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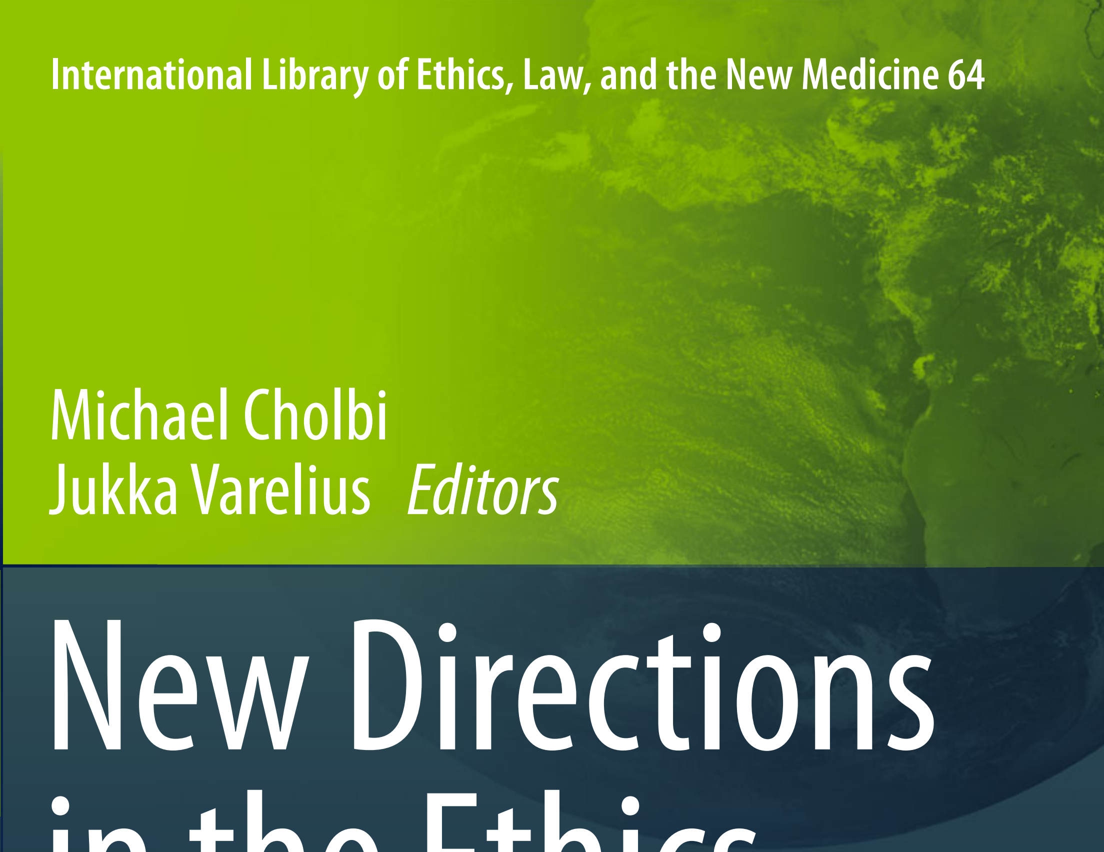

New Directions in the Ethics of Assisted Suicide and Euthanasia

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Chapter 1
Introduction

Michael Cholbi and Jukka Varelius

Although euthanasia or assisted suicide have been practiced for at least two millennia, the current scholarly debate about assisted dying began to take shape in the 1950's and 1960's. Thanks to a confluence of developments during that period, death became increasingly 'medicalized,' i.e., the time or manner of a person's death fell more and more under human technological control. One such development was changes in patterns of mortality wherein chronic degenerative illnesses such as cancer or organ failures supplanted accidents or infectious disease as the most common causes of death. Deaths of the former sort are typically preceded by lengthy courses of treatment and tend to culminate in dying that is medically supervised. Furthermore, intensive care and life support technologies enabled medical professionals to prolong, or even halt, the process of biological death. These developments tend to put death and dying within the scope of human agency: More and more, death occurs due to choices made near the end of life. The contemporary debate about assisted dying largely revolves around who may exercise such agency and under what conditions.

Physician-assisted dying thus became, along with abortion and research abuse, one of the central topics driving the emergence of contemporary bioethics. Medical professionals, philosophers, ethicists, theologians, and legal scholars have generated a scholarly literature on assisted dying consisting of hundreds of books and thousands of articles, written in multiple languages. It is nevertheless possible to identify four central threads in the debates laid out in this vast literature. The first of these centers on the moral norms that regulate the behavior of medical professionals and the compatibility of those norms with physician-assisted death. Some

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organizations of medical professionals, such as the American Medical Association (AMA), maintain that medicine has been historically defined by a categorical moral norm against doctors killing their patients (or enabling their patients to kill themselves). In a similar vein, some authors insist that medical morality is absurd unless doctors have an indefeasible duty to abstain from killing. This view entails that whatever the other merits of assisted dying, permitting physicians either to assist in their patients' suicides or to kill their patients is too great a deviation from this norm. Proponents of physician-assisted death maintain that the interpretation of medical morality that unconditionally prohibits doctors from ending their patients' lives is a misinterpretation. Proper moral norms for medical professionals entail, advocates of physician-assisted death argue, that when a patient's suffering is unbearable to him and there is no way of adequately alleviating it other than ending his life a doctor ought to adhere to the patient's request to be helped to die. There are no esoteric moral norms internal to the profession of medicine that could outweigh this duty (see, e.g., Garcia 2007; Pellegrino 2001a, b; Seay 2011).

A second thread in this debate concerns the nature of a person's involvement in bringing about another person's death. As mentioned above, some opponents of assisted dying contend that physicians may not kill their patients. However, the current ethical and legal consensus is that physicians are morally obligated to honor patients' decisions to forego or cease treatments that may extend their lives (for example, cancer patients opting not to receive additional chemotherapy or terminally ill individuals who request removal of life support).[1] On its face, these claims seem to be in tension with the aforementioned precept that doctors may not kill their patients. How, advocates of a right to physician-assisted dying ask, can doctors have a right knowingly to hasten death without also having a right to assist their patients in dying or to kill patients who request it?

Here opponents of physician-assisted dying invoke several different distinctions. One is the distinction between *killing* and *letting die*. Opponents of physician-assisted dying argue that doctors may let a patient die, but may not kill a patient. Physician-assisted dying is thus ruled out, but measures through which a patient dies due to the progress of her illness are not. A second apparently relevant distinction is between *acts* and *omissions*: When a doctor assists a patient to die, the death results from the doctor's positive act, whereas (for instance) when a doctor does not administer potentially life extending treatment to a patient who competently declines the treatment, the death results from the doctor's omission, that is, from the doctor from refraining from acting. The former, it is argued, is morally impermissible, the latter morally permissible. A third distinction invoked in this regard, associated with the Doctrine of Double Effect, is between death being *intended* as an outcome of one's actions and death's being merely a *foreseen* outcome of one's actions. According to this doctrine, it is permissible to act so that one foresees an otherwise morally impermissible outcome (for example, the death

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[1] The latter, withdrawing life-sustaining measures, has come to be known as 'passive' euthanasia.

of an innocent person) so long as (a) that outcome is not intended, and (b) a sufficiently good outcome is intended instead. Applied to practices such as abortion to save a mother's life, the doctrine appears to permit doctors acting in the awareness that death will result so long as death is not intended. Assisted suicide and euthanasia are similarly precluded because their intent is death, whereas withdrawing treatment, etc., result in deaths that are merely foreseen.

All three of these distinctions involve different ways in which an exercise of agency can bring about another person's death. If plausible, such distinctions could explain why killing a patient (or assisting in her death) is impermissible although acts that knowingly lead to a patient's death are not necessarily impermissible. Unsurprisingly, advocates of physician-assisted dying question both the coherence and moral significance of these distinctions. To such advocates, delineating between morally permissible and morally impermissible measures all of which knowingly result in a patient's death fails either because the distinctions themselves cannot be made out precisely or because the distinctions cannot bear the moral weight their advocates assign to them.

While some arguments in defense of these distinctions merely restate them, some novel defenses of the divisions have been presented. Yet advocates of physician-assisted death have usually not found the new defenses more convincing than the older ones. Some of them have even claimed that the distinctions are nothing but 'moral fictions,' ad hoc metaphysical devices used to buttress otherwise groundless moral positions. Not unpredictably, opponents of physician-assisted death have denied this. Some of them have argued that the distinctions between acts and omissions and between foreseeing and intending can still be relied on in the context of end-of-life decision-making (cf., e.g., Miller et al. 2009; Huddle 2012; McLachlan 2011).

The third thread in debates about assisted dying concerns how respect for patient autonomy and beneficence determine the moral and legal acceptability of physician-assisted death. The four principles approach introduced by Tom Beauchamp and James Childress (1979) has been highly influential in bioethics. Advocates of physician-assisted dying often appeal to two of these principles in justifying their position: the principle of respect for patient autonomy, that patients (at least when competent) have the primary right to determine which treatments or interventions they will be subject to, and the principle of beneficence, that medical professionals should act so as to benefit their patients. According to many advocates of physician-assisted dying, so long as it in a patient's interests and the patient provides informed consent, patients have a right to physician-assisted dying no less forceful than their right to other medical interventions.

Just as with the previous two threads, the third thread of the modern debate remains contentious. For advocates of physician-assisted death, the legalization of physician-assisted dying that has already occurred within some jurisdictions appears as "the triumph of autonomy" in bioethics and public policy. Yet opponents of physician-assisted death insist that the two principles are far too abstract and too few in number to adequately account for all the complexities, nuances, and ambiguities related to concrete end-of-life decision-making. With respect to autonomy, they dispute both whether the conditions for informed, rational consent to one's own death can be met and whether the value of autonomy should be accorded primacy in medical decision making. With respect to beneficence, opponents of physician-assisted dying question whether, given the value typically attached to human life, ending a person's life can really be a beneficent act. Furthermore, they maintain that much more research concerning the principles, possible alternative starting points for assessing questions related to physician-assisted death, and the specific features of the kinds of cases in which end-of-life choices would be made is needed for it to be possible to adequately assess the moral and legal acceptability of physician-assisted death. Again, proponents of physician-assisted death have not been convinced by these strategies. Some of them have even proposed that the call for more research is simply a strategy by which opponents of physician-assisted death try to retain the *status quo* in which the procedures remain illegal in most jurisdictions. In this view, the purpose of opponents of physician-assisted death is to ensure that the moral and legal acceptability of such procedures remains under "interminable scrutiny" (see, e.g., Beauchamp 2006; Parker 2005).

A final thread in these debates is less about physician-assisted dying per se than about the predicted consequences of its legalization or acceptance. Opponents of physician-assisted dying may concede that euthanasia or assisted suicide are morally permissible if undertaken voluntarily, etc., but nevertheless contend that the acceptance of such practices would weaken our general respect for human life and the prohibition on killing. As a consequence, other more morally objectionable practices, such as involuntary euthanasia or the killing of the disabled, would emerge. Such *slippery slope* worries reflect anxieties about societies' ability to implement physician-assisted dying without inviting abuse or corrosion of moral standards.

While the claims that permitting physician-assisted death would have devastating societal consequences were once difficult to evaluate, the legalization of the procedures within some jurisdictions has allowed for the possibility of conducting empirical studies by which to assess such claims. According to the pertinent empirical research done so far, the number of deaths has not dramatically increased in the jurisdictions that allow (some form of) physician-assisted death, members of vulnerable groups have not been pressured to die against their will, and no signs of general devaluation of human life can be detected within the jurisdictions examined. Yet these kinds of research results have not persuaded those who advocate slippery slope arguments against physician-assisted death. The advocates of the arguments have responded by maintaining that the research results from the so far rather few jurisdictions examined cannot be generalized so that the case for the procedures in some other areas, and still less in general, could be assessed on their basis. It has also been suggested that the examinations have been methodologically inadequate so that the data they provide do not reliably describe the situation even in the jurisdictions they studied. (cf., e.g., Rietjens et al.

2009; Materstvedt 2009) Advocates of physician-assisted death may be inclined to interpret such doubts as nothing more than further strategic moves in the debate.

While this overview gives a rather gloomy picture of the modern debate, it would be unfair to say that no progress has occurred. For instance, though the plausibility and usefulness of the results of the empirical studies on the effects of legalization of physician-assisted death remains debated, that such studies have been made and their results are being discussed is arguably a step forward. At least, the discussion can direct future research towards the right path so that adequate data relevant to assessing the slippery slope arguments is ultimately acquired. For another example, there have been some attempts to find novel solutions that would satisfy both proponents and opponents of physician-assisted death. Perhaps the most noteworthy of them is the procedure called terminal sedation in which the decision to provide palliation to a suffering patient is accompanied by the decision to forgo the provision of nutrition and hydration and, accordingly, the ultimate result is the patient's death. Yet insofar as terminal sedation is very similar to active euthanasia, opponents of physician-assisted death are unlikely to accept the procedure. And to the extent that it does not provide a patient with the kind of ending for her life that she would autonomously want, terminal sedation may not satisfy those proponents of physician-assisted death who emphasize the value of patient autonomy (cf., e.g., van Delden 2007).

Why have the opposing camps failed to reach a consensus or even a general agreement on the moral and legal acceptability of physician-assisted death? There are three possible diagnoses. In a *pessimistic* view, the starting points and values of proponents and opponents of physician-assisted death are in many respects so different from each other that their achieving any agreement on the matter is impossible. On this view, the controversy between advocates and opponents of physician-assisted death is interminable. A *moderate* view entails that although the two parties in the debate will continue to endorse differing points of departure and values related to end-of-life questions a practical compromise that satisfies both of them can be found. In the most *optimistic* view, further investigation into the pertinent questions will ultimately lead to a full rational resolution of the debate.

We take no stance on which of these three diagnoses is correct. However, regardless of which of these diagnoses proves correct, it seems clear that the modern debate has stagnated, and as a result, the ethical and legal debates surrounding assisted suicide and euthanasia would benefit if they were to expand beyond their narrow focus on the four aforementioned threads. Taking a broader range of perspectives, evidence, and arguments into account may help us to see assisted dying in a new light, and more optimistically, help to determine which of the above three positions—the pessimistic, the moderate, or the optimistic—is the correct one. This volume was developed with precisely that purpose in mind, to showcase scholarship that investigates the ethics or legality of physician-assisted dying from fresh points of view. Our hope is that engaging with this scholarship will challenge those who believe that assisted dying remains a high stakes issue to think more imaginatively about it and refine their positions accordingly.

The first three chapters raise challenges to what has become perhaps the most common defense of physician-assisted dying, that individuals are autonomous and so have the right to determine the manner or circumstances of their deaths, including a right to enlist the help of others to bring about their deaths. Emma C. Bullock ("Assisted Dying and the Proper Role of Patient Autonomy") considers the role of patient autonomy in justifying physician-assisted dying. Bullock argues that the fact that a patient autonomously chooses to die does not entail that dying is in her best interests. On the contrary, evidence from psychology and behavioral economics indicates that we often fail to make rational self-determining choices. Bullock proposes that the place of autonomy is therefore not to serve as an index of a patient's interest in dying. Rather, autonomy is better seen as a "side constraint" that permits physician-assisted dying when it is also objectively in the patient's best interests. Of course, advocates of "strong" paternalism have long believed that we ought to prevent suicide and assisted dying when it is not in a person's best interests. Thomas Schramme ("Preventing Assistance to Die: Assessing Indirect Paternalism Regarding Voluntary Active Euthanasia and Assisted Suicide") addresses a variation of this paternalist argument: that there may be "indirect" paternalistic grounds for interfering with assistance in some suicides even if there are not legitimate grounds for interfering with the suicidal acts themselves. Schramme notes that the introduction of a third party assistant into the equation complicates the underlying ethical issues, especially given the possibility that suicidal individuals may not have a justified entitlement to assistance in dying. Ultimately, Schramme concludes that the indirect paternalist argument does not succeed in showing that suicidal individuals cannot have a right to the assistance of others. For such individuals may genuinely need such assistance in order to exercise their right to die and those who provide it are enabling suicidal persons to pursue the morally legitimate end of minimizing their own suffering. Julian Savulescu ("Autonomy, Interests, Justice, and Active Euthanasia") shares Bullock's skepticism regarding the power of autonomy to justify physician-assisted dying in a straightforward way. In his estimation, appeals to autonomy do not show that those who wish to be helped to die have a claim to active euthanasia on the part of medical professionals. Simply having a preference for ending one's life prematurely cannot, Savulescu argues, ground a claim to active euthanasia. Savulescu also rejects the other main arguments presented for physician-assisted dying so far. However, he contends that patients who voluntarily undergo palliated starvation, believing that this in their best interests, have a right to do so based on respect for autonomy. But in such cases, a person may well die more quickly, and thereby make use of fewer medical resources, if she were to undergo active euthanasia. The proper ethical basis for active euthanasia is therefore respect for autonomy together with distributive justice, according to Savulescu.

Chapters 5–7 attempt to extend the existing debate into a highly controversial area, physician-assisted dying for those suffering from mental illness, decline, or distress. In "Mental Illness, Lack of Autonomy, and Physician-assisted Death," Jukka Varelius argues that physician-assisted suicide could be morally permissible for psychiatric patients facing unbearable and incurable suffering, even if those patients lack the autonomy to opt for assisted dying. Varelius proposes that lacking autonomy need not be a decisive reason to deny assisted suicide to such individuals, for here the value of patient autonomy is primarily instrumental, that is, that autonomy is not to be respected for its own sake but because autonomous choices are likely to reflect individuals' conceptions of how their lives should go. He also suggests that the suffering of non-autonomous patients can be morally more significant than that of autonomous patients. Accordingly, non-autonomous patients with unbearable and incurable suffering have compelling reasons to seek to end their lives that an autonomous person would endorse. Kasper Raus and Sigrid Sterckx ("Euthanasia for Mental Suffering") consider whether a right to euthanasia can be extended to individuals with physical suffering without also extending a similar right to patients with mental suffering, which they define as suffering that is not caused by any diagnosable physical or psychiatric condition. As they see it, there is no a priori basis for denying the right to euthanasia to individuals in the latter category given that their suffering is not crucially different from the physical suffering often thought to justify euthanasia. That said, Raus and Sterckx are reluctant to endorse euthanasia for mental suffering, in part because if it were administered by medical personnel, it would amount to treating mental suffering as medical in nature. Dementia is another condition where questions about the justifiability of physician-assisted dying have been raised. Jocelyn Downie and Georgia Lloyd-Smith ("Assisted Dying for Individuals with Dementia: Challenges for Translating Ethical Positions into Law") investigate whether those with dementia would be able to access assisted dying within the various jurisdictions that presently permit it. They find that despite many individuals reporting that they would want access to assisted dying were they to develop dementia, the very features of the laws that license physician-assisted dying for other conditions often preclude its being available for dementia. For example, dementia patients are not terminally ill until late in the progression of their disease, have suffering that is primarily mental or existential rather than straightforwardly physical, often lack competence, and are unable to communicate their wishes. Downie and Lloyd-Smith conclude with a critical examination of a recent legislative proposal in Canada that may provide wider access to physician-assisted dying for those with dementia.

The next three chapters raise novel questions about the ethical responsibilities of clinicians with respect to physician-assisted dying. David M. Adams ("Clinical Ethics Consultation and Physician-assisted Suicide") starts from the fact that nowadays, many key care decisions made in medical settings involve professional consulting ethicists. Consulting ethicists typically assist family members, patients, and medical personnel in deliberating about morally complex care decisions. Adams proposes that currently accepted conceptions of the aims and principles meant to guide clinical ethics consultation are deficient when it comes to consultation regarding physician-assisted suicide. According to these conceptions, clinical ethicists are to provide counsel on the basis of current law, institutional policies, professional standards, scholarly consensus, and prevailing practices. In the case of assisted suicide, current law and institutional policies are in flux, professional standards do not all align, and no scholarly consensus exists regarding the ethics of physician-assisted dying. In light of the unsettled legal and moral status of assisted suicide, Adams concludes that clinical ethicists must engage the relevant parties in a process of moral inquiry and deliberation aimed at reaching a shared agreement among them as to whether assisted suicide should be permitted in a given case. As noted above, much of the literature on physician-assisted dying is concerned with whether it is compatible with the established norms of the medical profession. Richard Huxtable and Jonathan Ives ("Licence to Kill: A New Model for Excusing Medically Assisted Dying?") suggest a new way of thinking about this matter. Acknowledging that there are reasonable grounds both for permitting and prohibiting physician-assisted dying, they propose a compromise or "middle way" that is novel in two respects. First, they suggest that only medical specialists trained in assisted dying ("thanatologists") be allowed to assist patients to die. Secondly, rather than conferring prospective legal immunity on thanatologists when they participate in assisted dying, Huxtable and Ives suggest that thanatologists may be retrospectively excused for assisting in dying if certain conditions are met. In their estimation, this compromise may satisfy both advocates and opponents of physician-assisted dying insofar as it retains the presumption that physician-assisted dying is wrong but permits thanatologists to rebut this presumption in particular cases. "Medically Enabled Suicides," by Michael Cholbi, considers whether medical professionals have an obligation to involve themselves in patient deaths even when their involvement does not take the form of direct assistance. Cholbi considers a category of suicides wherein individuals both intentionally put themselves in a particular physiological condition (for example, a planned drug overdose) and make use of existing treatment protocols, such as advance directives, that direct medical personnel to withhold or withdraw medical interventions. Such patients intentionally end their lives, and hence engage in suicide, when they die as a result of such protocols being honored. Cholbi proposes that these medically enabled suicides are likely to be attractive to those for whom assisted dying of the usual kind is not legally or practically feasible. He argues that neither the apparent harmfulness of suicide nor medical professionals' conscientious objection to participating in their patients' death are sufficient to show that such professionals may refuse to involve themselves in medically enabled suicides.

Chapters 11 and 12 relate physician-assisted dying to other medical technologies or techniques. David Shaw ("Saving Lives with Assisted Suicide and Euthanasia: Organ Donation After Assisted Dying") explores the benefits of allowing those who engage in physician-assisted dying to donate their organs and the force that such a possibility has in augmenting the case for legalizing physician-assisted dying. Doing so, Shaw argues, is harmless and would increase the number of organs available for transplant while ensuring that healthy tissues do not go to waste. Donating one's organs after assisted dying also enables the dying to bear the burdens of death more easily. While Shaw is concerned with the ethical intersection of natural organ donation and end-of-life decisions, Michael Gill

("Implanted Medical Devices and End-of-Life Decisions") addresses the ethics of deactivating artificial organs and other life-sustaining devices that have already been implanted in individuals. As Gill sees it, deactivating such organs or devices is unsettling because it brings two established tenets of medical ethics into conflict. On the one hand, deactivating such organs or devices seems like an example of withdrawing life-sustaining treatment, which many see (at least when done at the patient's competent request) as morally equivalent to permissible withholding of medical interventions. On the other hand, deactivating these organs or devices harms patients, in violation of the bioethical principle that doctors may not intentionally harm their patients. Gill argues that the moral equivalence is sufficient to justify doctors deactivating these devices when competent patients refuse it, and the prohibition on harming patients is not sufficient to justify doctors refusing to participate in deactivation.

The final two chapters bring two recent developments in philosophical methodology to bear on assisted dying. Adam Feltz ("Everyday Attitudes about Euthanasia and the Slippery Slope Argument") applies the methods of experimental philosophy to ascertain some common attitudes toward the ethics of euthanasia. In a pair of studies, Feltz found that describing euthanasia differently (as 'euthanasia,' 'aid in dying,' etc.) has rather modest effects on experimental subjects' judgments regarding whether euthanasia is ethically permissible. Feltz also found that subjects' judgments about its ethical permissibility were significantly influenced by whether the treatment was perceived as voluntary, an influence greater than general demographic differences and differences in more general moral judgments. In other words, test subjects generally gave little credence to the distinction between active and passive euthanasia, but find euthanasia increasingly problematic the less voluntary it is. Feltz observes that subjects' ability to distinguish among degrees of voluntariness with respect to euthanasia suggests that a premise common in 'slippery slope' arguments against voluntary euthanasia—that individuals struggle to differentiate among voluntary, non-voluntary, and involuntary euthanasia—appears unfounded. In "'You Got Me Into This…': Procreative Responsibility and its Implications for Suicide and Euthanasia," Rivka Weinberg mines the emerging field of procreative ethics for insights regarding the ethics of assisted dying. More specifically, Weinberg asks, on the assumption that assisted dying is at least sometimes morally permissible, who has the responsibility to assist a suicidal individual to die? Weinberg advances the thesis that parents may have a special responsibility to assist in light of (a) the risks that parents impose on the children they create (risks of suffering, unhappiness, etc.), risks the children do not agree to be exposed to, and (b) parental responsibilities to meet fundamental needs that children cannot meet at their own. While Weinberg acknowledges that many parents would find assisting a child to die emotionally taxing, she concludes that doing so reasonably falls within the sacrifices that parents are often obligated to make on their children's behalf.

