in Dying for Mature Minors*, *supra* note 43, at 132; Davies, *supra* note 8, at 128–29; *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 147.

[191] *See, e.g.*, Ho & Norman, *supra* note 185, at 53; Beaudry, *supra* note 185.

From this perspective, if "the lack of a broad array of social resources exacerbates people's hopelessness and despair, to the point that death appears to be the only relief from relentless trauma, the right 'treatment' may lie in first building a just society that can reduce people's burden and give them access to opportunities and hope."[192] Helping historically marginalized and stigmatized people to "access the means to live a worthwhile life in a society that has given up on them" is much more challenging than providing them with equal access to MAiD.[193] If we do not want MAiD to become a "release valve"[194] for a collective failure to provide adequate social, economic, and medical support to the most vulnerable individuals, these socioeconomic inequalities should be addressed before expanding MAiD.

For others, although the lack of adequate social, economic and medical means to live a worthwhile existence is problematic, limiting access to MAiD is not a sustainable option if policy changes are not imminent. It is neither just nor humane to impose continued living when it is not in these individuals' interest and their situation is not likely to change anytime soon because of a lack of political will.[195] Rather than protecting vulnerable and marginalized individuals, limiting the expansion of MAiD in this context "compounds our abandonment of them."[196] Some even speculate that allowing MAiD in cases where vulnerable and marginalized individuals or their SDMs are "forced" into hastening their death because of a lack of appropriate support and care could highlight socioeconomic inequalities and motivate the needed change in resource allocation and policy.[197]

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[192] Ho & Norman, *supra* note 185*,* at 53.

[193] Beaudry, *supra* note 185.

[194] *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, *supra* note 81, at 146.

[195] Tanner, *supra* note 189, at 164.

[196] *Id.*; *see also* Brown, *supra* note 63, at 163 (arguing for access to euthanasia by stating that "it is unacceptable to put patients through dreadful suffering now simply because we might, at some point in the future, be able to reduce the suffering of others [through improved palliative care] to a bearable level")

[197] *See, e.g.*, Tanner, *supra* note 189, at 164–65 ("Allowing assisted dying in these cases offers the sufferers a way out where they otherwise have none, and furthermore, seeing people forced into assisted dying in such cases could bring into relief the inadequacies of mental health treatment and motivate positive change. *Everyone* would hate for someone to not get proper treatment and feel like there is really no other way to relieve themselves of the suffering but to consider physician-assisted death."). Note that although Tanner makes this argument in the context of expanding MAiD to competent mental health patients, it could apply also in the context of incompetent patients lacking meaningful access to resources other than mental health resources. *See also The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*, *supra* note 143, at 171 (speculating that expanding access to MAiD where a mental disorder is the sole underlying medical condition "may increase resources directed to mental healthcare and social support services, as was the case with palliative care in Oregon, Belgium, Quebec, and the rest of Canada following legalization of assisted dying"); Joshua James Hatherley, *Is the Exclusion of Psychiatric Patients from Access to Physician-Assisted Suicide Discriminatory?*, 45 J. MED. ETHICS 817, 818–19 (2019) ("It is equally plausible that the institutionalization of PAS for psychiatric

Existing MAiD safeguards, which are largely centered on classical liberal conceptions of consent and autonomy, suggest that states where MAiD is legal have limited capacity or political will to palliate social vulnerability in the context of MAiD. Legalizing NVE, given these shortcomings, would normalize, rather than problematize, the eugenic dimensions and implications of NVE programs. It would *also* make it possible to end the lives of incompetent patients who would truly benefit from euthanasia. It is therefore necessary to finetune unique responses to reconcile these grave and tragically diverging ethical pulls. We use the word "tragic" because there may not be a perfect solution that is without moral blemish. However, even tragic and imperfect policies can be democratic (committed to serving as many perspectives and interests as possible) if they duly avoid unnecessarily sacrificing the interests of some to protect the interests of others. Securing access to robust pain management measures for incompetent patients is an example of such an imperfect compromise. The evolution of MAiD policies so far, and our commitment to taking rights seriously (as we discuss in the next Part), makes the alternative of embracing NVE a less democratic solution, with unavoidable eugenic dimensions. This assessment may change if and when our societies take social vulnerability more seriously.

VI. CONSIDERATIONS OF JUSTICE

The final part focuses on considerations of justice with inform NVE discussions. First, we introduce the concept of distributive justice, in which NVE is argued for on the basis of appropriate and equitable distribution of resources and note the how NVE advocates focused on beneficence may object to or alter the scope of distributive justice justifications in the context of NVE. Finally, we provide a framework for analyzing the question of justice through a disability lens to demonstrate the weakness of distributive justice as argument for NVE.

A. Distributive Justice: MAiD as a Form of Rationing

Some argue that non-voluntary MAiD must be legalized by virtue of distributive justice. This notion refers to "fair, equitable, and appropriate distribution in society."[198] Margaret Battin, for instance, argues that when resources are limited, "it is better to deny [treatment] just to those people who are . . . medically unsalvageable and will die soon anyway: the terminally ill, the extremely aged, and the seriously defective neonate."[199] She extends this logic to justify actively ending individuals' lives through MAiD. From her perspective,

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suffering may stimulate greater care and productivity in psychiatry and medical research.").

[198] BEAUCHAMP, *supra* note 179, at 41.

[199] MARGARET PABST BATTIN, THE LEAST WORST DEATH: ESSAYS IN BIOETHICS ON THE END OF LIFE 114 (1994).

MAiD is more economical than prolonged care and could result in significant resource savings; hence, legalization helps to bring about justice in a society with finite resources.[200]

Scholars in favor of MAiD on grounds of beneficence may disagree with this conclusion. For instance, Savulescu believes such claims to be invalid because we cannot "harm someone to save resources."[201] As he explains, distributive justice "is about who gets a slice of some finite cake. It is about giving public goods to some, but not others. It is not typically about doing things to people actively, in particular killing them, to bring about a just state of affairs."[202] Thus, to bring about justice, MAiD has to be considered only in cases where death is in the individual's best interests.[203] Otherwise, the action amounts to murder, not MAiD.[204] Yet, scarce resources can legitimately limit the social, economic, and medical means available to support someone. If such deprivation is the source of a person's intolerable suffering, MAiD can be envisioned as an option to relieve her.[205] If so, the person's interests, "given the constraints of scarce resources and the moral imperative to distribute these justly,"[206] justify MAiD. Distributive justice, however, "does not directly or necessarily require that we kill."[207]

In short, from this perspective, MAiD is justified solely when it can be shown that it is in the individual's best interests.[208] However, determining when death is in an incompetent patient's interests is, as we have seen so far, subject to great debate.[209] It is almost impossible to identify an objective threshold which, once crossed, allows us to confidently affirm that one's quality of life is so poor that death is better than continued existence.[210] This is why Savulescu identifies two additional circumstances when NVE can be justified by virtue of distributive justice: regardless of the difficulty of assessing objectively someone's interest in dying, he contends that NVE is ethically justifiable for cost-saving reasons when the individuals in question will certainly die soon (in a matter of days or weeks)[211] or when they display a lack of psychological continuity and connectedness.[212]

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[200] *Id.* at 115.

[201] Savulescu, *supra* note 81, at 36.

[202] *Id.*

[203] *Id.*

[204] *Id.*

[205] *Id.* at 36–37.

[206] *Id*. at 37

[207] *Id*.

[208] *Id.* at 40.

[209] *See supra* Part III.

[210] Savulescu, *supra* note 81, at 42.

[211] *Id.* at 46–47 ("Their deaths could be caused either by their disease or by limitation of life prolonging medical treatment, including the withholding or withdrawing of artificial nutrition. In such cases, non-voluntary AME would save resources over a slower death.").