The chapters of this volume cover topics that so far have not received sufficient attention in the debate on assisted dying. But this still leaves many angles on the ethics of assisted dying largely unaddressed, including its relationship to general societal, environmental, and technological questions and developments, such as the aging and growth of the human population, climate change and the sufficiency of food, air, and water, and innovations as regards human enhancement and environmental technology. The most discouraging prospect is that, in the future, an increasingly older, bigger, and sicker population of humans has to make do with a continuously decreasing stock of natural and other resources. Perhaps human enhancement or other technologies will ameliorate these problems. But even so, it is likely that the conceptions we now have about the value of human life and death will undergo some changes. Accordingly, these kinds of questions and developments can also be expected to affect our attitudes toward the moral and legal acceptability of physician-assisted dying. This volume demonstrates that plenty of philosophical and bioethical questions remain about assisted dying. Yet it is an issue that transcends the bounds of 'medical ethics' as it has traditionally been conceived.[2]

References

Beauchamp, Tom L., and James F. Childress. 1979. *Principles of Biomedical Ethics (first edition)*. New York: Oxcord University Press.

Beauchamp, Tom L. 2006. The right to die as the triumph of autonomy. *Journal of Medicine and Philosophy* 3: 643–654.

Garcia, Jorge L.A. 2007. Health versus harm: Euthanasia and physicians' duties. *Journal of Medicine and Philosophy* 32: 7–24.

Huddle, Thomas S. 2012. Moral fiction or moral fact? The distinction between doing and allowing in medical ethics. *Bioethics* 27: 257–262.

Materstvedt, Lars J. 2009. Inappropriate conclusions in research on assisted dying. *Journal of Medical Ethics* 35: 272.

McLachlan, Hugh V. 2011. Moral duties and euthanasia: Why to kill is not necessarily the same as to let die. *Journal of Medical Ethics* 37: 766–767.

Miller, Franklin G., Robert D. Truog, and Dan W. Brock. 2009. Moral fictions and medical ethics. *Bioethics* 24: 453–460.

Parker, Malcolm. 2005. End games: Euthanasia under interminable scrutiny. *Bioethics* 19: 523–536.

Pellegrino, Edmund D. 2001a. Physician-assisted suicide and euthanasia: Rebuttals of rebuttals—the moral prohibition remains. *Journal of Medicine and Philosophy* 26: 93–100.

Pellegrino, Edmund D. 2001b. The internal morality of clinical medicine: A paradigm for the ethics of the helping and healing professions. *Journal of Medicine and Philosophy* 26: 559–579.

Rietjens, Judith A.C., Paul J. van der Maas, Bregje D. Onwuteaka-Philipsen, B.D., Johannes J.M. van Delden, and Agnes van der Heide, A. 2009. Two decades of research on euthanasia from the Netherlands. What have we learnt and what questions remain? *Journal of Bioethical Inquiry* 6: 271–283.

Seay, Gary. 2011. Euthanasia and common sense: A reply to Garcia. *Journal of Medicine and Philosophy* 36: 321–327.

van Delden, Johannes J.M. 2007. Terminal sedation: Source of a restless ethical debate. *Journal of Medical Ethics* 33: 187–188.

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Chapter 2
Assisted Dying and the Proper Role of Patient Autonomy

Emma C. Bullock

Abstract A governing principle in medical ethics is respect for patient autonomy. This principle is commonly drawn upon in order to argue for the permissibility of assisted dying. In this paper I explore the proper role that respect for patient autonomy should play in this context. I argue that the role of autonomy is not to identify a patient's best interests, but instead to act as a side-constraint on action. The surprising conclusion of the paper is that whether or not it is in the best interests for the patient to die is a morally objective matter. This allows for the possibility that it can be in the best interests of the patient to die even if she autonomously considers it to be in her best interest to continue living. I argue that concerns about 'mandatory' euthanasia can be met when patient autonomy is respected as a side-constraint on action. Ultimately, this means that assisted dying is permissible, not because the autonomous patient views her suffering to be unbearable, but because it is in her objective best interests and she permitted it via her consent.

2.1 Introduction

A governing principle in medical ethics is respect for patient autonomy. It is therefore unsurprising that debates on voluntary euthanasia and physician assisted suicide have focused on the relevance and scope of this principle. The aim of this paper is to argue for the proper role that patient autonomy ought to play in determining the permissibility of these two forms of assisted dying.[1] In the following I recap arguments

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[1] In this paper I use the umbrella term 'assisted dying' to cover both voluntary euthanasia (VE) and physician assisted suicide (PAS). This does not mean that the distinction between VE and PAS should be, or are being, elided. Indeed, one might argue that there is an important distinction between a doctor intentionally killing a patient (VE) and intentionally helping a patient to commit suicide (PAS). The decision to use this umbrella term is that the argument presented here applies to both VE and PAS.

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against an overemphasis on patient self-determination and argue that self-determination has a subsidiary role in determining whether assisted dying is permissible. I suggest that whether or not assisted dying is in the best interests[2] of the patient ought to be determined objectively. The role that patient autonomy plays in determining the permissibility of assisted dying is as a permission or constraint on action. The advantage of this account is that it fits well with emerging models of medical decision-making[3] that, with good reason, downplay the importance of patient self-determination but do not rule out the importance of patient autonomy entirely. To date, discussion on the moral permissibility of assisted dying has failed to catch up with this movement.[4] This paper aims to bridge this gap by outlining the proper role of patient autonomy with regard to assisted dying.

There might be good reasons to deny that assisted dying is morally justified, regardless as to whether it is determined to be in the patient's best interests and the patient autonomously consents to it.[5] I do not address these arguments here. Instead, the focus of this paper is to assess what the argument from respect for patient autonomy amounts to and to outline the role that patient autonomy should play in determining the permissibility of assisted dying.

2.2 Informed Consent and Respect for Patient Autonomy

The central case for the moral permissibility of assisted dying is that it constitutes respect for individual autonomy (see Young 2014a, b).[6] The argument from autonomy draws upon the claim that a person has a right to shape her own life through her choices and extends this right to *include* the right of patients to choose the manner of their death (Gray 1999, 21; see also Battin 2005, 20). Patient autonomy

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[2] Throughout this paper I use the term 'best interests' to narrowly refer to the promotion or protection of the patient's well-being. A broader usage of the term might include values in addition to well-being, such as financial gains and legal obligations.

[3] For models and defences of shared-decision making see Birchley (2014), Maclean (2006), Sandman and Munthe (2009, 2010). For defences of various forms of paternalism see Conly (2013), Loewy, (2005), Scoccia (2008), Thaler and Sunstein (2008).

[4] Little has been written on the diminishing relevance of patient autonomy in recent bioethics literature as related to assisted dying. The exception is Varelius (2006), which explores the proper ends of medicine in view of a growing distinction in the bioethics literature on objective characterisations of the goals of medicine and, on the other hand, respect for patient autonomy (Varelius 2006, 121–2).

[5] For a comprehensive overviews of objections to assisted dying see Brock (1993).

[6] This is not the only argument in favour of the moral permissibility of forms of assisted dying. A second important argument focuses on patient well-being and the moral demand to reduce patient suffering (Brock 1993, 206). However, this second argument is often directly linked to the argument from autonomy with the burden of the patient's suffering being determined by the autonomous patient (Brock 1993, 207).

is argued to have a ‘pivotal role’ in end-of-life decision making: “…permitting people the opportunity to decide the timing and circumstances of their own demise if that is what they wish” (Biggs 2001, 96). The ‘right to die’ is thus derived from a more general right to direct the course of our own lives (Chetwynd 2004, 175).[7]

The appeal to patient autonomy in relation to the right to die can be traced to the rise of the doctrine of informed consent (Beauchamp 2006, 644). According to the doctrine, a patient has the right to refuse medical treatment on the condition that she is (A) fully informed of the nature, benefits and risk of each procedure, and (B) her consent or refusal is freely chosen (Declaration of Helsinki 2008). The main justification for informed consent procedures is the importance of respecting patient autonomy (Manson and O’Neill 2007, 17; see also Beauchamp and Childress 1989, 75), protecting: “…the [patient’s] right to decide how one is to live one’s life, in particular how to make critical life-decisions” (Feinberg 1986, 54).

One way in which to unpack the role of informed consent as related to assisted dying is to reflect on the kind of autonomy that informed consent ought to protect. Problematically, the concept of ‘autonomy’ is vague and has various meanings in different contexts. As Faden and Beauchamp have noted, the term has been loosely associated with ideas as diverse as: “…privacy, voluntariness, self-mastery, choosing freely, the freedom to choose, choosing one’s own moral position, and accepting responsibility for one’s choices” (Faden and Beauchamp 1986, 7). The concept has also been used to bear connotations with freedom, independence and self-determination (Schermer 2002, 1; see also Feinberg 1986, 28).

In the following I explore two key ways in which respect for patient autonomy as required by the doctrine of informed consent can be understood. First, respect for patient autonomy, understood as self-determination, may be required since this is the best means of protecting the patient’s well-being (Sect. 2.2). Secondly, respect for patient autonomy could be viewed as a side-constraint on action (Sect. 4.2), regardless as to whether this leads to a decline in patient well-being. Specifically, I argue, that the doctrine of informed consent protects patient autonomy as a side-constraint on action rather than as a means for protecting patient well-being. By making this distinction we get a clearer idea of the role that patient autonomy ought to play in determining the permissibility of assisted dying.

2.3 Autonomy as Self-Determination

Although moral philosophy has conceptualised autonomy in a variety of ways, respect for patient autonomy is commonly equated with respect for patient self-determination (see Foster 2009, 3 and Macioce 2012, 101). On this view, a patient’s autonomy is identified with the patient’s ability to make choices that shape her life

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[7] An important caveat to this argument is that respect for patient self-determination does not require health care practitioners to assist in patient dying at the patient's request (Brock 1993, 207). The argument from autonomy should thus be seen as a constraint on morally permissible assisted dying; it does not amount to the claim that it is morally obligatory to carry out requests for assisted dying.

in accordance with her own conception of the good life (Brock 1993, 205–6). Various reasons have been given for the importance of respect for patient autonomy understood as patient self-determination. These arguments range from the claim that (a) the exercise of self-determination gives our life meaning (see Nozick 1974, 50; Varelius 2006, 379–380; Glover 1990, 81; Buchanan and Brock 1990, 38–9),[8] to the claim that (b) respect for self-determination is the most effective means for promoting and protecting the patient's well-being.

The argument that (b) respect for self-determination equates to maximal well-being promotion has been defended on the basis that: "[w]hen patients are competent and have access to information, they are the best judge of what is in their interests and whether the expected benefits of a proposed treatment outweigh the burdens" (English et al. 2004, 108).[9] Such arguments can be traced back to Mill, who argues that respect for individual choice is the best means for maximising utility: "…since the individual's 'choice of pleasure' rests with her own judgement" (Mill 2008, 112; see also Erbay et al. 2010, 36; Savulescu 2003, 138–139). The view that individual self-determination ought to be respected because it allows for well-being maximisation has been generally supported within medical ethics, it being argued that we ought to respect patient self-determination because patients have a special expertise regarding their well-being (see, e.g., Veatch 2000, 704; Tännsjö 1999, 16). In the context of the debate on assisted dying, the connection between self-determination and well-being has also been emphasised:

> It might seem that individual well-being conflicts with a person's self-determination when the person requests euthanasia […] But when a competent patient decides to forgo all further life-sustaining treatment then the patient, either explicitly or implicitly, commonly decides that the best life possible for him or her with treatment is of sufficiently poor quality that it is worse than no further life at all…there is no objective standard, but only the competent patient's judgment of whether continued life is no longer a benefit. (Brock 1993, 206–7)

If it is correct that respect for patient self-determination is morally required because this is the best or only means of protecting or promoting her well-being, this means that that the: "…possible courses of action physicians can legitimately take is ultimately determined by the autonomous decisions of their patients" (Varelius 2006, 123).[10] This would further entail that: "the moral acceptability of voluntary euthanasia and physician-assisted suicide is also dependent on the patients' autonomous decisions" (Varelius 2006, 123–4).

Whilst the view that respect for patient self-determination is the best means of protecting patient well-being is widespread, an emerging trend in the medical ethics literature is to question the focus on patient self-determination as a means for protecting and promoting patient well-being altogether. The movement away from an emphasis on the importance of respect for patient self-determination has been

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[8] Here I focus on arguments based on the connection between self-determination and maximisation of patient well-being only.

[9] For a detailed overview of defences of the claim that respect for self-determination facilitates the attainment of maximal best interests see Bullock (2014, 4).

[10] Varelius (2006, 123) refers to this as 'subjectivism' about the goals of medicine.

made on several fronts, ranging from empirical data indicating that the choices patients make are often not self-determined, to models that facilitate shared-decision making, and defences of paternalism. The shared conclusion of these positions is that a policy of respect for a patient's self-determined choices can, in fact, pull apart from the protection and promotion of the patient's well-being.

A key argument for rejecting the importance of respecting patient self-determination, as a means for protecting patient well-being, draws upon evidence from behavioural economics that individuals are poor decision-makers rarely making decisions that direct their lives in a meaningful way (Thaler and Sunstein 2008). Work in behavioural economics suggests that patient decision-making is impaired by a vast number of cognitive influences (Conly 2013). Empirical evidence suggests that people are unable to predict their reactions to future emotional events, or how happy or unhappy an event will make them to the extent that they do not know their own preferences (Blumenthal-Barby 2013, 212). Patient's thereby often lack what the proponent of respect for patient self-determination assumes: "…a set of preferences which are clearly-defined, well-understood, and rank-ordered so that people can make logical trade-offs among them" (Schneider 1998, 69). In addition to the hindrances faced by patients when making 'self-determined' medical decisions, a growing body of work indicates that patients would prefer to rescind their decision-making authority altogether. The desirability of making a medical decision decreases the more severely ill the patient is (Botti and Iyengar 2006, 32), and a number of studies have shown that preferences for decision making are generally weak (see Ende et al. 1989, 26–27; Robinson and Thomson 2001, i34; Strull et al. 1984).

All of the above could simply be seen as a failure to respect self-determination in practice.[11] The problem with this response is that influences on patient self-determination are endemic: irrelevant suggestions can alter a patient's assessment of a decision and external influences on a patient's decision are unavoidable (Thaler and Sunstein 2006, 250). Moreover, these cognitive influences are not easily avoided even when the patient is aware that her decision is subject to them (see Schiavone et al. 2014; Thaler and Sunstein 2008). It simply turns out that individuals are rarely, if ever, capable of exercising self-determination in a way that is free from non-self-determined cognitive influences. The argument that patient's often lack self-determination cannot therefore be addressed by facilitating better respect for patient self-determination in medical practice.

In view of empirical research that patients lack self-determination, autonomy (understood as a means for protecting well-being) has been increasingly recognised as something that is overvalued (Conly 2013, 25). This has led to the development of decision-making models that explicitly move away from the focus on patient self-determination. The development of 'nudge' paternalism is one example of a new model of decision-making that reflects the general concern that patient self-determination is overvalued. Nudge paternalism interferes with the individual's choices by making it more difficult for them to choose an option that they themselves judge to

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[11] I would like to thank Jukka Varelius for raising this point in comments on a draft of this paper.

be detrimental to their best interests, and easier to choose the option that they judge to be favourable (Thaler and Sunstein 2008, 5). The position is justified on the basis that patients would probably make different decisions in the absence of their cognitive hindrances (Schiavone et al. 2014, 105). Whilst respect for patient self-determination is still treated as being important, a patient's decisions are not taken at face-value. Rather than viewing patients as experts in the exercise of their self-determination the nudge paternalist argues that health care practitioners are justified in 'nudging' the patient towards the option that is likely to serve their true interests and preferences.

In addition to models of nudge paternalism, 'widely advocated' models of shared decision making in healthcare practice have arisen in order to address similar concerns (see Birchley 2014; Sandman and Munthe 2009, 2010). The claim that the patient necessarily gets the decision right from the start is argued to be 'implausible' (Sandman and Munthe 2010, 73). Instead of 'abandoning' patients to the decision they make: "…regardless of the possibly catastrophic consequences that might follow" (Maclean 2006, 329) medical practitioners are encouraged to advise and support their patients, thereby increasing the chance that the patient will reach a decision that is consistent with the patient's goals and values (Maclean 2006, 337). Once again, whilst still respected, the role of patient self-determination takes a lesser role, the priority changing to making the decision that best protects the patient's well-being (see also Loewy 2005, 464; Callahan 1992).

2.4 A Revised Role for Patient Consent

Acknowledging the limited role that patient self-determination has to play in protecting patient well-being leaves us with at least two options with respect to the argument from autonomy for the moral permissibility of assisted dying. One option would be to deny that assisted dying is ever permissible given a patient's limited ability to make decisions that protect her well-being. A second option is to revise the role that autonomy plays in end-of-life decision making. This option allows for the permissibility of assisted dying on the basis of a principle for respect for autonomy as a side constraint on action, rather than out of respect for patient self-determination. It is this second option that I explore in the following.

I want to suggest the following two necessary (although not sufficient) conditions for the moral permissibility of assisted dying:

- assisted dying is in the objective best interests of the patient
- assisted dying has been consented to by the patient[12]

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[12] These are moral, rather than legal, conditions. Advocates for the legalization of assisted dying similarly agree on the importance of determining that the patient is suffering and that she consents to the intervention (Young 2014a, b). This paper focus on the moral framework underlying these legalistic conditions. Specifically, I argue that the *determination* of whether or not the person is suffering or whether her life is overly burdensome is not reducible to the self-determining patient's conception of her best-interests.

Given that we ought to be suspicious that a patient can exercise her self-determination in a way that protects her best interests I argue that the determination of whether it is in the patient's best interests to die ought to be determined objectively. Secondly, I argue that the role patient autonomy plays in determining the permissibility of assisted dying is as a permission or constraint on action. Whether or not assisted dying is permissible thus depends on objective facts about the patient's best interests *and* the presence of the patient's consent. Whilst these conditions do not justify assisted dying, they account for the role that patient autonomy ought to play in end-of-life decision-making. Importantly, they provide a way of thinking about the role of patient autonomy in a way that is in line with the increasingly reduced focus on the importance of patient self-determination as a means for protecting patient well-being.

2.4.1 Objective Interests

Given a well-founded and growing unease of treating respect for patient self-determination as a guarantor of patient well-being promotion, a patient's best interests ought to be thought of independently of her self-determining choices. An independent approach for determining the best interests of the patient, and whether or not it is good for her to die, can be drawn from an objective theory of well-being. Such an account identifies a patient's best interests in a way that is not solely dependent upon her preferences and values:

> The idea of the objective list is simply that what is intrinsically good for a person is fixed independently of that person's attitudes or opinions; the items on the list for an individual are there independently of whether the individual has favourable attitudes toward them or himself judges that the items are valuable for him (Arneson 1999, 118–119).

Since the objective list account of well-being is independent of the individual's preferences and desires it is possible for the account to determine that something will contribute to an individual's well-being even if it directly *conflicts* with that individual's preferences:

> What is essential is that these are theories according to which an assessment of a person's well-being involves a substantive judgement about what things make life better, a judgement which may conflict with that of the person whose well-being is in question (Scanlon 1993, 188).

An objective list account identifies the substantive goods that contribute to the well-being of an individual and holds that they are good for the individual independently of that individual's preferences. Objective lists generally contain more than one substantive good, such as:

- Life, consciousness, and activity
- Health and strength
- Pleasures and satisfactions of all or certain kinds
- Happiness, beatitude, contentment, etc.

- Truth
- Knowledge and true opinion of various kinds, understanding, wisdom
- Beauty, harmony, proportion in objects contemplated
- Aesthetic experience
- Morally good dispositions or virtues
- Mutual affection, love, friendship, cooperation
- Just distribution of goods and evils
- Harmony and proportion in one's own life
- Power and experiences of achievement
- Self-expression
- Freedom
- Peace, security
- Adventure and novelty
- Good reputation, honour, esteem etc. (Frankena 1973, 87–8).[13]

An objective list theory of well-being provides a basis for balancing different substantive goods in different situations beyond relying upon patient self-determination. Accordingly, it is possible that in some instances the medical decision that will be in the patient's best interests might not involve respecting her self-determination.

A central suspicion regarding objective list accounts of well-being is that they are too rigid to account for the differences in individual values and interests: "…as if the same things must be valuable for everyone" (Scanlon 1993, 188). Specifically, it is argued that whatever is included on the list there are likely to be persons who do not want certain things to appear on it, and for others to want to add items that are not already included. In order to illustrate this concern Griffin uses the example of: "[a] group of scholars [who] may, with full understanding, prefer an extension to their library to exercise equipment for their health" (Griffin 1986, 45). In this example, the scholars regard their well-being to rest on increasing their knowledge, rather than improving their health. According to Griffin this is a problem for objective theories of well-being (assuming that health is always prior as a value to knowledge) as it is too rigid to account for what matters to the individual (Griffin 1986, 51).

The supposed difficulty in responding to this objection is finding a way to allow for a variation in individual well-being with an account that identifies well-being *independently* of the individual's experiences and desires. However, it is possible for an account of well-being to include variances in individual preferences and values without the account being reduced to them. Instead, a theory of well-being can be subject-related,[14] assessing the objective well-being for a particular individual, as opposed to individuals in general. The possibility of developing a

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[13] The items on this list are not presented in any order of priority.

[14] Here, I use the term 'subject-related' in order to contrast my position with such subject-relative views that do not allow the ordering of items on the list to differ between individuals whilst remaining independent of their views on the matter (cf. Varelius 2003, 368 ff.).

subject-related account of well-being that focuses on the well-being of each individual is not ruled out by the adoption of an objective account. Indeed, an objective account:

> […] does not deny that an individual's attitudes may partly determine what is prudentially valuable for her. An individual's attitudes do not determine what items properly belong on her objective list, but among the items that appear, some may include requirements concerning her attitudes and opinions. For example, an objective-list view might well hold that one good thing for an individual is that her important life aims be satisfied, with importance determined by her own subjective ranking of her aims (Arneson 1999, 117).

Thus, even though an objective list is not reducible to a subject's preferences or desires, this does not mean that an objective list cannot accommodate individual aims, goals, preferences and values. One way in which this could be accommodated would be to include self-determination on the list: "[…] claiming that the informed and reflective living of one's own life for oneself itself constitutes a good" (Crisp 2008). Significantly, just because self-determination features on the list this does not concede that self-determination should always be respected. Rather, exercising self-determination is only one element on the list, amongst others, that contributes to overall well-being. Instead of prioritising self-determination, self-determination becomes one good to consider among many.

Furthermore, an objective list can also be treated as being related to circumstantial factors. Imagine, for instance, that Griffin's scholar is in the midst of a heart attack. Given the scholar's preference for furthering her knowledge over protecting her health, would it be right to hand her a rare academic text book to read in her last moments rather than taking her to hospital for treatment? The answer to this question is almost certainly no. The items on an objective list not only vary from individual to individual in terms of their personal preferences, but the ordering of items on the list can also vary from circumstance to circumstance. Such an account is not *reducible* to the subject's preferences but remains *related* to an individual's tastes and circumstances. The objection that objective list accounts are too rigid cannot be sustained.[15]

An advantage of a subject-related objective account of patient best interests is that it sits well with some intuitions regarding the permissibility of assisted dying. Take for instance Scoccia's example of an instance in which we are reluctant to assist in a suicide:

> Imagine that Frank suffered a shoulder injury a year ago that will prevent him from ever again playing competitive golf, his life's passion. He is no longer depressed about his situation but feels certain that he has nothing to live for and would be better off dead. Legalization with limits rightly denies [assisted dying] eligibility to Frank. To extend eligibility to people like him would, as Daniel Callahan says, be 'self-determination run amok'. [Callahan (1992)] [He] should be denied suicide assistance [because he is] better off alive than dead notwithstanding [his] belief to the contrary (Scoccia 2008, 367).