[212] *Id.* at 42–44, 47 (explaining that in such cases, death is not harmful, and the wrongness of

These two arguments are susceptible to attract the support of scholars who adhere to a hypercognitive understanding of personhood for whom either the state of personhood is restricted to patients with a certain threshold of cognition, or those with a lack of psychological continuity or connectedness mean they have less moral value than those currently with a sufficient level of cognition. However they are likely to be opposed by a number of scholars for whom NVE in the absence of suffering results in an unjustifiable violation of the incompetent patient's right to life, on the basis that incompetent patients have the same intrinsic right to life as any person, which is not disrupted by their level of cognition, psychological continuity or connectedness.[213]

B. Justice Through a Disability Lens

Theorists of fairness, following a "luck egalitarian" logic (i.e., a commitment to redressing misfortunes resulting from unchosen natural or social situations[214] may argue that enhanced, rather than reduced, health resources ought to be redirected towards incompetent patients for two possible reasons. First, incompetent patients suffering a great deal may be said to be disadvantaged through no fault of their own, and therefore deserve compensation. Second, in the case of infants who have not had the opportunity of experiencing key facets of a human life, assuming this is an experience worth having at all, an egalitarian logic could justify prioritizing their needs considering this particular disadvantage. This argument is more powerful if one conceives of the value of experiencing a human life and/or certain of its benefits (e.g., a relationship with a caregiving parent) as quantitatively or qualitatively superior to, or even incommensurable with, the value of diminishing the subjective experience of pain.

Liberal rights-based approaches also have trouble accommodating the notion of tradability of human life for economic reasons. This is because of the qualitative or "lexical" priority such approaches give to basic liberties, including the right to life, as life is a *sine qua non* condition to enjoy any other rights or liberties.[215] Rights, if they are to be meaningful, must be able to trump this utilitarian logic.[216] The idea that "[b]udgetary considerations in and of themselves cannot normally be invoked as a free-standing, pressing and substantial objective for the purposes [of

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killing is lessened and sometimes even eliminated).

[213] *See, e.g.*, Singh, *supra* note 16, at 72; Hertogh, *supra* note 69, at 223.

[214] *See, e.g.*, KASPER LIPPERT-RASMUSSEN, LUCK EGALITARIANISM 1–4 (2015).

[215] *See generally* JOHN RAWLS, A THEORY OF JUSTICE (1971) (articulating this particular argument). In Rawls's framework, this means that the right to life is so fundamental that it cannot be traded or compromised for other benefits.

[216] *See generally* RONALD DWORKIN, TAKING RIGHTS SERIOUSLY (2013) (articulating this particular argument). Within Dworkin's framework, if rights are to be taken seriously, they cannot be overridden by ordinary utilitarian considerations.

justifying a violation to the rights listed in the Canadian Charter of Rights and Freedoms in the Canadian Constitution]" is present in legal interpretations of constitutional rights as well.[217] In bioethics, the practice of using quality of life assessments to manage limited health resources and justify the sacrificing of a life has been criticized for failing to treat individuals with equal concern and respect.[218]

More specifically, Western political and legal cultures do not rank rights along a spectrum of stringency, whereby the rights of some warrant greater protection than those of others. While it seems logical to treat rights in this scalar way if they are conceptualized as mapping onto a scalar conception of moral status, or as reflecting varying interests and capacities, this conception of rights would be incompatible with egalitarian commitments and the universalism of human rights.[219] Even scholars who problematize the foundations of Western legal orders' egalitarian commitments and defend a scalar view of moral status agree that

> it would be dangerously invidious to give public expression to a view that accords a higher degree of moral inviolability to people with higher psychological capacities or a worthier moral nature. Even if such a view were true, it is virtually certain that if it were widely exposed and recognized as true, it would then be distorted or otherwise abused in efforts to justify the unjustifiable.[220]

In terms of equality rights, some have suggested that "disability," in and of itself, should never constitute a basis for granting MAiD.[221] This is because disability is a marker of identity, like being Black, Indigenous, or Jewish, and clearly, none of these other identities should be used as a basis to qualify for

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[217] Nova Scotia (Workers' Compensation Board) v. Martin, 2003 SCC 54, at para. 109 (Can.).

[218] *See* Harris, *supra* note 61, at 118–22.

[219] *See, e.g.*, G.A. Res. 217, *supra* note 150, preamble; Charter of Human Rights and Freedoms, *supra* note 150, arts. 1, 4, 10; G.A. Res. 61/106, *supra* note 158, at arts. 1, 5, 12; Canadian Charter of Rights and Freedoms, *supra* note 150. For a critique of this common egalitarian presumption and an unusual defence of a "two-tiered" theory of moral standing justifying gradients in the wrongness of killing below a certain cognitive threshold, see Jeff McMahan, *Challenges to Human Equality*, 12 J. ETHICS 81, 104 (2008).

[220] *Id*.

[221] United Nations Special Rapporteur on the Rights of Persons with Disabilities, the Rapporteur on Extreme Poverty and Human Rights & the Independent Expert on the Enjoyment of All Human Rights by Older Persons, quoted in *Disability Is Not a Reason to Sanction Medically Assisted Dying – UN Experts*, UNHR OFFICE OF THE HIGH COMMISSIONER (Jan. 25, 2021), https://www.ohchr.org/en/press-releases/2021/01/disability-not-reason-sanction-medically-assisted-dying-un-experts ("[The experts expressed] alarm at the growing trend to enact legislation enabling access to medically assisted dying based largely on having a disability or disabling conditions, including in old age. . . . Under no circumstance should the law provide that it could be a well-reasoned decision for a person with a disabling condition who is not dying to terminate their life with the support of the State.").

euthanasia programs.

More importantly, equality rights can also be interpreted to entail positive obligations on the part of states to remedy systemic discrimination and widespread harms, be they symbolic or not.[222] Interpreted in this way, rights to life and equality may not necessarily require banning voluntary MAiD, but would require providing a wider array of options to citizens. Societies committed to respecting life, liberty, and equality ought to ensure that sufficient resources and supports are provided to people who are contemplating MAiD, so that citizens do not die "deaths of despair"[223] due to neglect and social injustice, or insufficient care and support system arrangements. Equipped with more options and resources, individuals faced with the decision of whether to die would therefore be more autonomous and less subject to the forces of ageist and ableist oppression, both external and internalized.

However, first, this particular remedy (redistribution to enhance autonomy) does not apply in the same way for incompetent patients and, second, distributive injustice is only one of the various kinds of injustice suffered by people with disabilities. Other forms of injustice experienced by people with disabilities include epistemic injustice and status-based injustice. Epistemic injustice may correspond to an assumption that their quality of life and well-being is lower than it is.[224] Status-based injustice occurs when their standing as right-holders and legal personhood are unduly challenged.[225] Incompetent patients face incommensurably greater obstacles in overcoming the epistemic and status-based injustice victimizing them. In particular, the epistemic distance between their subjective experience of life and society's appreciation of their suffering can be abyssal; after all, they belong to a category of human beings whose status as members of political and moral communities has been systemically put into question. Given this bleak, longstanding history of injustice, vulnerable citizens are at the mercy of medical experts and their SDMs and can, in some cases, only rely on robust conceptions of the rights to life and equality to stand between themselves and rightlessness.

In summary, legalizing NVE in the name of considerations of *justice,*

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[222] *See e.g.*, Sandra Fredman, *Providing Equality: Substantive Equality and the Positive Duty to Provide,* 21 SAJHR 163, 163 (2005).

[223] We borrow this expression from CASE & DEATON, *supra* note 86, to refer to deaths of potentially socially preventable despair—in contrast to deaths that are medically unavoidable.

[224] Epistemic injustice refers to the systematic devaluation or disregard of statements made by certain groups, often due to prevailing negative social stereotypes associated with them. This concept is instrumental in recognizing instances of unjust exclusion, such as the marginalization of patients, and the disproportionate privileging of certain voices, typically those of experts, in discourse. *See* ELIZABETH BARNES, THE MINORITY BODY: A THEORY OF DISABILITY 168–84 (2016).