A benefit of a theory of well-being that determines whether or not it is objectively good or bad for patient to die is that it reflects standard practices and

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[15] The above discussion on subject-relatedness is adapted from Bullock (2012).

intuitions regarding the permissibility of assisted dying. We are, for instance, reluctant to permit assisted dying in cases where the patient is young or the disease is not terminal *even if* their decision is completely self-determined. This is because we rightly judge that it is not in the patient's best interests. Likewise, it is often recognised that pain and suffering arising from a terminal disease towards the end of a natural life are good reasons for permitting assisted dying.

It is certainly controversial to argue that sometimes it is objectively best for a patient to die, regardless of the patient's wishes.[16] Suspicions arise about how a doctor can possibly judge whether or not assisted dying is in the best interests of the patient. At this point I remind the reader that the aim of this paper is not to provide a justification for assisted dying. Certainly, it might turn out that such objective values cannot be determined and so we might not *know* whether or not assisted dying is ever justified. The purpose of this exposition is instead to determine the role that patient autonomy ought to play in matters of assisted dying, not to determine whether assisted dying is ever permissible.

2.4.2 Autonomy as a Side-Constraint

Determining the permissibility of assisted dying cannot end with the claim that whether or not it is in the best interests of the patient to die can be determined objectively. Indeed, such a position could be easily objected to by those who are rightfully worried that the legalisation of assisted dying would lead to mandatory euthanasia. This is where the proper role of informed consent comes into play.

Above I indicated that autonomy is often understood as self-determination. However, a second important way in which patient autonomy can be interpreted is as a side-constraint on the actions of others. Autonomy as a side-constraint prevents others from doing what they want with the individual, even when they correctly judge the interference to be objectively in the individual's best interests. It can thus be invoked as a reason why a medical practitioner should not do something to her patient, specifically: "…that Y should not do something to X because: (a) X has a right to consent to things being done to her; and (b) the appropriate consent has not been given" (Foster 2009, 8–9).

Given the defence of an objective-list account of well-being, it is an interesting question as to why we should care about patient autonomy at all. Those who doubt that there is any additional value to exercising autonomy beyond its contribution

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[16] Note that this position is different to the claim that there are objective standards for determining the permissibility of assisted dying, such as 'the patient is suffering' or 'the patient has an incurable illness'. Whilst these conditions are relevant for determining the permissibility of assisted suicide, on my account, it could turn out that it is *not* in the objective best interests of a patient suffering from an incurable illness to die. It could equally turn out that it is in the best interests of a patient to die (when suffering from an incurable illness) even if she would prefer to continue living.

to individual well-being might be motivated to adopt a paternalistic approach to medical decision-making. However—without reaching any conclusions on medical paternalism in general—it seems to me that we have a special reason to respect patient autonomy as a side-constraint when it comes to life or death decision making. This is because whilst it is only morally *controversial* to interfere with an individual paternalistically in order to promote her well-being, assisted dying is both morally and legally serious. Arguments opposing the legalisation of assisted dying on the basis that it constitutes murder (see, e.g., Brock 1993, 208; Dworkin 1993, 21; Glover 1990, 45) are far more compelling than the comparatively mundane objection to paternalism that it constitutes unwarranted interference with an individual's decision (see, e.g., Mill 2008, 92; Feinberg 1986). Thus, in cases of assisted-dying we should not only be concerned with patient well-being, but given the gravity of the decision, the patient's consent or refusal.

Justifications for autonomy as a side-constraint are both legal and moral in nature. In moral terms, Nozick argues that: "[s]ide constraints upon action reflect the underlying Kantian principle that individuals are ends and not merely means; they may not be sacrificed or used for the achieving of other ends without their consent" (Nozick 1974, 30–31), expressing the "inviolability of other persons" (Nozick 1974, 32). Others have suggested that autonomy as a constraint on action is justified on the basis that each individual has full ownership of her body and: "…no one else, not even the State, can interfere with the exercise of that ownership, in whatever way it manifests itself" (Macioce 2012, 102).

In legal terms, autonomy as a side-constraint is protected by the laws of battery and assault (Maclean 2006, 323). Manson and O'Neill argue that informed consent procedures can only be successfully justified on the basis of laws of battery and assault. They argue that it is in the nature of medical practice to carry out procedures that would normally infringe upon an individual's human rights. Informed consent permits a doctor to carry out actions that would usually be illegal or unethical and so: "…is a way of justifying action that would otherwise violate important norms, standards or expectations" (Manson and O'Neill 2007, 75). For example, an individual is protected in law from having his teeth removed by another individual. It is, however, sometimes necessary for dentists to remove rotten teeth in order to prevent infection and further pain in their patient. Without the patient's consent the dentist will be breaching ethical norms and laws (Manson and O'Neill 2007, 76). In order to prevent such medical procedures being classified as battery or assault, the patient can thus consent to her rotten tooth being removed without the dentist being prosecuted.

When we understand patient autonomy as a side-constraint on action instead of viewing patient self-determination as a means for protecting patient well-being we get a clearer picture of how assisted dying might be justified on the basis of an appeal to patient autonomy. I have argued that whether or not it is good or bad for a patient to be assisted in her death is to be determined objectively. But whether or not assisted dying is permissible will also depend on whether or not the patient has autonomously consented to the assistance, where autonomy is understood as having the role of a side-constraint on action. Take a case in which it is determined that it is objectively in the best interests of a patient to be assisted in their death.[17] At this point the patient or her proxy can consent to the procedure or refuse to consent to the procedure as protected under the doctrine of informed consent. The role of patient autonomy as a side-constraint is to permit or refuse the procedure. Whether or not the procedure contributes to the patient's overall well-being is not reducible to her self-determination.

2.4.3 Assisted Dying and the Proper Role of Informed Consent

Given a growing reluctance towards the view that respect patient self-determination is the best means for promoting and protecting patient well-being, I have suggested a new model for determining the permissibility of assisted dying that incorporates a role for respecting patient autonomy. The two necessary conditions for permissible assisted dying are as follows:

(a) assisted dying is in the objective best interests of the patient
(b) assisted dying has been consented to by the patient.

Determining (a) will involve communication with the patient and acknowledging her self-determination.[18] However, given growing suspicions of the efficacy and accuracy of patient self-determination the patient's values and views on the nature of her well-being should be used as one piece of information amongst others in the determination of her best interests. Self-determination thus still has a role to play—it is just not the only role, and it is certainly not the central role in determining whether or not it is in the patient's best interests to die.

Condition (b) provides an important restriction on permitting assisted dying and better captures the legal role of informed consent. Patient consent matters, but not because she has the ability to determine what is best for her, but because it protects her from unwanted interference.

Keeping focus on the importance of consent as a side-constraint mutes the worry that overriding patient self-determination as a means for promoting patient well-being will lead us into full blown medical paternalism, and the legitimate worry that patients will be killed against their wishes. Autonomy as a side-constraint on action allows that *even if assisted dying is judged to be in the patient's best interests this does not mean it is permissible.* The absence of the patient's consent as a side-constraint (explicit, or hypothetical in the case of incompetent patients) renders assisted dying impermissible. Ultimately, this means that assisted

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[17] I do not detail the conditions here but it will plausibly include things like, being near the end of life, having a terminal condition and/or the experience of great suffering.

[18] As encouraged by models of shared decision making. See Sandman and Munthe (2009, 2010) and Maclean (2006).

dying is permissible not because it is the patient's preference, but because it is in her objective best interests and she permitted it via her consent.

2.5 Conclusion

The doctrine of informed consent is commonly justified by the claim that we ought to respect patient autonomy. This demand to respect patient autonomy is a central argument used in favour of permitting assisted dying. Specifically, it is claimed that respect for patient autonomy entails respect for a patient's decisions about the nature of her death. An aim of this paper has been to square this argument from autonomy with the legitimate concern that medical ethics has overemphasised the role of patient self-determination in determining patient well-being.

I have argued that respect for patient autonomy can be understood in at least two ways, firstly as patient self-determination and secondly as a side-constraint on action. Whilst there are many reasons to be suspicious of patient consent as self-determination I have shown that this does not mean that assisted dying is never justified, nor moreover that informed consent should be dispensed with. Instead, respect for patient autonomy as *a side-constraint on action* has a fundamental role to play in determining the permissibility of assisted dying. Specifically, I have argued that two necessary conditions for the moral permissibility of assisted dying are:

(a) assisted dying is in the objective best interests of the patient
(b) assisted dying has been consented to by the patient.

Whilst these conditions are not sufficient for permitting assisted dying, the model importantly identifies the role that patient autonomy ought to play in end-of-life decision making in view of well-motivated arguments for attributing a lesser role to patient self-determination. The proper role of informed consent in relation to assisted dying is not to protect the patient's self-determined views on the nature of her well-being, but to act as a side-constraint on objective assessments of whether or not it is good for the patient to die.

References

Arneson, Richard J. 1999. Human flourishing versus desire satisfaction. *Social Philosophy and Policy* 16: 113–142.

Battin, Margaret Pabst. 2005. *Ending life: Ethics and the way we die*. Oxford: Oxford University Press.

Beauchamp, Tom L. 2006. The right to die as the triumph of autonomy. *Journal of Medicine and Philosophy* 3: 643–654.

Beauchamp, Tom L. and Childress J. F. 1989. *Principles of Biomedical Ethics* (3rd Edition). Oxford: Oxford University Press

Biggs, Hazel. 2001. *Euthanasia, death with dignity, and the law*. Oxford: Hart Publishing.

Birchley, Giles. 2014. Deciding together? Best interests and shared decision-making in paediatric intensive care. *Health Care Analysis* 22: 203–222.

Blumenthal-Barby, J.S. 2013. Choice architecture: A mechanism for improving decisions while preserving liberty. In *Paternalism: Theory and practice*, eds. Christian Coons, and Michael Weber, 178–196. Cambridge: Cambridge University Press.

Botti, Simona, and Sheena S. Iyengar. 2006. The dark side of choice: When choice impairs social welfare. *Journal of Public Policy and Marketing* 25: 24–38.

Brock, Dan W. 1993. *Life and death: Philosophical essays in biomedical ethics*. Cambridge: Cambridge University Press.

Buchanan, Allen E., and Dan W. Brock. 1990. *Deciding for others: The ethics of surrogate decision making*. Cambridge: Cambridge University Press.

Bullock, Emma C. 2012. Informed consent and justified hard paternalism. Doctoral thesis, University of Birmingham.

Bullock, Emma C. 2014. Free choice and patient best interests. *Health Care Analysis* 1–19. doi: 10.1007/s10728-014-0281-8.

Callahan, Daniel. 1992. When self-determination runs amok. *Hastings Center Report* 22: 52–55.

Chetwynd, S.B. 2004. Right to life, right to die and assisted suicide. *Journal of Applied Philosophy* 21: 173–182.

Conly, Sarah. 2013. *Against autonomy: Justifying coercive paternalism*. Cambridge: Cambridge University Press.

Crisp, Roger. 2008. Well-being. *Stanford encyclopedia of philosophy*. http://plato.stanford.edu/archives/win2008/entries/well-being/. Accessed 2 Jan 2012.

Declaration of Helsinki. 2008. Ethical principles for research involving human subjects. http://www.wma.net/en/30publications/10policies/b3/. Accessed 11 Oct 2008.

Dworkin, Ronald. 1993. *Life's dominion: An argument about abortion and euthanasia*. London: Harper Collins Publishers.

Ende, Jack, Lewis Kazis, Arlene Ash, and Mark A. Moskowitz. 1989. Measuring patients' desire for autonomy: Decision making and information seeking preferences among medical patients. *Journal of General Internal Medicine* 4: 23–30.

English, Veronica, Gillian Romano-Critchley, and Ann Sommerville. 2004. *Medical ethics today: The BMA's handbook of ethics and law*, 2nd ed. London: BMJ Books.

Erbay, Hasan, Alan Sultan, and Selim Kadıoğlu. 2010. A case study from the perspective of medical ethics: Refusal of treatment in an ambulance. *Journal of Medical Ethics* 36: 652–655.

Faden, Ruth R., and Tom L. Beauchamp. 1986. *A history and theory of informed consent*. Oxford: Oxford University Press.

Feinberg, Joel. 1986. *Harm to self: The moral limits of the criminal law*. Oxford: Oxford University Press.

Foster, Charles. 2009. *Choosing life, choosing death: The tyranny of autonomy in medical ethics and law*. Portland: Hart Publishing.

Frankena, William K. 1973. *Ethics*, 2nd ed. New Jersey: Prentice-Hall.

Glover, Jonathan. 1990. *Causing death and saving lives: The moral problems of abortion, infanticide, suicide, euthanasia, capital punishment, war and other life-or-death choices*. London: Penguin.

Gray, William. 1999. Right to die or duty to live? The problem of euthanasia. *Journal of Applied Philosophy* 16: 19–32.

Griffin, James. 1986. *Well-being: Its meaning, measurement, and moral importance*. Oxford: Clarendon Press.

Loewy, Erich H. 2005. In defense of paternalism. *Theoretical Medicine and Bioethics* 26: 445–468.

Macioce, Fabio. 2012. What can we do? A philosophical analysis of individual self-determination. *Eidos* 16: 100–129.

Maclean, Alisdair. 2006. Autonomy, consent and persuasion. *European Journal of Health Law* 13: 321–338.

Manson, Neill C., and Onora O'Neill. 2007. *Rethinking informed consent in bioethics*. Cambridge: Cambridge University Press.

Mill, J.S. 2008. *On liberty*. Oxford: Oxford University Press.

Nozick, Robert. 1974. *Anarchy, state, and utopia*. New York: Basic Books.

Robinson, Angela, and Richard Thomson. 2001. Variability in patient preferences for participating in medical decision making: Implication for the use of decision support tools. *Quality in Health Care* 10: i34–i38.

Sandman, Lars, and Christian Munthe. 2009. Shared decision-making and patient autonomy. *Theoretical Medicine and Bioethics* 30: 289–310.

Sandman, Lars, and Christian Munthe. 2010. Shared decision making, paternalism and patient choice. *Health Care Analysis* 18: 60–84.

Savulescu, Julian. 2003. Is the sale of body parts wrong? *Journal of Medical Ethics* 29: 138–139.

Scanlon, Thomas. 1993. Value, desire and quality of life. In *The quality of life*, eds. Martha C. Nussbaum, and Amartya Sen, 185–200. Oxford: Clarendon Press.

Schermer, Maartje. 2002. *The different faces of autonomy: Patient autonomy in ethical theory and hospital practice*. London: Kluwer Academic Publishers.

Schiavone, Giuseppe, Gabriele De Anna, Matteo Mameli, Vincenzo Rebba, and Giovanni Boniolo. 2014. Libertarian paternalism and health care policy: A deliberative proposal. *Medicine, Health Care and Philosophy* 17: 103–113.

Schneider, Carl E. 1998. *The practice of autonomy: Patients, doctors and medical decisions*. New York: Oxford University Press.

Scoccia, Danny. 2008. In defense of hard paternalism. *Law and Philosophy* 27: 351–381.

Strull, William M., Bernard Lo, and Gerald Charles. 1984. Do patients want to participate in medical decision making? *JAMA* 252: 2990–2994.

Tännsjö, Torbjörn. 1999. *Coercive care: The ethics of choice in health and medicine*. London: Routledge.

Thaler, Richard H., and Cass R. Sunstein. 2006. Preferences, paternalism, and liberty. In *Preferences and well-being*, ed. Serena Olsaretti, 233–364. Cambridge: Cambridge University Press.

Thaler, Richard H., and Cass R. Sunstein. 2008. *Nudge: Improving decisions about health, wealth, and happiness*. London: Yale University Press.

Varelius, Jukka. 2003. Autonomy, subject-relativity, and subjective and objective theories of well-being in bioethics. *Theoretical Medicine and Bioethics* 24: 363–379.

Varelius, Jukka. 2006. Voluntary euthanasia, physician-assisted suicide, and the goals of medicine. *Journal of Medicine and Philosophy* 31: 121–137.

Veatch, Robert M. 2000. Doctor does not know best: Why in the new century physicians must stop trying to benefit patients. *Journal of Medicine and Philosophy* 25: 701–721.

Young, Robert. 2014a. 'Existential suffering' and voluntary medically assisted dying. *Journal of Medical Ethics* 40: 108–109.

Young, Robert. 2014b. Voluntary euthanasia. In *Stanford encyclopedia of philosophy*, ed. Edward N. Zalta. http://plato.stanford.edu/archives/sum2014/entries/euthanasia-voluntary/>. Accessed 29 Apr 2015.

Chapter 3
Preventing Assistance to Die: Assessing Indirect Paternalism Regarding Voluntary Active Euthanasia and Assisted Suicide

Thomas Schramme

Abstract The chapter focuses on cases of assisted suicide and voluntary euthanasia in relation to the rarely discussed notion of indirect paternalism. Indirect paternalism involves not just a paternalistic intervener and a person whose welfare is supposed to be protected, but also another party, whom I call "assistant." Indirect paternalism interferes with an assistant in order to prevent harm to another person. I will introduce a strategy that paternalists can pursue to justify indirect paternalism. It specifically targets an element of assistance cases, namely the fact that people do not necessarily have a justified claim or entitlement to demand such assistance. To prevent people from providing assistance seems normatively different from preventing a person to do something to herself by her own means. I critically discuss arguments from the goals of medicine and from the conscientious objection. These aspects are not deemed decisive when considering the case of indirect paternalistic intervention. Finally, I argue against the rationale of indirect paternalism by showing that there are at least two situations where it does not succeed. One such situation that undermines the justification of indirect paternalism is present when the offered service is itself harmless, another pertinent situation consists of a person necessarily requiring assistance to be really free. At least in some cases, these very conditions are given when contemplating assistance to die.

3.1 Introduction

Assisted suicide and voluntary active euthanasia have been discussed in bioethics for a number of years. Many arguments have been put forward, either supporting or rejecting such methods. Sometimes people reject the practices for principled reasons; sometimes they are worried about possible consequences of turning killing

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on request or helping people to die into a common procedure. In this chapter I will focus on a possible yet neglected rationale for preventing assistance to die. This is indirect paternalism: We might interfere with an assistant's freedom to act in order to prevent harm or secure the good of another person who has asked for such assistance. I believe that indirect paternalism poses more complicated normative issues than "normal" cases of paternalism, which only involve one party interfered with. Direct paternalism briefly is an interference with the freedom of persons to choose or act in order to prevent harm to these persons themselves. A common case involving direct paternalism is suicide prevention. One possible strategy for defending the practice of assistance to die would be to draw an analogy between suicide and assisted killing on request. If we do not have sufficient reason, this argument goes, to prevent suicide on paternalistic grounds, we also do not have sufficient reason to prevent assisted suicide or voluntary active euthanasia. I want to show that this strategy of drawing a straightforward analogy between the direct form of paternalism and indirect paternalism fails. Yet I will nevertheless argue that indirect paternalism is not justified in certain circumstances.[1]

There might be a worry regarding the pertinence of paternalism as a rationale for intervening into assisted causes of death. It seems that it is not usually the good of the person willing to die that is decisive when considering interference, but for instance the immorality of killing itself. I agree that there might be other reasons than paternalistic ones that might justify a ban on assisted suicide or euthanasia, most importantly the already mentioned worries regarding the consequences of turning assisted killing into a regular practice. There might also be mixed motives when considering intervention. Yet it is important to acknowledge that even if intervening parties might be only concerned with the morality of killing, and not at all with the welfare of the people interfered with, it might nevertheless be a form of paternalism to interfere with a choice to die: Moral paternalism, which aims at securing the moral good of a person, can also take both a direct and an indirect form. Hence I believe there are actual cases of real or considered paternalistic interventions into assistance to die.

For the purposes of the present chapter I will not distinguish between assisted suicide and voluntary active euthanasia. Though legally it is often important to know who has proximately caused the death of a person, for the normative problem I am pursuing this is not a major matter of concern. Both assisted suicide and voluntary active euthanasia are instances of what I call assistance cases. In one case the assistant provides the necessary means for a person who then kills herself, in the other case the assistants are themselves, as it were, the means to cause the death of a person willing to die. There might of course be reasons as to why a person cannot kill herself, most obviously when they are physically unable to do so, for instance when they are paralyzed. So active euthanasia might be the only possible means for a person willing to die to actually succeed in this plan.

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[1] This chapter draws on two other papers that focus on different problems but fall in the same area (Schramme 2013, 2015).

The plan of the chapter is as follows: I will first introduce the notion of indirect paternalism. Indirect paternalism involves not just a paternalistic intervener and a person whose welfare is supposed to be protected, but also another party, whom I call "assistant". Indirect paternalism interferes with an assistant in order to prevent supposed harm to another person. This sounds like established cases of preventing harm to others, but an important aspect of indirect paternalism is the fact that the assistance is sought by the person whose good is supposed to be secured by intervention. In the second section I will introduce a strategy that paternalists can pursue to justify indirect paternalism. It specifically targets an element of assistance cases, namely the fact that people do not necessarily have a justified claim or entitlement to demand such assistance. To prevent people from providing assistance seems normatively different from preventing a person to do something to herself by her own means. There are several aspects here that will require close inspection, especially when considering the situation of an assistant who is supposed to kill another person. Since I mainly focus on medical assistance to die, or physician-assisted suicide, which is after all the form of such assistance most often discussed in the relevant literature, I query an argument from the goals of medicine and another one from the conscientious objection. Yet I believe these aspects are not decisive when considering the case of indirect paternalistic intervention. Finally, I argue against the rationale of indirect paternalism by showing that there are at least two situations where it does not succeed. One such situation that undermines the justification of indirect paternalism is present when the offered service is itself harmless, another pertinent situation consists of a person necessarily requiring assistance to be really free.

3.2 Indirect Paternalism

Cases where a person A requires the support or service of another person B to achieve a particular outcome or to perform an action can be called assistance cases. If the required assistance is forbidden, or by other means hindered or made impossible, for reasons of securing the good of person A, then we can deem these interventions instances of indirect paternalism. Indirect paternalism is therefore a form of multiple-party paternalism.[2] Assistance to die might involve more than two parties, for instance when a psychiatrist evaluates the capacity of a patient to decide about their death and another party administers a lethal drug. Also, the paternalistic intent of a person or institution considering a ban on a particular service might not (only) aim at the person who requests a service but at the good of a potential assistant, for example when active euthanasia is prohibited for reasons of preventing

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[2] Though at least theoretically there might be multiple-party cases of paternalism that are not forms of indirect paternalism, see Feinberg (1986, 9). Feinberg used the term "two-party cases", but this might be confusing as there are more than two parties involved in the practice of indirect paternalism. He obviously meant that two parties are the target of a paternalistic interference, where one party is interfered with and the other benefits.

psychological harm to the person who kills another person on request. This would transfer the same case, which can be discussed under the rubric of indirect paternalism, (also) into a common case of paternalism where the intervenee, i.e. the person interfered with, and the supposed beneficiary are the same person.

A central feature of many assistance cases is that a particular type of action, which is deemed an example of grave harm changes its normative status by a seemingly tiny bit of addition: the voluntary consent of a person. An action by B done towards A—say, to cut flesh from his body—would normally be a crime, but is a body modification ("scarification") if requested. This ties in well with the legal principle *volenti non fit injuria*, which (roughly) translates to "no one is wronged willingly". For anti-paternalists in the tradition of John Stuart Mill's harm principle, only harm done to others (against their wishes) should be prevented, whereas "[o]ver himself, over his own body and mind, the individual is sovereign."[3]

Mill's general anti-paternalism has raised many doubts. Objections to the liberal harm principle might work in the following way: If harm is bad for a person, then it is always bad, whether it is wanted or chosen by the person herself or not. Indeed, harm, such as physical injury that involves pain, is intrinsically bad, so why should it matter for normative purposes whether the affected person desires it? There is, however, a convincing response to this objection. It stems from Joel Feinberg's interpretation of the harm principle (Feinberg 1986, 10 ff.). Feinberg reads the harm principle as requiring the prevention of wrongfully inflicted harms. He also offers two interpretations of the notion "harm", meaning firstly to injure or damage, and secondly to set back interests. We might want to call the first conceptualization "impersonal harm", because it does not necessarily involve a point of view of a person; it is simply something undergone, for instance an alteration of the bodily structure. The second reading of the notion of harm might be called "personal harm", as it involves the standpoint of a person.[4] Only things that happen to a person, which are deemed a setback of her interests, are instances of personal harm. For Feinberg this second reading leads to a proper understanding of the harm principle: It requires prevention of any wrongfully inflicted setback of interests. This principle obviously does not prohibit voluntarily chosen injuries, disadvantages or other detriments; indeed, these are not even considered harms, or personal harms in my own terminology. In short, according to Feinberg's account, we may stick to the general anti-paternalism implied by the harm principle and endorse the *volenti* maxim.[5]

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[3] Because B seems to harm A one might think that these cases were already banned by the Millian harm principle. Yet it should be obvious that the voluntary consent changes the normative status of the same action here and, as we will see, it is even slightly misleading to say that B *harms* A.