[225] *See* Elizabeth Purcell, *Oppression's Three New Faces: Rethinking Iris Young's "Five Faces of Oppression" for Disability Theory*, *in* DIVERSITY, SOCIAL JUSTICE, AND INCLUSIVE EXCELLENCE: TRANSDISCIPLINARY AND GLOBAL PERSPECTIVES 185, 198–200 (Seth N. Asumah & Mechthild Nagel eds., 2014).

including the distributive arguments incorporating best interests discussed in Part 7.1, is a *prima facie* weak or paradoxical argument. This is because the countervailing distributive, epistemic and status-based injustices experienced by incompetent patients outweigh positive justice-based considerations in favour of NVE.

CONCLUSION

In addition to providing a broad, interdisciplinary survey of recent ethical and legal scholarship on the topic, this Article concludes that the strongest arguments in favor of legalizing NVE are based on the beneficent goal of attenuating the intense suffering of incompetent patients. However, beneficence-based arguments are insufficient to justify legalizing NVE, because of countervailing considerations. These countervailing considerations sufficiently implicate equality and human rights, such that the main objections to this Article's conclusion that beneficence is an insufficient justification for legalizing NVE, are based on a position that is incompatible with typical liberal commitments to human rights and equality.

Fleshing out a substantive theory of the ethical and legal permissibility of NVE would require further work. However, our critical review of theoretically and politically salient arguments about NVE leads to the following tentative conclusions. First, the beneficence-based argument is by far the strongest argument in favor of legalizing NVE. Second, as they currently stand, beneficence-based arguments are insufficient to justify legalizing NVE, because of countervailing considerations. Third, these countervailing ethical considerations have not received sufficient attention within policy discourses dominated by values of autonomy[226] and pain-relief,[227] and deserve further research. They include concerns with systemic oppression, social inclusion and the rights of stigmatized populations, individual and social vulnerability, and the fact that (potentially aggressive) palliative care would often suffice to respond to immediate physical pain. Fourth, these considerations apply more forcefully to the case of incompetent patients. Not only do these considerations not pertain to voluntary MAiD to the same degree, but they are also—sometimes—outweighed by extremely compelling autonomy-based reasons in favor of voluntary MAiD. In summary, that these considerations weigh against NVE suggests that its legalization would rest on morally and legally precarious grounds. Lifting the express prohibition on NVE without more robust socio-economic or technological reforms addressing these concerns seems *prima facie* incompatible with typical liberal commitments to

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[226] *See* Jonas-Sébastien Beaudry, *The Way Forward for Medical Aid in Dying: Protecting Deliberative Autonomy is Not Enough,* 85 SUP. CT. L. REV. 335 (2018) at 337.

[227] *See* Beaudry, *supra* note 26, at 341, 352.

human rights and equality. States should nonetheless, for many of the reasons examined in this Article, encourage the development of targeted palliative measures to respond to the physical suffering experienced by incompetent patients. Furthermore, a comprehensive discussion of the ethical complexities surrounding prospective autonomy[228] and supported decision-making[229] in the context of assisted dying requires future exploration.

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[228] *See generally* Rich, *supra* note 5 (describing the major arguments for and against the moral and legal authority of advanced directives and finding the narrative articulation of a single self with multiple life stages the most persuasive defence for advanced directives).

[229] *See, e.g.*, Brenna M. Rosen, *Supported Decision-Making and Merciful Health Care Access: Respecting Autonomy at End of Life for Individuals with Cognitive Disabilities*, 80 WASH. & LEE L. REV. 555, 560 (2023); Leslie Francis, *Supported Decision-Making: The CRPD, Non-Discrimination, and Strategies for Recognizing Persons' Choices About their Good*, 1 J. PHIL. DISABILITY 57, 57–60 (2021).