[4] We could also say that impersonal harm is harm *for* a person, but only personal harm is harm *to* a person.

[5] Note that it is even possible to accept that impersonal harm is intrinsically bad, and still allow for other considerations, which have to do with personal interests, to outweigh this kind of harm and to conclude that there is no personal harm present where a person has an interest in an impersonal harm. A person may reasonably choose what is intrinsically bad, as long at it is not only intrinsically bad.

3.3 The Normative Difference Between Direct and Indirect Paternalism

There are still plenty of strategies to defend paternalistic intervention. For instance, doubts might be raised regarding the voluntariness of particular choices. In cases of desired killing, interveners might want to quarrel with the reasonableness or, indeed, sanity of a desire to die; or one might want to put doubt on the voluntariness of choice by pointing out strong societal influences in many countries on people's willingness to die or the terrible circumstances in which terminally patients often find themselves. Were these kinds of arguments to be successful, they would deem paternalistic intervention into these choices an instance of soft paternalism, as it would only account for a prevention of non-voluntary choices—something that is normatively less problematic than hard paternalism.[6]

I disagree with this strategy, mainly because I see voluntariness as a procedural feature that has to do with the way a choice has been reached. If no coercion or similar influences of will-formation are involved, a choice is voluntary.[7] We cannot identify involuntariness by the content of a choice. Voluntariness and reasonableness are simply not the same—on whichever account of the reasonable we might come up with (Feinberg 1986, 104 ff.; cf. Möller 2005, 164 ff.). The wish to die is not always irrational, though it might be under certain circumstances (cf. Cholbi 2013a, b). Although it is true that cultural and similar influences on choices can be strong, this is not by itself sufficient warrant for deeming certain choices involuntary. Indeed one might wonder how we would otherwise be at all able to draw a distinction between voluntary and involuntary choices, as every choice is strongly influenced by our circumstances, our upbringing, our friends, etc. Roughly speaking, a choice is voluntary when a person is under no coercive influence and endorses, or identifies with, her choice.[8] There is no principled argument that would exclude choices involving impersonal harm from the realm of voluntary choices.[9]

A more viable strategy for the paternalist against certain services is more closely related to a particular feature of indirect paternalism, namely that it involves more than one party, of which one is an assistant. As I said earlier, the

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[6] It is indeed arguable whether soft paternalism should be called "paternalism" at all (see Feinberg 1986, 12). But even if intervention into non-voluntary choices were not paternalism after all, this would of course still allow us to regard the cases we now refer to under the umbrella term "soft paternalism" as unjustified.

[7] Obviously it is an important issue what kind of undue influences there might be, which consequently undermine consent to (impersonal) harm. I cannot discuss this question here, but see, for instance, Kleinig (2010, 13 ff.).

[8] In these cases we might also want to use the notion "autonomous choice". I disregard the relation between autonomy and voluntariness for the purposes of this essay.

[9] There is an important debate regarding the possible coerciveness of inducements that I will ignore for the purposes of this chapter (see, for instance, Radcliffe 2010).

services we are considering, such as voluntary active euthanasia, require assistance by other people. Now, there seems to be an important difference between preventing a person directly from doing something and preventing another person from offering a requested service to that person, even where the very same actions are involved. In one word, indirect paternalism—which implies preventing assistance—might well be normatively different from direct paternalism.[10] This is mainly due to the fact that there does not seem to be an entitlement to be offered assistance, whereas a person usually is deemed to have the right of self-ownership. The latter allows persons to do lots of things to themselves.[11] So what we need to look at now, when considering a possible justification of assistance to die, is whether the person seeking assistance has a justified claim to such a service.

I believe there is indeed a normatively significant difference between direct and indirect paternalism, which would call for much more detailed reasoning than I can provide in this essay. There is very little that has been written so far on the topic of indirect paternalism [but see especially von Hirsch (2008) and Simester and von Hirsch (2011, 166 ff.)]. It seems that one can be an adamant anti-paternalist yet allow for indirect paternalism. Although in the following I will reject indirect paternalism *in some cases*, I do not deem this to amount to a rejection of the rationale per se.

3.4 When Indirect Paternalism is not Justified

There seem to be at least two circumstances where it would be implausible to argue that the difference between intervention and preventing assistance has any normative significance: When a person has a justified claim, or entitlement, to a service,[12] or when the service itself is not dubious for moral or other reasons, for instance reasons that deem a service imprudent. One aspect regards the person seeking a particular service, the other aspect is concerned with the nature of the service provided.

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[10] This is an important insight that is often ignored, for instance by Feinberg (see Hirsch 2008 and du Bois-Pedain 2010).

[11] Surely one may want to insist that the consent given by a person to the service of the assistant is normatively sufficient to justify providing assistance. Indeed, this seems to follow from the logic of the *volenti* principle. But one aspect of my chapter is to show why assuming a normatively different status of indirect paternalism is plausible and that the *volenti* principle cannot be an absolute principle.

[12] I take ‘claim’ to be a moral notion here. It can be seen as a moral right, but I avoid the terminology to prevent confusion with legal rights. A person might have a legal entitlement to all kinds of morally dubious services, but these contracts are not my concern here, rather whether those contracts should be allowed. I also take ‘claim’ as to imply a duty of others to refrain from interference, so it is not just a ‘liberty’, in the Hohfeldian sense (Hohfeld 1923), where a person has permission to do something and hence is not doing something wrong. A justified claim, or entitlement, as such, does not include a duty of others to provide necessary means to pursue a goal, but I want to consider later how far such provision might indeed be morally required.

The latter case applies to services such as selling sweets. Although we might have a paternalistic interest in banning it, because people tend to eat too many sweets, with well-known effects on their health, the service itself—offering a product in exchange for money—is neutral.[13] The possible negative consequences are due to the service users.

If the service is itself harmful, for instance because the offered good contains hazardous ingredients, a ban might either amount to avoiding third party harm and hence not be an issue of paternalism. Examples of these cases might be well-known health and safety measures we find in many legal requirements regarding production, sales, trades and services. A service or offered good might also be itself harmful, yet something a customer wants anyway. This differs from the situation just mentioned, where we can assume that people do not agree with certain harms, especially where they are not known or cannot serve as means to other purposes. If we remember the difference between impersonal and personal harm, we could say that a service such as killing is an impersonally harmful service, but it might not always be deemed a personal harm. Very often it is of course not easy to say whether a service is as such harmful in the way that is of significance for its normative assessment, namely in terms of posing personal harm. Obviously this makes many cases, where paternalistic intervention is considered, so difficult to assess.

Regarding one of the mentioned aspects that would undermine the justification of indirect paternalism we can therefore conclude that services that are in themselves morally and prudentially neutral may not be banned. This seems straightforward enough in theory, as there is no harm involved—so nothing we can protect a person against—but there are complications in practice. Regarding services that are in themselves harmful in a certain respect, such as killing another person, we need to ask whether they are of a type people would normally try to avoid, hence could be deemed general personal harms. Again, this obviously poses many more questions that cannot be discussed here, such as whether a general ban that prevents all potential service users from gaining access to the service can ever be justified. After all, there might always be at least one person for which this impersonally harmful service is not personally harmful. It seem that this is a problem of the normative assessment of general rules, such as legal bans, as opposed to individual, single case interventions, hence they point at a possible normative difference between interpersonal and legal paternalism.

The other condition undermining the rationale for indirect paternalism is fulfilled when a person has a moral claim or entitlement to a service, even where it could result in personal harm. Consider the case of parental education. Although we know that many parents raise their children in atrocious ways, we still respect children's right to be raised by their parents. Hence even if we find a particular service dubious for moral or other reasons, we might still be convinced that it should be allowed, even judged from a paternalistic point of view.

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[13] Though we might want to introduce bans on, say, the aggressive marketing of sweets.

It would also be wrong to argue that any service failing on both criteria, i.e. that is deemed problematic for moral or other reasons and that does not involve entitlement to the service, should therefore be banned. After all, we need to balance the good of individual liberty against such a ban. I rather want to argue that there seems to be more scope for the paternalist in indirect paternalism than in direct paternalism. Concerning direct paternalism, there is a kind of presumption of entitlement to do many things to oneself in virtue of self-ownership, but this does not automatically apply to the same actions performed by another person on request. This is probably best seen by the very example of suicide as opposed to assisted suicide. Although there might be a justification of the latter practice after all, the onus of justification is on the side of the defender of assisted suicide, whereas there seems to be presumption of the moral legitimacy of suicide (cf. Bergelson 2010).[14] Obviously, there might be good reasons to oppose suicide and hence to overcome the presumption. Yet, my chapter is not concerned with the legitimacy of suicide but with the evaluation of assistant cases. I argue that even where suicide is not regarded as morally wrong all things considered, it does not automatically follow that people have a claim to be assisted in suicide. This is different from the common argument that if suicide is not morally wrong, assistance in suicide cannot be morally wrong either.

I take it that the services considered for the purposes of this chapter—assisted suicide and voluntary active euthanasia—are indeed morally or prudentially problematic, hence fail on one (part) of the criteria: These services are not wholly neutral. They come along with at least impersonal harms. As I have just said, this would not alone justify a ban, as on balance a legislature might want liberty to prevail. It seems unlikely, though, that balancing alone would tip the scales in favor of the services under consideration. People who would like to argue against a ban on assistance to die need a more principled argument. One way would be to consider more closely the second criteria just mentioned. We therefore need to scrutinize whether people might have a justified claim to the services under consideration.[15] If they do, the normative difference between indirect and direct paternalism breaks down and the paternalist strategy fails.

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[14] In contrast, Hill (2014, 277), in a recent contribution to a companion asserts: “Thus if suicide is not immoral in certain cases, then it will be permissible for others to assist *unless there are further arguments against this*.” (Emphasis in original.) It might be worth stressing that I do not want to argue that an assistant’s help to kill a person might be itself morally wrong, but that the case for an entitlement to such service needs to be made.

[15] Some people might want to say that I am conceding far too much to the paternalist, as anti-paternalists would maintain that service users always have a claim right, if not to the provision of services, but to purchase services on a free market. In addition they might want to say that service providers have the right to sell their services, as long as these are neither immoral nor illegal. But this argument relies (a) on the ideology of the free market, a topic I would like to avoid, and (b) on a liberal reading of what might be regarded as immoral—namely only services that cause personal harm to others. My aim here is to scrutinize the paternalist strategy in relation to indirect paternalism without begging the question in favor of a strongly liberal, or even libertarian, point of view, although I have of course already hinted at certain aspects of a liberal viewpoint that seem to me unavoidable.

3.5 Some Arguments Specific to Health Care

There are two special problems for a defense of entitlements to assistance to die as applied to medicine particularly. The first one is the idea of traditional goals of medicine, which might stand against those claims. The second one is the possibility of conscientious objections by medical personnel. Both problems are of some importance, as it is certainly important to also normatively assess the situation of an assistant and not just the person requesting assistance. Nevertheless, I want to quickly establish why these points should not cause too much trouble for the anti-paternalist before moving on to the main question, namely whether controversial services can be justifiably claimed at all.

As far as the goals of medicine are concerned it is of course correct to state that health care's primary task is to cure disease and to alleviate suffering. Arguably, assistance in dying therefore seems to be in line with the traditional goals of medicine, at least insofar as it relieves suffering. Yet, it might be argued that normally health care treatments are offered only when they are indicated, i.e. when a health issue, usually a disease, is present, and there might of course be cases where assistance to die is sought although no disease is (yet) present. Although not completely beside the point, this argument cannot by itself establish why medicine should stick to its traditional goals. As long as services are being paid for by customers themselves, there does not seem to be a general reason against offering medical skills and knowledge for the desired use of healthy people. In fact, medicine has always and traditionally offered at least a few services that were not treatments of disease, for instance abortion. Indeed, the whole profession for a long time was a paid service. So why should it not offer the whole range of its possible services, as long as clients choose them freely and other people do not suffer any harm because of these services? It is notoriously difficult to establish goals internal to the tradition or actual practice of medicine.

Individual medical professionals must not be compelled to perform particular services, though. They might object due to conscientious reasons. Again, this is a valid point, and it seems all the more plausible regarding additional medical services than in the case of core treatments, where there is an extended debate about the justification of the conscientious objection. However, as long as there are some medical professionals who are willing and able to offer a service, such as killing a person on request, the possibility of conscientious objectors has no practical impact.

3.6 Moral Claims to Assistance to Die

Why should clients have a claim to the services under scrutiny? Note first that to have a claim to have particular services offered is not the same as getting these services for free, or even as having a guarantee that they will be offered, for instance by introducing state services in case nobody wants to offer them on a private market. I am only interested in the option of particular services, i.e. whether people have a legitimate claim to demand that it might be performed by willing assistants, not whether everybody should be in a position to use the service.[16] My argument here proceeds in two steps: Firstly, in the remainder of this section I will argue that respect for autonomy, a core principle that even paternalists agree with,[17] needs to be seen as a demand to secure real or effective liberty,[18] which, again, means to offer enabling conditions for important individual life choices. Secondly, I will explain, in the following section, why assistance to die is in congruence with established, widely accepted services. This is a kind of normalization argument, which proceeds by drawing analogies to uncontested practices. Its aim is to undermine the status of contestability of many services, such as voluntary active euthanasia. This latter point is not a strong argument, but I nevertheless see it as an important element in undermining the indirect paternalist approach.

People regularly need assistance when leading their lives. This might be due to all sorts of reasons, for instance vulnerability, lack of capability, lack of time, and so on. These reasons might differ in their normative significance of course. People also differ widely in what they regard as valuable activities and pursuits. Everybody has his or her own individual and sometimes idiosyncratic life plan or idea of the good life. I have argued at the beginning that people ought to have the freedom to do what they want as long as they do not cause harm to others. This is the traditional liberal stance. Obviously, paternalists would disagree and maintain that people ought to have the freedom only to pursue what is really worthwhile. This is a very basic quarrel between paternalists and anti-paternalists that I will need to ignore. But the point we have reached in this chapter is a slightly different one: We want to consider whether indirect paternalism might be an option, even when direct paternalism regarding the very same outcome—desired death—is not justified. So the paternalist would agree that direct paternalism would not be justified in the cases under consideration, hence the very basic point about worthwhile options does not apply. The issue then really is whether the introduction of services leading to the same result might legitimately be prohibited or otherwise prevented after all.

I stated earlier that the normative difference between indirect and direct paternalism hinges on the question whether service seekers have a claim to have a

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[16] This difference might not be significant in practice, after all, in case of assistance to die, as it is normally not discussed or in reality offered as a paid service. If indeed those services would only be affordable for rich people, this might lead to injustice. I disregard the issue of payments in this chapter.

[17] Many paternalists support intervention into choices only where it enhances autonomy. Some paternalists have a particular, more demanding, reading of the concept of autonomy, which does not comply with the interpretation I endorse (but see Cholbi (2013a, b), for an important alternative).

[18] I prefer the term "real liberty", because it has been used in related discussions, especially in Philippe van Parijs's book *Real Freedom for All* (1995). Occasionally "positive liberty" is also used in the debate, but it might cause some confusion with another notion of positive liberty that was discussed in a famous essay by Isaiah Berlin (2002).

service introduced. This, again, is different from asking the question whether service providers have a claim to offer assistance. The latter question relates to the justification of a free market, the former is a question about the relevance of assistance for leading one's own life. It is a question of what we mean when we say that we are free to do something, especially whether it requires the necessary means to be able to do it.

Liberty, self-determination, and autonomy are terms that are often used interchangeably, and indeed they are surely closely related. Liberty to do what one wants to do,[19] as long as one does not wrongfully harm other people, is a premise that is taken for granted at this stage of the argument. Where individual liberty has been granted, i.e. where we are allowed to do things to ourselves, respect for autonomy implies that we are not hindered by others to pursue our aims. But liberty is not effective where we rely on the assistance of other people to pursue these aims but they are hindered to offer their assistance. For example, to say a person is free to gain knowledge, where there are no teachers or books allowed, is making shambles of the notion of liberty to education. To be really free we constantly need the assistance of others. To respect autonomy therefore means to offer enabling conditions for services which support people in the pursuit of their individual lives (cf. Oshana 2003, 104; Möller 2009, 758).

To be sure, this way of understanding autonomy as real liberty raises some problems. For instance, there seems to be a potential confusion between liberty itself and having the means to make use of one's liberty. Indeed, a person who is not hindered from buying books might, in some important sense, be deemed free, even when she cannot afford these books. But note that here we are considering a different case, where in fact the assistance is banned from being provided at all. The analogy does not imply to only call those people free to educate themselves who *have* the necessary means, but the analogy is drawn to those who *have access* to the necessary means. So, in the analogical case, we cannot call someone free to gain knowledge where books and teachers are banned, in the same way as we cannot deem paralyzed persons free to kill themselves where assistance to die is prohibited.

This might lead us to conclude that the option of being killed by an assistant should only be offered to people who are paralyzed and cannot physically kill themselves, because they are not really free—in contrast to physically able people who have the necessary means—to kill themselves. But we should not forget that there are also mental conditions that might prevent us from killing ourselves. People might be squeamish or in other respects unable to perform suicide though they indeed voluntarily wish to die. It would seem more adequate, therefore, to offer assistance to die not merely to certain groups of people, but generally to all people and then to introduce a procedure to consider their eligibility, where the criterion should be their level of individual freedom, hence whether they have the

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[19] This formulation is less complicated than it should be. We might want to add that people should only be at liberty to do what they want to do when sufficiently informed, when no coercing influences are present, and so on.

necessary means to kill themselves (see also Simester and von Hirsch 2011, 177). Some people might have a claim to such assistance, others not, but we cannot in general say who belongs to which group.

I have briefly used the notion of contestedness when referring to assisted suicide and voluntary active euthanasia. This has a certain empirical aspect: These services are in reality contested, due to value judgments by real people. Yet, we might also ask whether there are good reasons for these judgments. This is an issue of scrutinizing a feature of the practices, not an issue of finding out about the perception of these practices in real people. That is why I now talk about the contestability of these practices.

So the second step in this part of my argument consists in pointing out that the ends that people pursue by using the services under consideration are decent and understandable: People who request active euthanasia or physician-assisted suicide want to end their suffering. Indeed, the sought services are merely extremes of widely accepted practices and they are often the only means available: In almost all societies, we offer services to alleviate suffering where we can and we usually allow people to die, even by their own hands. Hence, the services under consideration are in congruence with common practice in many countries, although admittedly we would have to say a bit more about the situations when the desire to die is really understandable and based on valid reasons (cf. Schramme 2013).

Similarly, the intentions and goals of the assisting parties are generally morally valid. They want to help suffering people. Obviously this might not always be the case, for instance if the provided assistance is merely performed on grounds of financial reward. Here we might want to reconsider a ban on certain ways to provide services, but this concern does not apply to common practices of voluntary active euthanasia or physician-assisted suicide.

In fact, one might see a special responsibility of medicine to provide the services sought because in many countries doctors have been installed with the power of control over effective and safe means to end one's life.[20] This license comes with an obligation to act in the public's interest. Now, if my argument has been successful, either medicine should give access to such reliable means to suicide or provide these means themselves, i.e. take on the role of assistants.

3.7 Conclusion

Our discussion of the possible normative difference between indirect and direct paternalism has brought us to the conclusion that, although it has normative significance, it is inconclusive as regards the services under consideration. If an

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[20] Thanks to Michael Cholbi for raising this issue.

individual is allowed to do certain things that are deemed morally or prudentially problematic—though she might not actually be able to perform it herself—then required services that offer the very same results should also be allowed. I therefore conclude that it does not matter, for cases of assistance to die, whether an action of a person or a related service by someone else is hindered or banned for paternalistic reasons. If we oppose direct paternalism, we should also oppose indirect paternalism in parallel cases. This might still leave the paternalist with a strategy, but it is then a strategy that is not specific to indirect paternalism. It concerns whether the person who seeks assistance voluntarily agrees with it. This is similar to the question whether the self-harming person acts voluntarily. Yet, where there is a justified claim to assistance and no personal harm involved, voluntary consent is sufficient to justify the use of a service. Hence the *volenti* maxim is still in place, though in a slightly more complicated way, because not all assistance cases seem to be solved simply by applying this maxim.

References

Bergelson, Vera. 2010. Consent to harm. In *The ethics of consent: Theory and practice*, eds. Franklin G. Miller, and Alan Wertheimer, 163–192. New York: Oxford University Press.

Berlin, Isaiah. 2002. Two concepts of liberty. In *Liberty: Incorporating four essays on liberty*, ed. Henry Hardy, 166–217. Oxford: Oxford University Press.

Cholbi, Michael J. 2013a. Kantian paternalism and suicide intervention. In *Paternalism: Theory and practice*, eds. Christian Coons, and Michael E. Weber, 115–133. Cambridge: Cambridge University Press.

Cholbi, Michael J. 2013b. The terminal, the futile, and the psychiatrically disordered. *International Journal of Law and Psychiatry* 36: 498–505.

Du Bois-Pedain, Antje. 2010. Die Beteiligung an fremder Selbstschädigung als eigenständiger Typus moralisch relevanten Verhaltens—Ein Beitrag zur Strukturanalyse des indirekten Paternalismus. In *Paternalismus im Strafrecht: Die Kriminalisierung von selbstschädigendem Verhalten*, eds. Andrew von Hirsch, Ulfrid Neumann, and Kurt Seelmann eds., 33–56. Baden-Baden: Nomos.

Feinberg, Joel. 1986. *Harm to self: The moral limits of the criminal law*. Oxford: Oxford University Press.

Hill, Thomas E. 2014. Killing ourselves. In *Cambridge companion to life and death*, ed. Steven Luper, 264–281. Cambridge: Cambridge University Press.

Hirsch, Andreas von. 2008. Direct paternalism: Criminalizing self-injurious conduct. *Criminal Justice Ethics* 27: 25–33.

Hohfeld, Wesley N. 1923. *Fundamental legal conceptions as applied in judicial reasoning*. New Haven: Yale University Press.

Kleinig, John. 2010. The nature of consent. In *The ethics of consent: Theory and practice*, eds. Franklin G. Miller and Alan Wertheimer, 3–24. New York: Oxford University Press.

Möller, Kai. 2005. *Paternalismus und Persönlichkeitsrecht*. Berlin: Duncker & Humblot.

Möller, Kai. 2009. Two conceptions of positive liberty: Towards an autonomy-based theory of constitutional rights. *Oxford Journal of Legal Studies* 29: 757–786.

Oshana, Marina A.L. 2003. How much should we value autonomy? *Social Philosophy and Policy* 20: 99–126.

Radcliffe, Janet Richards. 2010. Consent with inducement: The case of body parts and services. In *The ethics of consent: Theory and practice*, eds. Franklin G. Miller and Alan Wertheimer.

Schramme, Thomas. 2013. Rational suicide, assisted suicide, and indirect legal paternalism. *International Journal of Law and Psychiatry* 36: 477–484.

Schramme, Thomas. 2015. Contested services, indirect paternalism and autonomy as real liberty. In *New perspectives on paternalism and health care*, ed. Thomas Schramme. Heidelberg: Springer.

Simester, Andrew P., and Andreas Von Hirsch. 2011. *Crimes, harms, and wrongs: On the principles of criminalisation*. Oxford and Portland, Oregon: Hart Publishing.

Chapter 4
Autonomy, Interests, Justice and Active Medical Euthanasia

Julian Savulescu

Should doctors perform active euthanasia?

Theoretical background: definitions	
Euthanasia	X intentionally kills Y for Y's benefit
Medical euthanasia	Euthanasia performed by a medical professional as a part of their job
Suicide	Y intentionally kills himself
Assisted suicide	X intentionally helps Y to kill himself
Active euthanasia	X performs an action which itself results in Y's death
Passive euthanasia	X allows Y to die. X withholds life-saving treatment or withdraws life-saving treatment
Voluntary	Y requested death himself
Non-voluntary	Y is incapable of expressing a preference
Involuntary	Against Y's wishes

4.1 Four Arguments for Medical Euthanasia

There are 4 main arguments for euthanasia: (1) arguments appealing to consistency (e.g., from passive to active euthanasia); (2) the argument from respect for autonomy; (3) appeals to justice; (4) the argument from interests (mercy or relief of suffering). I will argue that only the last is directly relevant to active euthanasia as a medical intervention, though arguments together from autonomy and justice can in practice (through the backdoor) provide a ground for voluntary active medical euthanasia (AME).

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4.1.1 Consistency

Arguments appealing to consistency have the following form:

> Premise 1. P is acceptable practice.
> Premise 2. Q is not different in a morally relevant way to P.
> So, Q is acceptable practice.

Philosophers should be sceptical of this argument in the context of euthanasia. It can be an example of begging the question. The first premise assumes that current practice is justifiable. The argument, though valid, is not sound. Consider the most common examples.

> *Morphine*. Morphine is already used in doses in which it is foreseen that death will result (often invoking the doctrine of double effect). This is acceptable when the stated intention is to relieve pain. So, it is argued, it is acceptable to use other drugs which shorten life. However, this does not settle when, if ever, it is acceptable to use morphine (and other drugs) to shorten life. For example, morphine and sedatives have been used in doses which have been alleged to have shortened the lives of infants with Down syndrome and spina bifida (Gillon 1985, Kuhse 1992). This does not imply that euthanasia is justifiable in these cases. The same applies to quasieuthanasia practices involving sedatives.

The commonest area in which this argument from consistency is used is to move from passive to active euthanasia (Rachels 1975). Withdrawing life-prolonging treatment (passive euthanasia) is widely accepted and practised. One example is the case of Tony Bland (Hope et al. 2003). A person can be taken off a ventilator which provides support for his breathing and no crime is committed. Although a doctor turns off the switch, nature is said to have taken her course. But a doctor cannot administer an injection for the sole purpose of ending life. The slow death after treatment is withdrawn may cause great suffering for the patient and family. Given that a decision to end life has been taken, surely it is more humane to end life quickly, though actively.

There are at least 2 ways in which this argument is problematic. Firstly, and again, whether passive euthanasia is justified turns on whether there is good normative reason for it. Secondly, whether active euthanasia is justifiable in the stated form of the argument turns on whether it relieves suffering, or more specifically, produces more good than harm.

While I do not believe there is an intrinsic moral difference between acts and omissions, there is one way in which withholding or withdrawing treatment can be relevantly different from administering a lethal injection. Treatment may legitimately be limited (withheld or withdrawn) for reasons of distributive justice (Wilkinson and Savulescu 2011) that would not apply directly to medical euthanasia. There is a great moral difference between distributing a scarce resource like intensive care or artificial feeding between this patient and another, and administering a lethal injection. Justice may require that, since the benefit, need or entitlement of A is greater than B, that A gets the treatment. Withholding the treatment from B may result in her death, but it is not the intentional killing of B for B’s own sake.[1] This is brought out quite clearly by using a counterfactual: if more resources were available (or B could provide these herself) and B wanted treatment, would B be treated? I will return to distributive justice presently.

It might be argued that passive euthanasia is justified enough—so active euthanasia is permissible in those circumstances.[2] In circumstances in which passive euthanasia is justified, then those justifications will be on the grounds of either being in the best interests of the patient or being as a result of an autonomous refusal of medical treatment. I consider these grounds in the following section and whether they apply to active euthanasia.

4.1.2 Respect for Autonomy

The commonest justification of active medical euthanasia is respect for individual autonomy. Battin summarises this argument in this way: “one ought to respect a competent person’s choices, where one can do so without undue costs to oneself, where doing so will not violate our moral obligations, and where these choices do not threaten harm to other person’s or parties” (Battin 1994, 107).

Respect for individual autonomy is historically a political doctrine about the State’s authority over the individual. In particular, according to Mill’s liberalism, two principles, or “maxims”, determine the limits of State interference in individual action:

> The maxims are, first, that the individual is not accountable to society for his actions, in so far as these concern the interests of no person but himself. Advice, instruction, persuasion, and avoidance by other people if thought necessary by them for their own good, are the only measures by which society can justifiably express its dislike or disapprobation of his conduct. Secondly, that for such actions as are prejudicial to the interests of others, the individual is accountable, and may be subjected either to social or legal punishment, if society is of opinion that the one or the other is requisite for its protection. (Mill 1900, 150–151)

In relation to end of life, there are two distinct issues:

- how far and when the State is entitled to interfere in an individual’s life
- what the State should provide to individuals for them to live their lives

Respect for autonomy requires that we should not interfere in people’s choices, insofar as these choices affect only their own lives. This is true, as Mill emphasised,

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[1] It is in this sense that there is a relevant moral distinction between intended and foreseen effects. If I give the one magic life-saving bullet to A rather than B because A will live longer, or because A has had a rougher ride through life, or the coin fell in A’s favour, I am not saying that I intend B to die. That at least one dies is an *inevitable consequence of whatever is done*. I am intending to bring about the most just state of affairs. This is quite different from the usual way in which the distinction between intention and foresight is drawn: a doctor administers a lethal dose of morphine intending to relieve suffering but foreseeing that it will kill the patient. In this case, a death is not an inevitable consequence of whatever is done.

[2] Thanks to the Editors for raising this objection.

even when those choices are clearly prejudicial to that person's interests. Respect for autonomy requires not interfering with an autonomous desire to commit suicide.

How should the State respond when a person requests treatment or an intervention which he believes to be best for himself? Insofar as the treatment is a publicly funded intervention that is a part of a State sponsored medical service, the provision of that treatment necessarily affects others by consuming a public resource. The action passes outside the self-affecting realm. The principles which determine how these services are distributed, and indeed whether they should be provided at all, should be determined by the principles of distributive justice.

The situation is different if the individual is requesting assistance in dying (either euthanasia or assisted suicide) which does not affect others through the consumption of public resources—either purely private medicine or other related private services.

In countries with a national health service, the delivery of health services is a public service distributing public goods. In these countries, the aim of medicine is to offer medical treatment which there is good reason to believe (usually based on empirical evidence) provides more good than harm, and is better than the alternatives. The relevant outcomes for evaluating whether a treatment produces more good than harm are those based on community values and, I believe, those which themselves reflect ultimately some objective conception of human well-being. Let's assume that we give up this conception of medicine and adopt a conception of medicine as respecting competent people's choices. Consider the following cases:

1. Futile interventions. Ann has breast cancer. Her oncologist recommends surgery plus chemotherapy. She explains the reasons for this, based on existing evidence. Ann requests herbal therapy.
2. The money or the box. Mary has breast cancer. Her oncologist recommends surgery plus chemotherapy. She asks how much such treatment will cost. Her oncologist replies: "In the region of $100,000". She says, "I've had enough of life as it is. I don't want to live any longer. I'd prefer to take the money and have a good holiday."
3. Harmful interventions. Jim asks a surgeon to remove his penis because he believes it is the source of his repeated sinning.

If medicine is about respecting the autonomous choices of people for their own health, then it should accede to each of these requests. Some libertarians might defend such a conception of medicine. Most people, however, would find acceding to such requests alien to the telos or goals of medicine. If respect for personal autonomy is the basis for providing euthanasia, then a person could request euthanasia for any reason, or no reason at all. Such a person need not be dying, or in pain, or even ill at all. One could autonomously desire to die simply because one was tired of life, even if that life was happy and fulfilling. But that is not a good reason for medicine to provide a euthanasia service.

We do not believe that medicine should be offering any intervention which people request, even if it is related to their health, or their own conception of well-being. There is widespread agreement that doctors should not offer genital mutilating surgery, even if patients request it autonomously, and even if they believe it is in their interests to have such surgery. That is simply an intervention which there is no good reason to believe is of value to people.

Should we give greater weight to personal autonomy? Is not medicine committed to giving some weight to personal autonomy, even at the expense of a person's interests, such as when a person is told the truth about their medical diagnosis even when this will seriously affect their well-being? Here, I think there are two responses. Such arguments often employ a narrow conception of well-being. When we tell the truth, I think in many circumstances we are doing what is best for that patient, even if it makes the patient depressed or anxious. But even if such cases are really examples of promoting autonomy against a person's interests, it still remains to be shown that they are relevant to the case where a person desires what is arguably the greatest harm of all—death. Finally, truth telling is not a question of the allocation of a scarce public good (apart from the physician's time).

The conclusion that AME cannot be justified in terms of respect for autonomy is rather startling as it flies in the face of much of the movement towards greater respect for patient autonomy. Such enthusiasm for autonomy, I have claimed, stems from a confusion between respect for autonomy as a political doctrine and respect for autonomy as a ground for distributive justice.

One might object[3] that there are some objective conceptions of the value of death that ground a right to euthanasia. Imagine a community that endorsed the idea of active ending of life as a component of medical care, and saw a particular type of death (peaceful, neat, free from suffering, in a manner and timing of the individual's choosing) as intrinsically valuable—indeed objectively valuable. An analogy would be a good ending to a novel. In such a society, autonomy would provide a grounds for AME. There is such a society—the Netherlands, accordingly, on this argument, there is a strong autonomy argument for AME in the Netherlands. If this argument holds—then the question of whether or not there is an autonomy-based right to AME turns on the socially contingent issue of majority support for AME, and on the philosophical question of the objective value of death in a particular form.

This is in part an interests-based argument for AME—that certain kinds of dying are good for a person. As I will argue in the section on interests, it is hard to see how this kind of dying is superior to unconsciousness, that is, deep palliative sedation, from the perspective of the individual's own interests.

4.1.3 Justice

Active Medical Euthanasia to Bring About Justice. The relationship between distributive justice and euthanasia is a complex but important one. Battin puts one argument from justice in this way. When resources are limited, "it is better to deny

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[3] This is Dominic Wilkinson's objection.

[treatment] to those people who are … medically unsavalageable and will die soon anyway: the terminally ill, the extremely aged, and the seriously defective neonate" (Battin 1994, 114). Battin (1994, 115) extends the argument to active euthanasia. On this view, euthanasia should be available to bring about a just state of affairs.

On the face of it, this justification for euthanasia appears invalid. Euthanasia to bring about a just state of affairs is not euthanasia at all. It is important to remember that euthanasia is X killing Y for *Y's benefit*. Killing Y for Z's benefit is not euthanasia, but murder. Similarly, the Nazi program of so-called "euthanasia" was involuntary killing and not for the person's benefit at all, but to maintain the racial purity of the *Volk*.

Battin admits that it is stretching the term euthanasia to use it to describe killings for the purpose of distributive justice. But this is not merely a terminological question. 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. Thus we do not think that justice requires that we take a kidney from those who are healthy to provide kidneys for those with renal failure. Kidneys are not a public good in this sense. They only become public goods when they are freely donated. In a similar way, a person's life is not a public good, nor is it something that can be manipulated to bring about more just distribution of public goods. This is, to use the now hackneyed Kantian phrase, to use people as a means to some abstract concept, and not as an end in themselves.

Battin argues that euthanasia may save money and thus justice may require it. Distributive justice may certainly require that we offer a cheaper alternative to a person, even though a more expensive but more effective alternative exists. However, it cannot require that we harm someone to save resources. Thus any argument from justice cannot rest solely on the dollar cost or saving of euthanasia, but also on whether it is in a person's interests.

There is one way in which bringing about a just state of affairs might require active euthanasia. Justice may require that we withhold antibiotics or another life-prolonging treatment from one person, Y, because others would benefit more from scarce resources. The withholding of medical treatment may cause suffering. If so, it would be justifiable to kill Y if killing Y was the best way of relieving Y's suffering. This argument thus relies on the argument from interests for any plausibility. Given that Y is not entitled to a scarce public good, and will die as a result, it is more in Y's interests to be killed than allowed to die. It is really an argument about what is in someone's interests, given the constraints of scarce resources and the moral imperative to distribute these justly. Justice does not directly or necessarily require that we kill.

Consider an example.[4] Let's say you have a country where, on resource grounds cardiac transplantation is not available. It is therefore inevitable that

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[4] Thanks to Dominic Wilkinson for this example.

patients with end-stage cardiac failure will die. Would it be justifiable to provide AME to patients with end stage cardiac failure? The available options are: (1) provide no medical treatment, allow patient to suffer until they die naturally; (2) provide AME—ensuring that they do not suffer; (3) provide palliative care, minimising patient symptoms and suffering until they die naturally.

Of these three options, (2) would potentially lead to the least patient suffering, as well as the least cost. If the only options were (1) and (2), we should choose (2). However, we do have option (3), and other things being equal we should choose that as our policy, for two reasons. The first is that while the patient would have no further suffering at all with (2), they would also have no further potential conscious experience or possible benefit. The question is whether the patient's suffering is able to be diminished sufficiently for them (and/or their family) to appreciate continued life (and without ablating conscious experience). If the only way of treating the patient's suffering were by rendering them unconscious, the question then becomes, should we perform (2) rather than (3) because it will both guarantee zero suffering and cost less than terminal sedation. I will return to this point.

Secondly, while AME would cost less and guarantee absent suffering for patients with terminal illness, the same argument would hold for any patient with a life limiting illness (or indeed any patient with an illness). It would almost always be cheaper and suffering could be reduced more effectively. However, that isn't seen as the goal of medicine. The argument for AME as cheaper than existing treatment proves too much.

One last note on euthanasia as justice. Preventing harm to others may sometimes require that we do certain things to individuals (Mill's harm principle). For example, an individual may be detained and subjected against his will to medical examinations to determine whether he has Lassa fever or Ebola. This is not distributive justice. Moreover, it is not clear when, if ever, it would be justifiable to kill one person to prevent harm to others, short of times of war. The description of such a practice as euthanasia would be thoroughly misleading.

Whether a person has a right to active euthanasia as a medical intervention turns on whether that use of public resources can be justified under the principles of distributive justice. Whether a patient should be offered a medical intervention turns on whether that intervention produces a net health benefit to the patient, that is, how much the good produced by the intervention outweighs the harms. That is a question about what is a person's interests. The only justification for offering euthanasia as a medical intervention is that dying (sooner) is in a person's best interests.

Distributive Justice and the Entitlement to Active Medical Euthanasia. There is a much more important relationship between distributive justice and active medical euthanasia. If euthanasia can be shown to promote a state of affairs to which a person is entitled, then justice requires that people have access to euthanasia. On this view of the relationship between euthanasia and justice, justice requires that people be offered euthanasia.

Consider a parallel: cochlear implants. Deaf people are entitled to claim access to cochlear implants because this intervention is to be able to restore or establish hearing. Since deafness is a disability (Kahane and Savulescu 2009), and restoring hearing is one of the goals of medicine, it is appropriate that deaf people have access to such a treatment. How accessible we make cochlear implants depends on the magnitude of the benefits of such an intervention compared to the health benefits of other available interventions.

If euthanasia promotes a state of affairs to which people have a strong entitlement, then justice requires that they be offered euthanasia. When a medical intervention promotes longer life, or less pain, or restores the ability to ambulate, hear or see, or improves the quality of life in other ways, we believe that people have a strong entitlement to it. Euthanasia causes the death of the person. Death is not usually thought to be a benefit for the person who dies. However, if death could be shown to be a benefit for the person who dies, then that person would have a strong claim to euthanasia. But that of course requires showing that euthanasia is in a person's interests. The justice justification for access to euthanasia again requires the argument for interests.

If what is good for people is determined by what people desire, and distributive justice is about providing what people desire, then respect for autonomy would bear upon whether active medical euthanasia should be provided. However, no matter how much Jim wants his penis removed to atone for his sins, we do not believe that this desire should be given any weight in determining the distribution of medical resources. Distributive justice concerns the distribution of primary goods which Rawls defines as goods which every rational man is presumed to want. Primary goods include, social primary goods (rights, liberties, powers, opportunities, income and wealth) and natural primary goods (health, vigour, intelligence and imagination) (Rawls 1971, 62). However primary goods are defined, they cannot be defined just in terms of what people do actually now want.

4.1.4 Euthanasia in a Person's Interests

The crucial argument, I have argued, supporting active medical euthanasia is that from interests. According to this argument, euthanasia is justified in those cases in which it promotes a person's interests.[5] The idea here is that the person is still suffering greatly after other medical treatment and euthanasia is the last resort.

In essence, for euthanasia to be a beneficial intervention in these cases, death must be better for the person than continued life. Rachels relates a typical example of Jack, a patient with terminal melanoma. The story is related by a fellow patient.

> At the prescribed hour, a nurse would give Jack a shot of the synthetic analgesic, and this would control the pain for perhaps two hours or a bit more. Then he would begin to moan, or whimper, very low … Then he would begin to howl, like a dog. When this happened, he would ring for the nurse who would give him some codeine by mouth. …but it never

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[5] This is sometimes put as relieving suffering, as providing mercy (Rachels 1975). Battin (1994, 101) puts this as the principle of mercy: one ought to relieve a person's suffering, when this does not preclude the sufferer attaining some overriding good.

> did any real good—it affected him no more than half an aspirin might affect a man who had just broken his arm. Always the nurse would explain as encouragingly as she could that there was not long to go before the next intravenous shot—“Only about 50 min now.” And always poor Jack’s whimpers and howls would become more loud and frequent until the blessed relief came. (Rachels 2007, 152–153)

Such cases are meant to show us that at least in some cases, euthanasia is in a person’s interests. Although emotionally very powerful, such examples have serious limitations in guiding any practical discussion of when euthanasia is justified. Firstly, there is the empirical issue of whether this person’s suffering really is unrelievable. In today’s light, the case of Jack would be shocking to many palliative care physicians: Jack was clearly underdosed on narcotic analgesic. The pain he was experiencing was effectively relieved by narcotics, but he was experiencing breakthrough pain. The very sad fact is that Jack need not have suffered any pain at all: he only required larger doses of narcotic, together with rescue doses for breakthrough pain. However, Rachels, writing originally in the 1980’s, remarked of this case:

> The NIH clinic is, of course, one of the most modern and best equipped hospitals we have. Jack’s suffering was not the result of poor treatment in some backward rural facility; it was the inevitable product of his disease, which medical science was powerless to prevent. (Rachels 2007, 153)

Rachels was a top philosopher and one of the foremost writers on euthanasia. In my view, his article “Active and Passive Euthanasia” in 1975 is the best article in medical ethics (Rachels 1975). The fact that he made this remark shows just how difficult it is to determine whether a person’s suffering is relievable or not. The second problem is more fundamental and the one which I will focus on. It is very unclear when death is in a person’s interests.

However, without some idea of when death is better than continued existence, it is hard to make an argument for medical euthanasia in terms of the goals of medicine. The usual way of proceeding is on a case by case approach, as Rachels does, pointing to “paradigm cases” in which euthanasia seems justified. There are at least two problems with such an approach. Firstly, some people often do not share the intuition that euthanasia is justified in the case stated. The argument which is often operating in cases like that of Jack is:

> X is suffering greatly
> Suffering can be so great as to make death in a person’s interests
> Therefore, death is in X’s interests.

When the argument is spelt out in this way, it is clearly questionable. While X’s suffering is great, it remains open whether it is so great as to make life not worth living.

To summarise the argument to this point:

- Appeals to consistency between passive and active euthanasia may beg the question, in so far as the justification for passive euthanasia is that it is in a person’s interests.
- The argument from respect for autonomy cannot justify active medical euthanasia, at least not within a public health system. The distribution of medical

resources cannot be determined by an individual preference. Respect for autonomy may require that we withhold or withdraw a life-prolonging medical treatment. However, this does not imply that we must provide active euthanasia out of respect for autonomy. Arguments from passive "euthanasia" can only be used to justify active euthanasia when the basis for the passive euthanasia is best interests, and not respect for autonomy.

- The argument from justice would justify a claim to euthanasia if it could be shown that euthanasia was in a person's interests.
- The crucial argument in justifying AME within a public health service is the argument from interests. This question cannot be settled without some conception of a life which is not worth living or a death worth having.

This argument has other important implications. If the justification for euthanasia as a medical intervention is interests, non-voluntary euthanasia will be easiest to justify as those who are worst off will often not be competent in virtue of severe neurological impairment, as we shall see. However, the most important implication is that future progress requires explicit argument about which kinds of life are worse than death. In practice, most attempts at formulation of a policy of active euthanasia have required that a person be terminally ill, competent and wanting to die. For example, in the world's first Act legalising euthanasia, medical euthanasia could be provided under the following conditions. *Rights of the Terminally Ill Act 1995, Northern Territory, Australia*:

A patient can be killed if

- over 18
- suffering from an illness which will kill the patient (without the application of extraordinary measures)
- no medical measures acceptable to the patient which can cure it
- A second medical practitioner confirms the medical diagnosis and prognosis
- A psychiatrist has confirmed the patient is not suffering from treatable depression
- Both have confirmed the patient:
  - is suffering
  - has been informed of treatment options, including palliative care, counselling, psychiatric support and extraordinary measures
  - patient has considered the implications for family
  - patient is of sound mind and decision is made freely, voluntarily and after due consideration

But many people's lives with terminal illness are still worth living. Palliative care physicians and others are rightly sceptical that this is enough to provide a good reason to kill someone. This legislation was clearly based on respect for autonomy, not interests.

If the debate on medical euthanasia is to go ahead, we need a more systematic, coherent approach on the value of life and death. When is a human being's existence of equivalent value or less value to non-existence? One way of proceeding is to examine those cases in which a decision to withdraw or withhold treatment has been made on quality of life grounds. Are there any principles which might unify these decisions about actual cases?

The possible range of states which seriously detract from life's value are:

1. cognitive impairment
2. motor impairment
3. inability to communicate
4. sensory deprivation
5. affective or emotional disorder
6. volitional disturbance
7. memory disturbance
8. disturbance of identity
9. pain[6]
10. inability to control bodily functions (incontinence, poor swallowing, etc.)

Now clearly there is an issue of how much of each of these and how many are required to make life no longer worth living. Having surveyed the literature and worked on this for 10 years, I have not been able to identify or provide such an account.

One thought might be that it will always be difficult to determine the exact point at which burdens outweigh benefits (the zero point). However, it might be possible to be certain further from zero (i.e. where burdens considerably/clearly outweigh benefits). (cf. Sorites paradox).[7]

The clearest cases are not the cases of permanent unconsciousness (since in those cases it appears that suffering is zero). The clearest cases are where there is profound brain injury with absent communication/purposeful movement, but evidence of ongoing suffering, such as patients with severe dementia, pressure sores, or fractures.

Attempts have been made along these lines using reference to legal cases. For example, recently Willmott et al. concluded,

> To illustrate, in the four cases where treatment was withheld or withdrawn, the patients had profound brain injury with no prospect, or very little prospect, of neurological recovery (Slaveski, Melo, Herrington and Messiha). By contrast, the three remaining cases where life-sustaining treatment was commenced or continued involved patients in better neurological states (Northridge, JT and Astill). Although not couched in terms of quality of life, the capacity to engage meaningfully with the world seems to be relevant. It appears that, at least indirectly, judges consider how the proposed treatment will affect quality of life. (Willmott et al. 2014)

One condition that was a ground for introducing euthanasia for infants in the Netherlands is epidermolysis bullosa, a genetic condition in which the skin peels off. There is no cure and death ensues a short time after birth after periods of

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[6] I am not sure whether pain is bad in itself, or bad because of the way it affects a life in the other ways.

[7] Thanks to Dominic Wilkinson for this point.

severe pain and infection. In countries in which euthanasia is not allowed, such babies are often allowed to die by withholding or withdrawing life-prolonging medical treatment. (However, we have seen that the ground for this might be distributive justice, not that life is not worth living.)

Sometimes, there are attempts to apply the subjective standard to incompetent individuals like newborns. Some ask, what would the infant think about such a life, if he were competent. This is a hypothetical subjective standard for evaluating quality of life. Yet it cannot really be subjective because the projected evaluation must be according to certain objective criteria, like the degree of suffering, prospect of recovery, and the impairments listed above impairing in turn the capacity to have meaningful and rewarding social relationships, etc.

So evaluation of quality of life and whether life is worth living must be partly objective. What makes life objectively worth living? Happiness and pleasure, and the absence of pain and suffering. Being able to develop talents and achieve worthwhile things, having a rich set of social relationships, understanding and appreciating the world, and being able to have some impact on it, raising children, and so on. Life becomes not worth living when it becomes devoid of most of these, and is dominated by negative mental states, like pain, suffering, isolation, fear and so on.

I believe we need objective criteria to evaluate quality of life. But even if we can agree on these, it will remain a difficult question which to my knowledge has not been answered or even hardly addressed, as to when the threshold is crossed as to whether life is not worth living.

One example is Trisomy 18. It is associated with severe intellectual disability (more severe than Down syndrome) and most infants die within the first year but a small number live until 10 years of age. Sometimes there are other complex congenital abnormalities. It is often misleadingly described as lethal—it is not universally lethal. Is it a life worth living?

Perhaps in this grey zone where it is not clear whether objectively life is worth living or not worth living, we should defer to the judgements of carers such as parents.

There is thus a paradox. Those with the worst lives will have the greatest impairment of their minds but will be least able to articulate judgements of the worth of life. But in these cases it is hardest to draw a line on what actually makes life not worth living.

4.2 One Criterion for AME: Death and What Matters

Many people believe that death is a misfortune and a very bad thing for the person who dies. Thus, killing is prima facie wrong for this reason. However, this is a mistake. There are many definitions of death. Whole brain death, brainstem death, death of the whole organism and so on. But nearly everyone is united in thinking that death matters a lot—it is often seen as the worst thing that can befall an organism. But this is mistaken. Here is the argument. It is based on Derek Parfit's famous argument that personal identity is not what matters (Parfit 1984).

Ceasing to exist is at least as bad as death. This may at first seem puzzling as it suggests that people could cease to exist without dying. But there are some ways of ceasing to exist that would not involve dying, in any ordinary sense, and which would have none of the badness of dying. That was Parfit's claim. Consider an imaginary Star Trek teletransportation case. Imagine nanotechnology and synthetic biology progress. In 2050, organisms can be built precisely molecule by molecule, atom by atom. You can enter a teletransporter in London. Your whole body is scanned by a supercomputer and the atomic arrangement of your body is recorded, but the process of recording destroys the entire organism. Your entire organism is then reconstructed, atom by atom, in New York, milliseconds later. It appears that one minute you were in London, the next in New York. But of course, *you* ceased to exist when your whole organism was destroyed in London. (This is most easily seen in the case of twinning, when the reconstructor mistakenly makes copies both in London and New York—this is the subject of the wonderful Arnold Schwarzenegger film, *Sixth Day*). Would you enter such a teletransporter, provided it perfectly copied you? I would. But importantly, nothing of moral significance would be lost when you ceased to exist.

This example shows that what matters are mental states, not our original physical existence. More precisely, this example shows that what matters is that there will be someone in the future who will be psychologically just like us, even if that person won't *be* us since we shall have ceased to exist. That is Parfit's view, but the imagined case of Teletransportation isn't enough to show this view to be true. Things are different with Parfit's imagined case in which someone's brain is successfully divided and transplanted into the empty skulls of two other similar bodies. The two resulting people here would not be merely psychologically exactly like the original person, but this psychological relation would have its normal cause: the continued existence of enough of the same brain. Of those who are persuaded by this example that personal identity isn't what matters, many conclude that what matters is psychological continuity, even in a branching form, with its normal cause (Parfit 1984). What matters is not biological life and death, but something to do with mental states (or perhaps some embodiments of them).

Philosophers are criticised for using such thought experiments—they are said to be mere science fiction of no relevance to every day life. In fact, there is already real life analogue of teletransportation. Early in human development, until 14 days, the embryo can split into identical twins (or higher order identical multiples).

Some people, such as leaders in the Catholic Church, claim the embryo is person with a right to life from the moment of conception. For such people, twinning involves the ceasing to exist of a human being and replacement by two clones, like when the teletransporter mistakenly makes two copies, one in London and the other in New York.

Consider such a Catholic couple who naturally conceive an embryo, call him Danny. A few days after conception, Danny divides into identical twins: Patrick and David. Patrick and David are clones. Danny ceased to exist when he divided, just an amoeba ceases to exist when it divides. Danny could not be identical with

Patrick and David as this would imply that Patrick and David are identical with each other, that is, they are the very same thing. This is clearly false.

These examples show that what matters is not death, but loss of psychological continuity and connectedness. This has implications for ending life. It implies that when a human organism does not have mental states, it is not wrong to kill it. This lends support to the practice of withdrawing life prolonging interventions from people who are permanently unconscious (Sinnott-Armstrong and Miller 2013), early abortion and destruction of embryos.

Thus active medical euthanasia would be justified in cases of severe cognitive impairment or permanent unconsciousness, where there is the absence of psychological continuity and connectedness. This would apply to advanced dementia. In such cases life would be of little or no value. (Indeed, it could be worse, if the organism experienced pain or other negative mental states).

4.3 Voluntary Palliated Starvation and AME Through the Ethical Backdoor

We have seen that if euthanasia is to be practised by doctors as a part of medicine, it must be in the interests of patients. This requires determining that life is no longer objectively worth living. Even in those whose lives are worst, such as those with profound cognitive impairment, it is difficult to draw the line of when life is no longer worth living. However, when psychological continuity and connectedness are absent, it would not be bad to cease to exist. In such cases, euthanasia could be performed for reasons of relief of suffering, parental request, etc.

However, there is another way in which AME could be ethically required of doctors. I have argued that respect for autonomy is insufficient to ground AME. However, it is well established that people have the right to refuse life-prolonging medical treatment. Examples of respect for autonomy in health care are:

1. when we respect a competent person's informed refusal of medical treatment judged to be in her interests. An example is a Jehovah's Witness refusing a blood transfusion.
2. when we honour a living will of a now incompetent person refusing medical treatment. An example is an unconscious Jehovah's Witness with a card refusing blood transfusions.
3. when a substituted judgement procedure is used to predict which medical treatments a previously competent but now incompetent person would refuse. An example is an unconscious bleeding Jehovah's Witness whom it is decided would refuse a blood transfusion based on her prior beliefs, even though there has not been an explicit refusal.

I have argued that those wishing to die also have the basic right to refuse to eat and drink. In addition, they have a right to palliative care as they die from dehydration and starvation. I called this Voluntary Palliated Starvation (VPS). This does not require any specific legislation and is likely to be legal in most jurisdictions (White et al. 2014, Wilkinson and Savulescu 2014).

If people have a right to starve and dehydrate themselves to death based on respect for their autonomy, then this opens the backdoor to AME in the following way. Those availing themselves of VPS will certainly die, usually over a period of days to weeks. Given that they will die, in those cases in which they are heavily sedated and analgesed, there is an argument for AME being superior to palliative care. That argument is based on distributive justice—it saves resources for patients who will die, to die earlier rather than later.

This applies to terminal illnesses. If a person will die and they request to die sooner rather than later, then distributive justice speaks in favour of AME rather than palliative care. This flies in the face of my previous argument that justice must be about providing treatments which are in the interests of patients. But in fact, that argument requires qualification. Patients need not be provided with medical care that is in their interests when that care would bring about greater benefits to others (or at least others in equal need). While I have said that judgements about when life is worth living are difficult to make, it is clear that relative judgements of value of life between patients must be made and are made. For example, a longer life is better than a shorter life. It is better to be without pain than in pain (Wilkinson and Savulescu 2014). Thus relative value of life judgements are more tractable than absolute judgements of when a person's life is no longer worth living.

Thus a person might be denied medical care because it is very expensive, would produce only a very small benefit or only has a very small chance of working. These kinds of judgements are in fact the basis of determinations of "futility" (Wilkinson and Savulescu 2011). We need not claim such interventions are not in the interests of patients but only that they are cost-ineffective.

Thus we need not show that AME is in the interests of patients, but only that it is more cost-effective than other interventions. Given that resources could be saved in the dying phase, and the patient wishes autonomously to die, both respect for autonomy and distributive justice speak in favour of AME.

Since respect for autonomy applies to decisions about future health states when the person will be incompetent—advance directives or living wills—a person could refuse food and fluids in advance if, for example, she had advanced dementia. Since the person has that legal right, then she could equally request AME if she ever developed advanced dementia.

This is not to imply that AME must be performed when a patient will die but only that the patient has the right to it as an alternative, when he or she wants it and when he or she will die, regardless of whether that is by disease, limitation of treatment for justice reasons or because of a valid refusal of treatment.

Palliative care should be an option, provided it is sanctioned by principles of justice. Imagine that I am diagnosed with a progressive neurological disorder that will lead to death in 6 months, but which is currently minimally symptomatic.

If I choose VPS, I wouldn't need analgesia. I might become hungry and thirsty, but I could be prescribed appetite suppressants and medication to diminish thirst.

If I am depressed by my condition, palliative care would demand that I am given anti-depressants. Perhaps I am given some combination of opiates, amphetamines and mood-altering agents, to minimise sensation of thirst and engender a feeling of general euphoria.[8]

It isn't clear in such a case that AME would be superior to drug-induced well-being. Nonetheless, both should be options open to the patient.

4.4 Conclusion

Respect for autonomy does not ground a right to AME in the simple way many people have argued. However, respect for autonomy does ground a right, now and in advance, to refuse to eat and drink. And given that a person will die (whether by disease, limitation of treatment on distributive justice grounds or legal refusal of food and fluid), justice requires that AME be an option for that person. The combination of respect for autonomy together with distributive justice provides a justification for AME.

Thus, we can share the scepticism of opponents of AME about making quality of life judgements and decisions about when life is not worth living. We can in fact eschew such judgements. And we can share their belief that role of medicine should be to serve patients' interests. But that principle should extend to *all* patients, including those competing for limited resources. Because AME saves resources that can be used by patients who need them, distributive justice requires AME, at least for those who will die and request it.

Respect for autonomy, together with justice, speak together in favour of voluntary AME. What of nonvoluntary AME? This is the most controversial practice. Considerations of autonomy do not apply. For example, neonatal euthanasia is practised in the Netherlands (Verhagen 2013) for conditions like epidermolysis bullosa.

I have argued that it is difficult to argue that such practises are straightforwardly in the interests of patients, that is, that their lives are not worth living. However, I have also argued that justice can speak in favour of more cost-effective alternatives, when a patient will die.

Elsewhere, I have argued with Dominic Wilkinson for Organ Donation Euthanasia (Wilkinson and Savulescu 2012). We argued that organs could be extracted to save the lives of others if it was certain a person would die, for example, through the limitation of life prolonging medical treatment. This would be a case of altruistic euthanasia.

In a similar way, euthanasia could be provided on justice grounds in those incompetent patients who would certainly die. Their deaths could be caused either by their disease or by limitation of life prolonging medical treatment, including

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[8] Thanks to Dominic Wilkinson for this example.

the withholding or withdrawing of artificial nutrition. In such cases, nonvoluntary AME would save resources over a slower death. In addition, parental interests might support euthanasia. Moreover, considerations of lack of psychological continuity and connectedness in cases of unconsciousness or near-unconsciousness would reduce or eliminate the wrongness of killing in such incompetent patients.

This is not to say that AME should be provided whenever palliative care is an option. There need to be good reasons for AME. Many cases will be grey and perhaps in this case it should not be used. But some cases will be clear. So if a patient is going to die **soon** (say in days-a couple of weeks), and the patient is unconscious, or has minimal consciousness, the case for AME is strongest.

In short, in cases in which a human being will certainly die, whether by disease, injury, their decision or the legitimate decisions of others, euthanasia offers a more just way of dying when that human being would otherwise require palliative or other care during dying that imposes costs indirectly on others. Distributive justice may in this way justify both voluntary and nonvoluntary AME. But of course whether AME should be offered, or is the best option, will depend on weighing all the reasons in particular contexts.

References

Battin, Margaret Pabst. 1994. *The least worst death*. New York: Oxford University Press.

Gillon, Raanan. 1985. Philosophical medical ethics. *Rights. British Medical Journal* 290: 1890–1891.

Hope, Tony, Julian Savulescu, and Judith Hendrick. 2003. *Medical ethics and law: The core curriculum*. London: Churchill Livingstone.

Kahane, Guy, and Julian Savulescu. 2009. The welfarist account of disability. In *Disability and disadvantage*, eds. Adam Cureton, and Kimberley Brownlee, 14–53. Oxford: Oxford University Press.

Kuhse, Helga. 1992. Quality of life and the death of “Baby M”: A report from Australia. *Bioethics* 6: 233–250.

Mill, J.S. 1900. *Principles of political economy*. New York: P. F. Collier and Sons.

Parfit, Derek. 1984. *Reasons and persons*. Oxford: Clarendon Press.

Rachels, James. 1975. Active and passive euthanasia. *New England Journal of Medicine* 292: 78–80.

Rachels, James. 2007. The morality of euthanasia. In *The right thing to do*, eds. James Rachels, and Stuart Rachels, 151–155. New York: McGraw Hill.

Rawls, John. 1971. *A theory of justice*. Cambridge, MA.: Harvard University Press.

Savulescu, Julian. 2014. A simple solution to the puzzles of end of life? Voluntary palliated starvation. *Journal of Medical Ethics* 40: 110–113.

Sinnott-Armstrong, Walter F, and Franklin G. Miller. 2013. What makes killing wrong? *Journal of Medical Ethics* 39, 3–7.

Verhagen, A.A. Eduard. 2013. The groningen protocol for newborn euthanasia: Which way did the slippery slope tilt? *Journal of Medical Ethics* 39: 293–295.

White, Ben, Willmott Lindy, and Julian Savulescu. 2014. Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine* 22: 376–386.

Wilkinson, Dominic, and Julian Savulescu. 2011. Knowing when to stop: Futility in the ICU. *Current Opinion in Anaesthesiology* 24: 160–165.

Wilkinson, Dominic J.C., and Julian Savulescu. 2012. Should we allow organ donation euthanasia? Alternatives for maximizing the number and quality of organs for transplantation. *Bioethics* 26: 32–48.

Wilkinson, Dominic J.C., and Julian Savulescu. 2014. Disability, discrimination and death: Is it justified to ration life saving treatment for disabled newborn infants? *Monash Bioethics Review* 32: 43–62.

Willmott, Lindy, Ben White, Malcolm K. Smith, and Dominic J.C. Wilkinson. 2014. Withholding and withdrawing life-sustaining treatment in a patient's best interests: Australian judicial deliberations. *Medical Journal of Australia* 201: 545–547.

Chapter 5
Mental Illness, Lack of Autonomy, and Physician-Assisted Death

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Abstract In this chapter, I consider the idea that physician-assisted death might come into question in the cases of psychiatric patients who are incapable of making autonomous choices about ending their lives. I maintain that the main arguments for physician-assisted death found in recent medical ethical literature support physician-assisted death in some of those cases. After assessing several possible criticisms of what I have argued, I conclude that the idea that physician-assisted death can be acceptable in some cases of psychiatric patients who lack autonomy ought to be taken into account in assessing the moral and legal acceptability of physician-assisted death.

5.1 Introduction

Charlie spends most of his time desperately fighting and escaping tormentors that others cannot see. This has been going on for years. Because of his predicament, Charlie is suffering severely and has repeatedly attempted to kill himself. As he is convinced that the personnel of the mental institution in which he now resides are also conspiring against him, they fail to have meaningful contact with him. Yet, following the common psychiatric goal of suicide prevention, the staff have done their best to stop Charlie from killing himself. Especially as the suicide methods to which he has resorted have often, but not always, been as distorted as his conception of reality, this has not been difficult. However, since his distress is clearly very intense and his condition is deemed incurable, some of the mental health care providers treating Charlie have recently started to wonder whether they should help him to end his life rather than try to prevent him from killing himself.

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The question whether a health care provider sometimes ought to end her patient's life or to assist him to end it himself has recently attracted increasing public attention worldwide. The academic discussion on the topic has mostly focused on patients who suffer from physical illnesses or injuries but recently some ethicists have proposed that mental illness could sometimes provide grounds for physician-assisted death (see, e.g., Appel 2007; Cholbi 2013a, b; Hewitt 2010a, b, 2013; Parker 2013).[1] Yet proponents of the idea typically stress that physician-assisted death could be morally acceptable only in the cases of competent patients, patients who are able to make autonomous decisions about ending their lives. Given the seriousness of Charlie's condition, this requirement would rule him out as a candidate for physician-assisted death (see below). However, as just suggested (see also Burgess and Hawton 1998, 121; Hardcastle and Stewart 2002, 432–433), it could be taken that physician-assisted death might sometimes come into question even when a suicidal mentally ill person lacks decision-making ability.

In this chapter, I consider the idea that psychiatric patients lacking autonomy could be candidates for physician-assisted death in light of the main arguments for physician-assisted death presented in recent medical ethical literature. First I briefly characterize the starting points I have in doing that. On the basis of assessing the role of patient autonomy in making end-of-life decisions and the moral importance of non-autonomous mental suffering in the end-of-life context, I propose that the central arguments in favor of physician-assisted death advocate allowing the pertinent practices in cases of patients such as Charlie. Then I consider several possible objections to this suggestion. I conclude by briefly clarifying what I have and what I have not argued.

5.2 The Main Points of Departure

In today's medical ethics, it is commonly accepted that an autonomous patient can refuse and withdraw from (even) vital treatment. Accordingly, the debate on the moral acceptability of physician-assisted death focuses on cases in which a health care provider not merely refrains from or stops providing life-sustaining treatment to her patient, but takes what is considered a more active role in bringing about her patient's death. In what is called active voluntary euthanasia, this role typically consists of administering a lethal medication to a patient. In the procedure named physician-assisted suicide, a health care provider supplies her patient with

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[1] According to *The Royal Dutch Association of Medicine*—which allows that physical illnesses and injuries can provide grounds for physician-assisted death—suicide based on psychiatric reasons should not be treated differently from assisted suicide in medicine generally. In Belgium, also, suffering unrelated to physical illness or injury is acknowledged in law as a valid basis for physician-assisted death (see *The Royal Dutch Medical Association* 2011, 21–22 and, e.g., Naudts et al. 2006). On the legal status of physician-assisted death for patients suffering from physical illnesses or injuries see, e.g., the chapter by Jocelyn Downie and Georgia Lloyd-Smith in this volume.

appropriate means of ending his life by himself. I refer here to both of these procedures with the expression ‘physician-assisted death.’

The main arguments for physician-assisted death found in recent medical ethical literature refer to respect for patient autonomy and the relief of suffering. It is maintained, roughly, that, within the limits resulting from granting a similar right to others, an autonomous person has the right to live his life in accordance with his own view of how it should proceed. And this right is seen to entail that, when he autonomously wants that, a person is allowed to end his life and entitled to receive assistance from health care providers in doing that (cf., e.g., Beauchamp 1993, 101, 2006). Autonomy is thus here typically perceived in procedural terms, as, again roughly, deciding and acting freely, intentionally, and with sufficient understanding about what one is doing (see, e.g., Beauchamp and Childress 2009, 99 ff.). This allows individuals to have quite differing conceptions about how their lives are to go and to end. Below I call this argument for physician-assisted death the argument from autonomy.

In terms of suffering, proponents of physician-assisted death (but not only them) maintain that a person should not have to experience more distress than he can bear. Typically, only distress caused by severe physical illness or injury is seen to provide grounds for physician-assisted death. Yet, as was also already stated, some authors accept that mental illness can suffice, and sometimes also suffering unrelated to any illness or injury is deemed a legitimate ground for physician-assisted death (see, e.g., Wijsbek 2012 and also footnote 1). Whatever the nature of the suffering deemed relevant, it is commonly required that the distress that can warrant physician-assisted death must be enduring and unavoidable in the sense that there is no way of adequately alleviating it other than by ending the suffering patient’s life. Sometimes it is also maintained that only distress caused by a terminal illness or injury can provide grounds for physician-assisted death. Below I refer to the position that the alleviation of intolerable distress provides grounds for physician-assisted death as the argument from relief of suffering.

As already mentioned, authors writing on the moral acceptability of physician-assisted death usually emphasize that only a competent person can present a morally authoritative request to die. According to what has been called the standard analysis of the notion of competence, a competent patient has the capacity to understand, is able to reason and deliberate, possesses a set of interests and concerns relevant to the decision she is to make, and is able to communicate her decision (see, e.g., Appelbaum 2007, 1836; Beauchamp and Childress 2009, 114; Buchanan and Brock 1989, 23; Stewart et al. 2011). When a patient is unable to make autonomous choices about her treatment, the health care providers attending her must resort to surrogate decision-making methods. The main types of these procedures refer to the will that the patient possibly expressed when she was competent, the surrogates’ approximation of what she would now want if she had decision-making ability, and to what is seen to be in the patient’s best interests (see, e.g., Buchanan and Brock 1989).

Charlie lacks insight into his illness, he is unable to understand what is really happening around and to him, and his reasoning is often quite illogical. Therefore, I take it that he lacks decision-making ability in the sense described above.[2] In what has been referred to as the orthodox psychiatric view on suicide, because the desire to kill oneself nearly always results from mental illness, "it is always necessary to intervene in suicide attempts whenever possible," with the aim of preventing patients from killing themselves (see, e.g., Hewitt 2013, 361; Fairbairn 1995, 28–29; cf., e.g., Szasz 2011; Callaghan et al. 2013, see also, e.g., Appel 2012). Accordingly, as in Charlie's case so far, the surrogate decision-makers deciding on the behalf of a suicidal psychiatric patient most likely aim to stop the patient from ending her life. Below, I turn to assessing whether the argument from autonomy and the argument from relief of suffering provide reason for questioning this policy in the cases of patients such as Charlie.

5.3 The Relevance of Charlie's Lack of Autonomy

Do Charlie's lack of competence and his consequent inability to make an autonomous decision about ending his life mean that physician-assisted death cannot be morally justified in his case? Asking this leads to the question: Why is patient autonomy valued in health care? To assess that question, let us consider the case of Ben. Ben falls seriously physically ill and, consequently, seeks medical care. The health care providers treating him are obligated to request his autonomous consent for the therapies they offer him. If the way in which Ben then exercises his autonomy does not enable the health care providers to determine whether or not giving him the therapies would accord with how he wishes his life to proceed, Ben has failed to engage successfully in the main procedure protecting patient autonomy in current health care, medical informed consent. The central reason for a patient's autonomy being given a prominent role in health care is thus to ensure that the treatments which the patient receives do not conflict with her own view of how her life should go.

Consider that Ben's health care providers are to determine whether he ought to have a certain surgical procedure. The operation is a quite complicated one. If it is successful, Ben will regain some of the abilities he now lacks because of his illness. But the procedure cannot restore Ben to full health. The probability that the

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[2] Though it has often been considered clear that mentally ill patients lack decision-making ability, it has also recently been emphasized that even a severe mental disorder need not preclude at least periodical competence (see, e.g., Hewitt 2010a). Accordingly, it may be that psychiatric patients who are altogether unable to autonomously decide about their treatment are rarer than has commonly been supposed. Yet that does not preclude the possibility that patients such as Charlie exist (cf. also, e.g., Hardcastle and Stewart 2002, 431–432) nor makes them morally unimportant. Also, the possibility that a patient such as Charlie may be able to make some choices autonomously—such as choosing between tea and coffee at breakfast—does not entail that he is autonomous in the sense that he can make an autonomous choice about ending his life.

procedure goes well in Ben's case is approximately 65 %. If it does not go well, Ben may suffer from complications that could significantly worsen his condition. Now, as it depends on his evaluation of the life he could have if the operation is successful as compared to his current existence and on his assessment of whether the risk is worth taking, determining whether Ben ought to have the procedure appears quite difficult without recourse to his autonomous decision. Yet the case of Charlie appears significantly different. According to the procedural understanding of autonomy referred to here, even the decision to spend an indeterminable period in intolerable and pointless agony can, in principle, be autonomous. But it would seem clear that, rather than agreeing to live such a life, an autonomous person would typically do her best to avoid it. Indeed, a person's willingness to lead such an existence very strongly suggests that she lacks the kind of understanding about its nature and consequences that autonomy presupposes. Accordingly, there is also reason to think that, were he autonomous, Charlie would be very much against living the kind of life he now must endure. This suggests that the fact that Charlie is unable to make an autonomous decision about ending his life does not disqualify him as a candidate for physician-assisted death.

But does the fact that Charlie is not autonomous mean that his suffering is ultimately not of real moral significance? The view that non-autonomous distress—which besides the suffering of people such as Charlie includes the anguish of small children, the demented elderly, and non-human animals—would not really matter morally appears quite counter-intuitive. But could there still be something to it? Consider the case of Mary. After her husband went on a cruise with their children, some evil-minded people told her that the ship they were on sank and all of its passengers drowned. Consequently, Mary is devastated. As her feelings are not based on adequate understanding about what has actually happened, they are not autonomous. If Mary was informed in the way autonomy as it is here conceived presupposes, she would not be suffering. This, someone might take it, demonstrates that a person's suffering has real moral significance only if it is autonomous.

However, if she is not provided with adequate information, Mary's subjective evaluation of her existence does not differ from what it would be if her family really had drowned. In other words, as long as she remains in her uninformed state, Mary's distress is quite real to her. Charlie differs from Mary, among other things, in that he cannot grasp that he lacks adequate understanding about his situation. Therefore, even if he were provided with all possible evidence about what he really does and what actually happens to and around him, it would not affect how he experiences his life. He would just consider the provision of the information as a further stage in the plots against him. Hence, the possibility of successfully informing Charlie is not open.

But, just as Mary—in her uninformed state—would continue to be very distressed, in Charlie's view his suffering is quite real. Indeed, that he is unable to acquire insight into his condition means that his experiential world is more significant from his own viewpoint than it would be if he had the ability to understand his situation. If he understood that the tormentors he believes to be persistently pursuing him do not exist in the external reality, his suffering would not be as intense as it now is. And that it is unbearable from his point of view is the basis of the moral significance of his distress. Even though the viewpoint is uninformed, it is the only perspective available to Charlie, the one he most plausibly must make do with from day to day, as long as his life continues (cf. Sects. 5.6.3 and 5.6.4). Accordingly, though Mary's wellbeing should credibly be ultimately assessed in terms of her autonomous views on her life—the ones she would have after being informed,—the fact that Charlie lacks autonomy does not undermine the moral relevance of his distress. Indeed, a significant moral reason for Mary to be provided with adequate information about what has actually happened is that she is suffering without it. That it is non-autonomous does not undermine the moral significance of suffering in her case either.

Of course, there are philosophers who deny that what is good and bad for a person is to be determined by reference to her subjective states. According to proponents of the so-called objective theories of human good, whether an individual fares well or ill is to be defined in terms of, for instance, the extent to which she exemplifies ideals such as rationality and virtue. Some authors maintain that things that affect a person's interests need not enter her experience at all (cf., e.g., Ferkany 2012; Lauinger 2013; Sarch 2011; Tiberius 2007). Yet these kinds of considerations clearly do not undermine the moral relevance of Charlie's suffering. Because of the severity of his illness, Charlie is not capable of exemplifying ideals such as rationality or moral virtue to any significant extent. And even if he had interests that could be affected by events that never enter his experience, it would still be quite counter-intuitive to maintain that his life is going well for him. Indeed, if a theory of wellbeing entails that a person such as Charlie is doing fine, that is a reason to reject the theory rather than to accept the implication.

If (1) patients' autonomous choices are valued in health care because of their role in determining what patients would really want, (2) there is good reason to believe that Charlie would reject the kind of life he now leads were he autonomous, and (3) his lack of autonomy does not compromise the moral relevance of his suffering, it would seem that the fact that Charlie is not autonomous does not entail that physician-assisted death cannot come into question in his case. It appears clear that he is suffering in a morally relevant sense and that continuing to live the life that he is leading at present is not what he really wants or would want were he autonomous. But does the fact that Charlie's suffering is of the mental kind disqualify him as a candidate for physician-assisted death? The above remarks on his distress suggest that it does not but let us consider the question in more detail.

5.4 Mental Suffering in the End-of-Life Context

In the current medical ethical literature, the position that mental distress—suffering that is not directly caused by physical illness or injury (see also below)—can justify assisting a patient to end her life is a marginal one. Among those who do not reject physician-assisted death altogether, the main reason against the position would appear to relate to the perceived subjectivity of mental distress (see, e.g., Gill 2009, 31). It is taken that, because of this subjectivity, mental suffering is less real than distress directly caused by physical illness or injury—henceforth physical suffering—and, therefore, mental suffering does not have the same moral relevance as physical distress in the end-of-life context.

However, the realization in the 1950s that some mental illnesses can be treated with medication gave rise to a new research paradigm within which mental disorders came to be understood as distinctive neurobiological entities. The position that mental illnesses have a neurobiological basis has recently derived further support from pertinent genetic research and studies using novel neuroimaging techniques (see, e.g., Tsou 2012; Cross-Disorder Group of the Psychiatric Genomics Consortium 2013). Though the research into the neurobiological grounds of mental disorders is still at a fairly early stage, the results of the studies conducted so far suggest that, in terms of their basis, many mental illnesses can be as objective as physical trauma. And those who think that mental suffering is subjective and not as real as physical distress can, and would indeed often appear to do, accept that the mental distress resulting directly from severe mental illness is not as subjective as the mental suffering experienced by mentally healthy people. Accordingly, the view that mental suffering is subjective in a way that physical distress is not would rather appear to relate to the mental distress experienced by mentally healthy persons than to the mental suffering of patients with severe psychiatric disorders.

Moreover, as has been pointed out, people have different pain thresholds. Accordingly, individuals can react differently to a similar physical trauma. Their response can vary with factors such as their personal histories and their mental state while undergoing the trauma. It also seems that individuals are not always similarly affected by what—as far as is known—are similar experiences of physical pain. Even severe physical pain need not cause suffering: at least those who consider it a part of something they see worthwhile may not suffer as a result of undergoing it. And what is called chronic pain is known to sometimes outlast the physical trauma that is seen as its initial cause. (cf., e.g., Cholbi 2013b; Corns 2014; Niv and Marshall 2004; Hardy 2005; Saariaho et al. 2012) This suggests that physical suffering too is subjective, not only in the sense that it is experienced from the first person viewpoint, but also in that its causes partly depend on factors that can vary from one person to another.[3]

In light of empirical studies, mental suffering also plays an important role in connection with the requests for assistance in dying made by physically ill or injured patients. A major reason for their wish to end their existence, when that is what they desire, is often the mental distress related to the effects that their illness or injury has on their lives, effects such as loss of autonomy, inability to engage in

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[3] Pain is among the topics of the burgeoning neurosciences but at least so far the prospect of completely objective assessment of pain and suffering remains rather distant (see, e.g., Giordano 2010; and also Button et al. 2013). If it became possible, objective pain assessment could imply that mental pain and suffering is as objective as physical pain and suffering.

what they see as meaningful activities, indignity, hopelessness, and pointlessness. The studies also suggest that, because it usually is more continuous than physical suffering, mental suffering is often considered worse than physical distress (See, e.g., The Oregon Department of Human Services 2013; Dees et al. 2011). And, as demonstrated by physically healthy suicides, mental distress alone can be severe enough to make a person to (want to) end her life. Finally, the argument from autonomy allows a patient to end her life when that is what she autonomously wants. And, as has been explained, according to the argument from relief of suffering, a physician-assisted death is morally permissible when the patient's suffering is unbearable to her. Hence, both of the main arguments for physician-assisted death focus on the desires and experiences of the patient, on how her life feels for her, on what it is like from her own viewpoint.

In view of the considerations of this section, there would not seem to be adequate reason to consider mental suffering morally less significant than physical distress in the end-of-life context. Accordingly, if it is accepted that her physical suffering can provide grounds for ending a patient's life, there does not appear to be sufficient reason to rule mental suffering out as grounds for physician-assisted death. The relevance of mental suffering in the end-of-life context is indeed already acknowledged, at least implicitly, in that even patients who are not suffering physically are allowed to refuse and to withdraw from vital treatment (when they do it autonomously).[4]

5.5 Countervailing Considerations Pertaining to Charlie's Distress?

That it is permissible to punish criminal offenders for their crimes by inflicting mental suffering on them is quite commonly accepted. Furthermore, many people apparently think that, whether or not it is connected to punishment, mentally distressing experiences can develop one's character: suffering refines and purifies and, at best, makes one merciful, compassionate, and noble. As with, for instance, artistic creation, mental suffering can also be seen as an unfortunate but essential experience that is considered highly valuable. And, for example, grief, as distressing as it can be, is widely believed to be an appropriate emotion in particular circumstances, when, say, one has lost a close friend or relative. Finally, some of those with masochistic inclinations may be able to enjoy even mental suffering for

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[4] It might be objected that if mental suffering is deemed relevant in the end-of-life context, then the request for euthanasia made by a heartbroken teenager who has just lost the person she believes to be the love of her life must be obeyed (cf., e.g., Young 2014). However, as has already been pointed out (see, e.g., Varelius 2014), accepting the above conception of morally acceptable physician-assisted death, the teenager does not qualify as a candidate. For, in cases like hers, the suffering typically is not enduring and unavoidable in that there is no way of adequately alleviating it other than that of ending her life.

its own sake.[5] Perhaps then, there is also at least some reason to endorse the mental distress that Charlie is experiencing, something that speaks against physician-assisted death in his case?

The kind of suffering that Charlie is undergoing would not seem to qualify as an acceptable punishment for any crime (cf. also, e.g., Adams 2014). And, as things are, Charlie has done nothing to deserve to be harshly punished. It also seems clear that the mental suffering that a person experiences can be helpful in building her character—as distinguished from, for instance, just making her numb—only if she can learn something from the distress. That, in its turn, most plausibly requires mental abilities that Charlie, because of the severity of his mental illness, lacks. Charlie might learn something valuable from his distress if he recovered from his condition. But, then again, he might not (see also, e.g., Olsen 2006). And, at any rate, the probability of his recuperating from his illness is very low.

Neither is Charlie's distress something that he has decided to accept because he sees it as an inevitable part of some whole that he deems valuable. His distress might be seen as an appropriate response to his circumstances in the sense that other people are also known to have become similarly mentally ill after undergoing as gravely deprived a childhood as he did. Yet falling seriously mentally ill is clearly not a reaction that is morally required from people with a similar—or any—background. Mental suffering is arguably to be endorsed, if at all, only in situations in which avoiding it would result in, or sustain, an unfortunate loss of contact with reality. But after Charlie fell ill, his situation has been the opposite. Charlie is also not a masochist. Consequently, I take it that there is no good reason to endorse the suffering he undergoes.

5.6 Possible Objections

As far as the above considerations are plausible, the main arguments for physician-assisted death found in recent medical ethical literature support physician-assisted death also in cases of psychiatric patients such as Charlie. Yet several possible objections for allowing a physician to assist a patient such as Charlie to end his life suggest themselves. Below I briefly assess eight criticisms that seem to be the most central ones.

5.6.1 Charlie's Condition Is not Terminal

As already noted, it has been maintained that only suffering caused by a terminal illness or injury can provide grounds for physician-assisted death. An advocate of

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[5] As it does not affect the main argument of this chapter, I will not now go into the question whether a masochist actually enjoys her ability to endure suffering rather than the suffering itself (or both).

the view might argue that in Charlie's case the fact that his condition is not terminal rules out the possibility of physician-assisted death. Therefore, even if the above considerations were acceptable, the conclusion of this possible objection could be that the mental health care providers treating Charlie ought not to help him to end his life.

The view that Charlie's condition is not terminal could be questioned (see Cholbi 2013b, 501–503). But, for the sake of argument, let us assume that his illness is not fatal. Would the non-terminality of Charlie's condition then suffice to disqualify him as a candidate for physician-assisted death? Allowing physician-assisted death only in the case of terminal patients limits the end-of-life choices open to non-terminal patients and, hence, restricts the scope of their autonomy (see also, e.g., Plaisted 2013). Accordingly, considerations motivating one of the two main arguments for physician-assisted death—the argument from autonomy—would also appear to support permitting physician-assisted death in the case of non-terminal patients.

In terms of relieving the patients' suffering, other things being equal, the only difference between a terminal patient who suffers unbearably and a non-terminal patient in intolerable distress is that the agony of the latter is likely to last longer.[6] When avoidance of unbearable suffering is seen as a central consideration in favor of physician-assisted death, as it now is, it would therefore seem that helping a non-terminal patient in ending his life is more justified than assisting a terminal patient to die (see also, e.g., Beauchamp and Davidson 1979). Accordingly, seen from the viewpoints of the argument from autonomy and the argument from relief of suffering, physician-assisted death would appear to be at least as justified in the case of non-terminal patients as it is in the case of terminal patients. And, in light of the above considerations, both of the arguments are also relevant in Charlie's case.

5.6.2 Is Charlie's Condition Certainly Incurable?

It might be argued, however, that mental disorders differ from physical disorders and injuries in that the incurability of the former is never certain (cf., e.g., Cowley 2013). Accordingly, a critic could argue, even if it were very improbable, it is still possible that Charlie will recover from his illness. In view of this prospect, the critic could conclude that the mental health care providers treating Charlie ought not to help him to end his life.

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[6] It might be objected that ending the life of a terminal patient is not as bad as terminating the life of a non-terminal patient because the former would soon die anyhow. However, this presupposes that ending the life of a patient in unbearable suffering is a bad thing. It is deeply regrettable that there are cases in which people suffer so horribly that they want to end their existence. But when the situation is as severe as that, ending the patient's life is arguably not a bad thing. Therefore, this possible objection is unconvincing.

However, people are known to have recovered from physical illnesses thought to be incurable.[7] New findings in medical science may also suddenly alter existing conceptions of which physical illnesses and injuries can be healed and which cannot. On the other hand, though the prognoses of patients suffering from severe mental illnesses such as schizophrenia are currently often less pessimistic than they used to be, not all patients with severe mental illness return to a normal existence (see, e.g., Frese et al. 2009; cf., e.g., Tamminga and Lahti 2001). Accordingly, it is not at all clear that there really is the kind of difference between physical illnesses and injuries and mental disorders that this possible objection presupposes.

Someone might now object that, instead of allowing physician-assisted death, it would still be more reasonable to apply a version of Pascal's Wager here. In this view, as the costs of staying alive for the patient are small as compared to the benefits he would gain if he recovered from his illness, the best bet is against dying. However, considering that even many healthy people can have great difficulties with finding accommodation and employment and maintaining relationships, the life of a person who recovers after years or decades of severe mental illness can unfortunately be rather unappealing to several people, possibly including Charlie. Accordingly, even if he recovered from his illness, he might also find the life he would then have to be overly burdensome. Moreover, given the severity of Charlie's suffering, it would seem that the costs of his staying alive, while he remains ill, could be insignificant to him only if he were sedated into unconsciousness during the possibly quite futile wait for a cure for his condition. Though someone might be willing to choose such an existence, it would not—to say the least—seem to be the only reasonable choice to be made in Charlie's situation (see also Sect. 5.6.4).

5.6.3 *What if Charlie Changes His Mind?*

A critic could still insist that even if Charlie does not recover from his illness, his mind as regards the desirability of death might change. If a competent patient holds on for an extended period to her wish to die, we can be reasonably convinced that she really does want to die. But precisely because he is severely mentally ill, the critic could continue, the case of Charlie is different (also) in this respect. Charlie's thinking follows its own peculiar logic and, hence, it may be that tomorrow he will be quite happy with his life. Because of this possibility, the critic could conclude that assisting Charlie to end his life would be morally unacceptable.

This possible critic is quite correct in that patients should not be helped to end their lives if that is not what they want. It is also true that the possibility of

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[7] That some of such cases involve misdiagnoses does not lessen their relevance here.

Charlie's changing his mind about the desirability of dying cannot be ruled out with absolute certainty. However, again, that degree of certitude is not available in the cases of physically ill or injured patients who request assistance in ending their lives either. The facts that Charlie has been suicidal for years and that the mental health care providers treating him foresee no dramatic alteration in his state of mind also argue against this possible objection. Indeed, to be plausible, the view that Charlie should be made to continue his life because of the possibility that he suddenly gains the desire to live should be supported with good reasons for thinking that he really would change his mind.

5.6.4 Ending Charlie's Life Is Undignified and Inhumane

When suffering patients autonomously choose to die, they exercise their human capacities and control the ending of their lives. But in the cases of incompetent persons such an expression of agency is not possible. Consequently, a critic might maintain that terminating the life of an incompetent person, or even just assisting in it, amounts to treating the person like an animal that is put out of its misery. Behaving like that toward Charlie would be both undignified and inhumane. In the case of human beings, the criticism could continue, more considerate and respectful ways of acting should be found. Therefore, the critic could conclude that physician-assisted death does not come into question in Charlie's case, the main argument of this chapter notwithstanding.

Let us assume that physician-assisted death would be undignified and inhumane in Charlie's case. Would this possible objection then be plausible? That depends on how physician-assisted death compares with its alternatives. Given that recovery and change of mind are quite improbable in Charlie's case, there are two options to consider. First, Charlie continues his life as it now is. Second, he is sedated heavily enough for his persecutors to leave him alone. Now, putting up with the situation can, at least sometimes, be deemed a dignified response to one's suffering. But if one is able to tolerate it, one's distress is not unendurable. And, as already mentioned, physician-assisted death is now assumed to be acceptable only in cases of intolerable suffering. Coming to terms with one's distress would also appear to presuppose mental capacities—the ability to step back from it and to put it into some perspective—which Charlie lacks. And having to experience further meaningless suffering for years or even decades is arguably, if not evidently, less humane than its alternatives, including the option of ending such existence.

In terms of the second alternative, if it were possible to medicate Charlie so that he would regain contact with reality but just cease to have the hallucinations and delusions he now has, his condition would not be as severe as it is. As things are, it would seem that sedation could alleviate Charlie's agony only if the medication were strong enough to significantly affect the level of his consciousness. Perhaps persons whose level of awareness is somewhat lower than normal could lead a dignified or at least a humane existence? But, unfortunately, that it would be possible for Charlie to lose his persecutors without being sedated to, or at least very near to, unconsciousness seems like an unrealistically sanguine prospect. And spending years, or even decades, sedated into (near) unconsciousness hardly qualifies as leading a dignified or a humane existence. Accordingly, even if physician-assisted death were undignified and inhumane, it would seem that the most probable alternatives available in Charlie's case are at least as, if not more, undignified and inhumane.[8]

5.6.5 Can Physician-Assisted Death Really Be Acceptable in Cases of Non-autonomous Patients?

The view that even non-autonomous patients could qualify as candidates for physician-assisted death could be deemed counterintuitive despite the reasons for it presented above. If the view is accepted, a critic could maintain, then we must also endorse physician-assisted death in the cases of infants. But advocating that health care providers ought to help small children in ending their lives is clearly implausible. Therefore, the critic could conclude, the above considerations do not show that physician-assisted death could come to question in Charlie's case either.

However, withholding and withdrawing even life-sustaining treatment from incurably physically ill or injured severely suffering infants is widely accepted (cf., e.g., Porta and Frader 2007). This demonstrates that the distress of non-autonomous children is usually already deemed significant in the end-of-life context. But, of course, if physician-assisted death comes into question in the case of infants, it can be acceptable only if they are incurably ill, their suffering is unbearable, and ending their lives is the only adequate way of avoiding it. When these criteria are satisfied, that a health care provider—not the patient herself—ends the life of an infant is arguably not morally unacceptable (see also, e.g., Vanden Eijnden and Martinovici 2013; cf., e.g., Kon 2007). Accordingly, this possible objection is implausible.

5.6.6 Charlie Is Not the Only One Whose Interests Count

Above, the focus has been on what is good from Charlie's viewpoint. Yet, obviously, Charlie is not the only party in the case. At least the interests of the mental

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[8] Of course, the notion of human dignity can be understood in significantly different ways. Accordingly, someone might argue that the common understanding of human dignity employed above should be replaced with a different one, one that would also imply that assisting Charlie to end his life would be more undignified than its alternatives. However, as I am unable to here assess whether there could be a justifiable notion of human dignity of the kind it refers to, I must now put this possible objection aside.

health care providers treating him and those of the members of his family are also involved (see also Sect. 5.6.7). It could thus be argued that even if assisting Charlie to end his life were best from his viewpoint, it does not necessarily follow that physician-assisted death would be morally warranted in his case. The interests of the other parties may argue strongly enough against helping Charlie to end his life to make it morally unacceptable.

However, the main purpose of the institution of mental health care is arguably, if not evidently, that of serving the good of those who suffer from psychiatric problems. Accordingly, whether assisting Charlie to end his life accords with the relevant interests of mental health care providers—primarily their interests *qua* the professionals they are—should mainly depend on whether doing that is what is best from Charlie's viewpoint (cf. also, e.g., Kantymir and McLeod 2014). Given that Charlie is especially vulnerable (cf., e.g., Tavaglione et al. 2015), it is also not unreasonable to require his family members to give extra weight to his interests. At least apart from very exceptional circumstances, it is difficult to imagine that a member of his family could have an interest that would justify continuing, to the indeterminable future, the agony that Charlie's life is for him. And, for reasons presented above, sedating him into unconsciousness could be deemed undignified and inhumane. Accordingly, if ending his life were best for a patient like Charlie, it would seem that giving due weight to the interests of mental health care providers and to those of the patient's family members would, at least normally, not suffice to make physician-assisted death impermissible in the case.

5.6.7 Accepting Physician-Assisted Death in Charlie's Case Would Compromise the Value of Human Life in Society

Maintaining that physician-assisted death could be acceptable in cases like that of Charlie, a critic might still argue, would be to say that the lives of the severely mentally ill have no worth. Besides being bad in itself, sending such a message would, the criticism could continue, surely compromise the value put on human life in a society. Therefore, the conclusion of the objection could be, physician-assisted death is not acceptable in cases of patients like Charlie, irrespective of what has been argued above.

However, the main argument of this chapter does not entail that the lives of the severely mentally ill have no value or that human life has no significant worth. The argument concerns only the cases of the severely mentally ill who have a persistent wish to die because of their continuing unbearable and incurable suffering. And the 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. Interpreting the main argument of this chapter as saying that the lives of the mentally ill have no value—or that human life in general has no worth—would simply be to make a mistake. Accordingly, it would arguably be better to inform people who might make the error about the proper implications of allowing physician-assisted death in cases of persons such as Charlie than to force persons like him to reluctantly continue lives of unbearable distress for years, or even decades.

5.6.8 Incompetent Patients Are More Likely to Be Abused Than Competent Patients

Finally, a critic might maintain that competent patients are usually able to stand up for themselves whereas incompetent patients often are not. Therefore, the possible objection could continue that abuses of the laws permitting physician-assisted death would 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. And that, the critic could conclude, is why physician-assisted death should not be allowed in the cases of patients such as Charlie.

Incompetent patients are, in general, more vulnerable to abuse than competent patients. Yet it does not necessarily follow that there would actually be more maltreatment in the cases of incompetent patients. To a significant extent, whether there would be would appear to depend on how physician-assisted death would be arranged. When physician-assisted death is allowed in the cases of competent patients, the pertinent rules include requirements to the effect that a request for death must be assessed by independent parties, for instance, by at least one medical expert besides the one responsible for treating the patient in question (see, e.g., The Oregon Death with Dignity Act). A corresponding requirement should evidently also be used in the case of incompetent patients. Whether formulating additional rules so as to adequately account for the possible remaining threats of abuse would be impossible is an empirical question that I am unfortunately unable to answer. But, in the absence of good evidence for the claim that abuses of the laws permitting physician-assisted death would really be significantly more frequent in the cases of incompetent patients than in those of competent patients, this possible objection appears unconvincing.

5.7 Conclusion

In this chapter, I have considered the question whether physician-assisted death could be morally acceptable in the cases of persistently suicidal unbearably and incurably suffering psychiatric patients who are unable to make autonomous end-of-life choices. I focused on one case of that kind, the case of Charlie, from the viewpoint of the main arguments for physician-assisted death found in recent medical ethical literature, the argument from autonomy and the argument from relief of suffering. First I argued that patients' autonomous choices are valued in health care because of their role in determining what patients would really want; that there is adequate reason to believe that an autonomous person would not choose a life of meaningless unbearable suffering; and that a patient's lack of autonomy does not make his suffering morally unimportant. Then I maintained that mental suffering is not relevantly different from physical distress in the end-of-life context and argued that there is no good reason to endorse the suffering of a patient like Charlie. On these grounds, I proposed that that the main arguments for physician-assisted death found in recent medical ethical literature also support physician-assisted death in the cases of patients such as Charlie.[9] After this, I briefly assessed eight possible objections to the suggestion and proposed that they are not sufficiently convincing to disprove it.

As already proposed, I did not argue that it is permissible for health care providers to end the lives of their patients against the patients' will. Neither did I maintain that health care providers should urge their patients to commit suicide or to have euthanasia. Nor did I argue that physician-assisted death is acceptable when there is a cure for the condition that makes life intolerable or adequate ways of alleviating a patient's distress other than ending her life. Though I touched upon some considerations related to the moral acceptability of physician-assisted death other than the arguments from autonomy and from relief of suffering, I did not show that physician-assisted death is morally acceptable in the cases of incompetent patients such as Charlie: perhaps there are stronger objections to the idea than the ones discussed here (cf., e.g., footnote 8) and someone might also reject my responses to the latter.

Hence, the conclusion of this chapter is modest: the main arguments for physician-assisted death found in recent medical ethical literature support physician-assisted death also in cases of incompetent psychiatric patients whose illness is incurable and who persistently want to end the existence that they find unbearable. How many patients like this there are, is an empirical question I am unable to answer. But even if they were rare—as they hopefully are—the above considerations support the view that such patients should not be ignored in connection with assessing the moral and legal acceptability of physician-assisted death. As already suggested above, the idea is not novel (see Burgess and Hawton 1998, 121; Hardcastle and Stewart 2002, 432–433), but the explication of the support the main arguments for physician-assisted death provide for it and the assessment of the possible criticisms of it presented above, I believe, are.[10]

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[9] An affective disorder, such as depression, would appear to influence agency differently than a delusional disorder from which Charlie suffers. Yet it would seem that sometimes an affective disorder can also make a patient incompetent to make autonomous end-of-life choices (cf., e.g., Meynen 2011). The above considerations support physician-assisted death in such cases too, provided, again, that the patient is suffering incurably and unbearably and wants to end her existence.

[10] I thank Michael Cholbi for valuable comments on an earlier version of this chapter and Marion Lupu for revising my English. All remaining errors are mine.

References

Adams, David M. 2014. Belief and death: Capital punishment and the competence-for-execution requirement. *Criminal Law and Philosophy.* doi:10.1007/s11572-014-9293-6.

Appel, Jacob M. 2007. A suicide right for the mentally ill: A Swiss case opens new debate. *Hastings Center Report* 3: 21–23.

Appel, Jacob M. 2012. "How hard it is that we have to die": Rethinking suicide liability for psychiatrists. *Cambridge Quarterly of Healthcare Ethics* 21: 527–536.

Appelbaum, Paul S. 2007. Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine* 357: 1834–1840.

Beauchamp, Tom L. 1993. Suicide. In *Matters of life and death: New introductory essays in moral philosophy*, 3rd ed, ed. Tom Regan, 69–120. New York: McGraw-Hill Inc.

Beauchamp, Tom L. 2006. The right to die as the triumph of autonomy. *Journal of Medicine and Philosophy* 3: 643–654.

Beauchamp, Tom L., and James F. Childress. 2009. *Principles of biomedical ethics*, 6th ed. New York: Oxford University Press.

Beauchamp, Tom L., and Arnold I. Davidson. 1979. The definition of euthanasia. *Journal of Medicine and Philosophy* 4: 294–312.

Buchanan, Allen E., and Dan W. Brock. 1989. *Deciding for others: the ethics of surrogate decisionmaking*. Cambridge: Cambridge University Press.

Burgess, Sally, and Keith Hawton. 1998. Suicide, euthanasia, and the psychiatrist. *Philosophy, Psychiatry, & Psychology* 5: 113–126.

Button, Katherine S., John P.A. Ioannidis, Claire Mokrysz, Brian A. Nosek, Jonathan Flint, Emma S.J. Robinson, and Marcus R. Munafò. 2013. Power failure: Why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience* 14: 365–376.

Callaghan, Sascha, Christopher Ryan, and Ian Kerridge. 2013. Risk of suicide is insufficient warrant for coercive treatment for mental illness. *International Journal of Law and Psychiatry* 36: 374–385.

Cholbi, Michael J. 2013a. Kantian paternalism and suicide intervention. In *Paternalism: Theory and practice*, eds. Christian Coons, and Michael E. Weber, 115–133. Cambridge: Cambridge University Press.

Cholbi, Michael J. 2013b. The terminal, the futile, and the psychiatrically disordered. *International Journal of Law and Psychiatry* 36: 498–505.

Corns, Jennifer. 2014. The inadequacy of unitary characterizations of pain. *Philosophical Studies* 169: 355–378.

Cowley, Christopher. 2013. Euthanasia in psychiatry can never be justified. A reply to Wijsbek. *Theoretical Medicine and Bioethics* 34: 227–238.

Cross-Disorder Group of the Psychiatric Genomics Consortium. 2013. Identification of risk loci with shared effects on five major psychiatric disorders: A genome-wide analysis. *The Lancet* 381: 1371–1379.

Dees, Marianne, Myrra Vernooij-Dassen, Wim Dekkers, Kris C. Vissers, and Chris van Wee. 2011. 'Unbearable suffering': A qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics* 37: 727–734.

Fairbairn, Gavin J. 1995. *Contemplating suicide: The language and ethics of self-harm*. Florence: Routledge.

Ferkany, Matt. 2012. The objectivity of wellbeing. *Pacific Philosophical Quarterly* 93: 472–492.

Frese III, Frederick J., Edward L. Knight, and Elyn Saks. 2009. Recovery from schizophrenia: With views of psychiatrists, psychologists, and others diagnosed with this disorder. *Schizophrenia Bulletin* 35: 370–380.

Gill, Michael B. 2009. Is the legalization of physician-assisted suicide compatible with good end-of-life care? *Journal of Applied Philosophy* 26: 27–45.

Giordano, James. 2010. The neuroscience of pain, and a neuroethics of pain care. *Neuroethics* 3: 89–94.

Hardcastle, Valerie G., and Rosalyn W. Stewart. 2002. Supporting irrational suicide. *Bioethics* 16: 425–438.

Hardy, Rona. 2005. Re-weaving the self: Approaches to chronic pain. *Healthcare Counselling & Psychotherapy Journal* 5: 14–17.

Hewitt, Jeanette. 2010a. Rational suicide: Philosophical perspectives on schizophrenia. *Medicine, Health Care and Philosophy* 13: 25–31.

Hewitt, Jeanette. 2010b. Schizophrenia, mental capacity, and rational suicide. *Theoretical Medicine and Bioethics* 31: 63–77.

Hewitt, Jeanette. 2013. Why are people with mental illness excluded from the rational suicide debate? *International Journal of Law and Psychiatry* 36: 358–365.

Kantymir, Lori, and Carolyn McLeod. 2014. Justification for conscience exemptions in health care. *Bioethics* 28: 16–23.

Kon, Alexander A. 2007. Neonatal euthanasia is unsupportable: The Groningen protocol should be abandoned. *Theoretical Medicine and Bioethics* 28: 453–463.

Lauinger, William A. 2013. The strong-tie requirement and objective-list theories of well-being. *Ethical Theory and Moral Practice* 16: 953–968.

Meynen, Gerben. 2011. Depression, possibilities, and competence: A phenomenological perspective. *Theoretical Medicine and Bioethics* 32: 181–193.

Naudts, Kris, Caroline Ducatelle, Jozsef Kovacs, Kristin Laurens, Frederique Van Den Eynde, and Cornelis Van Heeringen. 2006. Euthanasia: The role of the psychiatrist. *British Journal of Psychiatry* 188: 405–409.

Niv, David, and Marshall Devor. 2004. Chronic pain as a disease in its own right. *Pain Practice* 4: 179–181.

Olsen, J.Mark. 2006. Depression, SSRIs, and the supposed obligation to suffer mentally. *Kennedy Institute of Ethics Journal* 16: 283–303.

Parker, Malcolm. 2013. Defending the indefensible? Psychiatry, assisted suicide and human freedom. *International Journal of Law and Psychiatry* 36: 485–497.

Plaisted, Dennis. 2013. An undignified side of death with dignity legislation. *Kennedy Institute of Ethics Journal* 23: 201–227.

Porta, Nicolas, and Joel Frader. 2007. Withholding hydration and nutrition in newborns. *Theoretical Medicine and Bioethics* 28: 443–451.

Royal Dutch Medical Association. 2011. The role of the physician in the voluntary termination of life. http://knmg.artsennet.nl/Publicaties/KNMGpublicatie/Position-paper-The-role-of-the-physicianin-the-voluntary-termination-of-life-2011.htm. Accessed 29 Oct 2013.

Saariaho, Tom, Anita Saariaho, Irma Karila, and Matti Joukamaa. 2012. Early maladaptive schema factors, chronic pain and depressiveness: A study with 271 chronic pain patients and 331 control participants. *Clinical Psychology & Psychotherapy* 19: 214–223.

Sarch, Alexander. 2011. Internalism about a person's good: Don't believe it. *Philosophical Studies* 154: 161–184.

Stewart, Cameron, Carmelle Peisah, and Brian Draper. 2011. A test for mental capacity to request assisted suicide. *Journal of Medical Ethics* 37: 34–39.

Szasz, Thomas. 2011. *Suicide prohibition: The shame of medicine*. Syracuse: Syracuse University Press.

Tamminga, Carol A., and Adrienne C. Lahti. 2001. Treatments for chronic psychosis. *Dialogues in Clinical Neuroscience* 3: 281–292.

Tavaglione, Nicolas, Angela K. Martin, Nathalie Mezger, Sophie Durieux-Paillard, Anne François, Yves Jackson, and Samia A. Hurst. 2015. Fleshing out vulnerability. *Bioethics* 29: 98–107.

The Oregon Department of Human Services. 2013. Annual Oregon's death with dignity act report year 15.http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/arindex.aspxhttp://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/arindex.aspx. Accessed 2 December 2013.

Tiberius, Valerie. 2007. Substance and procedure in theories of prudential value. *Australasian Journal of Philosophy* 85: 373–391.

Tsou, Jonathan. Y. 2012. Intervention, causal reasoning, and the neurobiology of mental disorders: Pharmacological drugs as experimental instruments. *Studies in History and Philosophy of Biological and Biomedical Sciences* 43: 542–551.

Vanden Eijnden, Serge, and Martinovici Dana. 2013. Neonatal euthanasia: A claim for an immoral law. *Clinical Ethics* 8: 75–84.

Varelius, Jukka. 2014. On the relevance of an argument as regards the role of existential suffering in the end-of-life context. *Journal of Medical Ethics* 40: 114–116.

Young, Robert. 2014. 'Existential suffering' and voluntary medically assisted dying. *Journal of Medical Ethics* 40: 108–109.

Wijsbek, Henri. 2012. 'To thine own self be true': on the loss of integrity as a kind of suffering. *Bioethics* 26: 1–7

Chapter 6
Euthanasia for Mental Suffering

Kasper Raus and Sigrid Sterckx

Abstract The ethical (un)acceptability of euthanasia for severe physical suffering is undoubtedly one of the most controversial topics of our time. Perhaps even more controversial is the debate on whether euthanasia could also be justified for cases of mental suffering, which we understand as suffering without an underlying diagnosable condition or cause. Various widely debated cases from The Netherlands and Belgium have made this issue more than just a philosophical exercise. In this chapter we look into the ethical aspects of seeing mental suffering as a possibly allowable indication for euthanasia. First, we clarify the important concepts—such as ‘physical suffering’, ‘psychological suffering’, and ‘mental suffering’—that are used throughout this chapter. Next we focus on the following key question: can one consistently claim a right to request euthanasia for patients with diagnosable physical or psychological sources of suffering, while denying the same right to patients with mental suffering without medical diagnosis? We do so by identifying various reasons that could be given to justify why mental suffering is relevantly different from physical or psychological suffering. We will discuss the claims that mental suffering should be seen as special as it: (1) diminishes a person’s competence; (2) is a different type of suffering; (3) is undiagnosable; and (4) can never be proven to be incurable. We conclude with two important reasons to remain cautious about allowing euthanasia in cases of mental suffering.

6.1 Introduction

The ethical (un)acceptability of euthanasia is undoubtedly one of the most controversial topics of our time. Legal today in only a few places, the practices of euthanasia and physician-assisted suicide (PAS) raise profound questions about, among

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others, the value of life, autonomy, suffering and human dignity. Moreover, while some studies indicate that the acceptance rates of euthanasia or PAS among physicians, nurses and the general public are high in many places (e.g. Cohen et al. 2006; Inghelbrecht et al. 2009), this is not the case for euthanasia or PAS *for mental suffering*, not even in Belgium and The Netherlands, where euthanasia has been legalised (Kouwenhoven et al. 2012). However, despite its controversial nature, some authors have discussed the latter topic and have come to the conclusion that there is no reason to treat euthanasia after psychological suffering (understood in this chapter as suffering due to a diagnosable psychological condition) or mental suffering (understood here as suffering without a diagnosable physical or psychological source) as relevantly different from euthanasia in response to physical suffering (i.e. either both should be forbidden or both should be allowed) (Varelius 2007; Cholbi 2013a, b).

Since euthanasia and physician-assisted suicide give rise to various kinds of questions and controversies, we wish to clarify at the outset what is and what is not the focus on this chapter. We should emphasise that we shall not be discussing a right to die for people with mental suffering. It is sometimes argued that all people, including people who experience mental suffering, have a medical way to end their lives, namely by voluntary palliated starvation where patients still receive palliative care while stopping all intake of food and fluids (Savulescu 2014). The legal and ethical right to bodily integrity implies that all competent people have a right to refuse all treatments and, possibly, all forms of care. Addressing this fascinating issue would involve weighing a patient's right to autonomy and bodily integrity against other values, but this is not the topic of the present chapter. What is at issue in this chapter is not whether people with mental suffering have a right to die, but rather whether they have a right to *active assistance* in dying by medical professionals.

The debate on whether or not mental suffering can be seen as a proper indication for euthanasia can be approached as a philosophical exercise. From such a perspective, the questions to be asked are whether there is a morally relevant cut-off point to distinguish proper from improper indications for euthanasia, and whether, in accepting euthanasia in some cases, one is logically compelled to extend the right to euthanasia further and further (Huxtable and Möller 2007). Such a so-called 'logical' slippery slope from allowing euthanasia on explicit request and for severe physical suffering to allowing euthanasia for other indications, has often been invoked as an important reason against euthanasia in general (see for example Hendin 1998).

However, whether the justifications for euthanasia extend to cases where patients' suffering is mainly or solely mental in nature is at times more than a philosophical exercise. In countries that have legalised euthanasia, such as Belgium and The Netherlands, there have been cases that have stirred both national and international debate on the ethical acceptability of euthanasia and PAS and its proper indications. A famous legal case in The Netherlands was the Sutorius case (Hoge 2002), where a General Practitioner (family physician) was tried for helping a man who suffered from tiredness of life, to die. The Supreme Court felt that the man's suffering was not medical in nature (as there was no diagnosable source or condition) and that therefore Sutorius, being a General Practitioner, was unable to assess the unbearableness and incurability of the condition. Sutorius was found guilty, yet no sentence was imposed. The questions as to whether people suffering mentally can autonomously request euthanasia, and whether their suffering falls within the medical domain, are issues that will be discussed further on in this chapter.

In Belgium some recent cases have stirred controversy over the limits of euthanasia. International controversy has, for example, arisen over the case of 43 year old identical twins who were born deaf and were, due to a genetic condition, also slowly going blind. They requested and received euthanasia as they experienced the prospect of slowly becoming isolated from the world as intolerable. Another case was that of a 44 year old man who requested euthanasia after a failed sex change operation. He also received euthanasia. Unlike in the Dutch cases mentioned above, these cases were never taken to court and the information can only be obtained from numerous media reports.

In this chapter we will look into the ethical aspects of seeing mental suffering as a possibly allowable indication for euthanasia. We will not be discussing the ethical (un)acceptability of euthanasia in general as this is not the topic of this chapter. The key question we are concerned with is the following: can one consistently claim a right to request euthanasia for patients with diagnosable physical or psychological sources of suffering, while denying the same right to patients with mental suffering without medical diagnosis, and, if so, what grounds can be given for this distinction and do they hold up to ethical scrutiny? We will approach this issue from the Belgian and Dutch context, where euthanasia was legalised in 2002. Therefore we will start by briefly sketching the main provisions of the Belgian and Dutch euthanasia laws.[1]

6.2 The Belgian and Dutch Euthanasia Laws

The Belgian law allows physicians to perform euthanasia provided certain conditions are met. For example, there has to be a request for euthanasia that is well-considered, repeated and fully voluntary. Patients requesting euthanasia have to be seen by an independent second physician to assess whether all legal due criteria are met. The Belgian euthanasia law also contains stipulations concerning what kind of suffering is considered to be a proper indication for euthanasia. Euthanasia is only legal when:

> The patient is in a state, without prospect from a medical perspective, of persistent and unbearable physical or psychological suffering which cannot be relieved and which stems from a serious and incurable condition caused by accident or disease [Art. 3(1) of the law, authors' translation].

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[1] Since 2009, euthanasia is also legal in Luxembourg. The Luxembourg euthanasia law is similar to the Belgian and Dutch laws, but as few empirical data are available on the use of euthanasia in Luxembourg, we will not discuss it here.

The Belgian euthanasia law was amended in February 2014. Whereas euthanasia was previously only possible for patients aged 18 and older, the law has now been extended to include euthanasia for competent minors. However, following debate in Belgium's Parliament and Senate, this extension is limited to euthanasia for *physical* suffering for patients who are close to death. Euthanasia for non-physical suffering is thus still illegal for competent minors. However, what exactly counts as physical suffering and what counts as psychological suffering is not made clear in the Belgian euthanasia law.

This means that euthanasia for *psychological* suffering is allowed in Belgium for patients *over the age of 18* if it results from a *serious and incurable condition*. Thus, for example, clinical depression, schizophrenia and anorexia nervosa could be proper indications for euthanasia according to the Belgian euthanasia law, provided of course that the numerous other criteria stipulated in the law would be met. Available research indicates that euthanasia for patients suffering from psychological or psychiatric conditions occurs in Belgium, but is rare (Chambaere et al. 2010).

The Dutch euthanasia law (2002), on the other hand, does not mention any distinction between physical and psychological suffering and allows euthanasia to be used for 'suffering that is unbearable without any prospect of improvement' (Art. 2b of the law, authors' translation). The Dutch law thus does not require the origin of the suffering to be a diagnosable condition. Hence, euthanasia for mental suffering due to a non-diagnosable source is allowed in The Netherlands, provided that the suffering is unbearable, there is no prospect of improvement, and the other legal requirements are met. As is the case for Belgium, the number of patients receiving euthanasia for mental suffering (both from diagnosable and non-diagnosable conditions) is small (Onwuteaka-Philipsen et al. 2012) and the famous Sutorius case (mentioned above) resulted in a conviction for the physician. Nevertheless, some physicians admit to having granted requests of euthanasia for patients without a diagnosable disease (Rurup et al. 2005). Overall, the difference between the Belgian and Dutch laws is noticeable. The Dutch law appears to entail the view that suffering is suffering, regardless of its nature or origin.

The Belgian and Dutch euthanasia laws both allow euthanasia for both physical and mental conditions. A further question that arises is whether a euthanasia law should also cover cases of unbearable suffering *without* diagnosable condition. In this chapter we will focus our discussion on these most controversial cases. Before proceeding, however, we should like to make some clarificatory remarks regarding the concept of mental suffering.

6.3 Suffering: Clarifying the Concepts

This chapter is concerned with what we shall call 'mental suffering', as opposed to physical or psychological suffering. When attempting to analyze what exactly constitutes 'mental suffering', one quickly finds oneself inside a conceptual maze.

In the literature one discovers a great deal of different terms and concepts that are used to refer to mental suffering, and there is no consensus on how to define or use these concepts. Examples of concepts that are used include ‘psychological pain’ (Mee et al. 2006), ‘psychogenic pain’ (Joffe and Sandler 1967), ‘existential suffering’ (Kissane 2012), ‘psycho-existential suffering’ (Murata and Morita 2006), and ‘social suffering’ (Bourdieu 1999). In the light of this conceptual confusion, we would like to provide some clarity about what we mean when we use the term ‘mental suffering’. First, we shall explain why we refer to ‘suffering’ rather than ‘pain’ and (roughly) what we see as the difference between them. Second, we will explain why we refer to this suffering as ‘mental’ and how the concept of ‘mental suffering’ will be used in the remainder of this chapter.

We will talk about mental *suffering* rather than mental *pain*. The difference between pain and suffering is often unclear as both terms can have similar and overlapping meanings. The Oxford English Dictionary, for example, defines *pain* as ‘[p]hysical or bodily suffering; a continuous, strongly unpleasant or agonizing sensation in the body’, but also as the ‘state or condition of consciousness arising from mental or physical suffering’. In a somewhat circular way the Oxford English Dictionary defines *suffering* as the ‘bearing or undergoing of pain’. Each concept is thus explained by referring to the other. This is understandable since pain and suffering are notoriously difficult to define as they involve a certain kind of experience, but it is unclear how to describe or define that experience. Pain and suffering are sometimes said to involve an unpleasant sensation (e.g. the definition of pain quote above) or a sensation one has a desire to avoid. However, some sensations can be unpleasant (e.g. itching), while most people would not label them as pain (although they can perhaps be a cause of suffering). Other sensations might fall in the category of sensations we want to avoid or, when experiencing them, make them stop, while they are not commonly labelled as ‘pain’ or ‘suffering’ (e.g. being tickled).

Although we fully acknowledge the conceptual complexities surrounding ‘pain’ and ‘suffering’, for the sake of clarity we propose to use both concepts in a more strict sense in this chapter. As there seems to be a tendency to link *pain* to a *physical* sensation, we shall use the concept in this sense, namely as referring to a certain unpleasant bodily experience. An influential definition of ‘pain’ has been provided by the International Association for the Study of Pain (IASP):

> An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. (Merskey and Bogduk 1994, 210)

Suffering, on the other hand, is usually understood as a broader and composite phenomenon that has, *inter alia*, physical, moral and emotional dimensions. An influential study of ‘suffering’ was performed by Cassell (1994, 33), who has also proposed an influential definition:

> the state of severe distress associated with events that threaten the intactness of person.

The intactness of person, according to Cassell, can be threatened by physical pain, but equally by emotional experiences (e.g. grief).

Dees et al. (2010) have reviewed some of the literature on ‘unbearable suffering’ and listed various ways in which suffering has been defined. Their classification shows that many different definitions exist, which have in common that they describe suffering as a broad phenomenon that can, but need not, include physical pain. People who are in pain can be suffering and people who are suffering can be in pain, but in both cases this is not necessarily the case. We shall use the term suffering in this broad sense. For this reason, we will talk about mental *suffering* rather than mental *pain*.

In this chapter, we will sometimes use the terms ‘physical suffering’, ‘psychological suffering’ and ‘mental suffering’. The term ‘physical suffering’ will be used as a synonym for ‘pain’. By ‘psychological suffering’ we will refer to suffering that is the result of a diagnosable psychological or psychiatric condition (e.g. a clinical depression). ‘Mental suffering’ will be understood as suffering that is not caused by a diagnosable physical or psychological condition. We choose the term ‘mental suffering’ because some other proposed concepts (e.g. psychogenic suffering) might be easily confused with what we call psychological suffering.

As we understand and use the term, ‘mental suffering’ covers *different types* of suffering, such as emotional, existential or spiritual suffering. Admittedly, the distinction between physical suffering and mental suffering is somewhat artificial, for suffering is rarely *only* physical or *only* mental. However, we believe that making the distinction is helpful in the context of the questions we will attempt to address in this chapter. The concepts we use can be represented schematically as follows (Table 6.1).

At the same time, using the term ‘mental suffering’ does have an important drawback, namely that it might suggest that the suffering has nothing to do with the body and that it is ‘all in the mind’. Therefore, we would like to clarify that the terms ‘physical’, ‘psychological’ and ‘mental’ refer to the *cause* of the suffering rather than to its nature or experience. This does not preclude the possibility that ‘mental suffering’ may affect or interact with the body in some ways or may even be measurable (for example using fMRI), even though there is no physical cause. Some studies indicate that when people experience emotional suffering (e.g. grief), parts of the brain are activated that are also activated when people experience physical suffering (Gündel et al. 2003; Mee et al. 2006).

Table 6.1 Schematic representation of concepts

A	Physical suffering (or pain)	Distress caused by diagnosable bodily state or condition
B	Psychological suffering	Distress caused by diagnosable psychological state or condition
C	Mental suffering (includes emotional, existential, and spiritual suffering)	Distress caused by no diagnosable bodily or psychological state or condition

6.4 Is Mental Suffering Special?

Various possible arguments could be given as to why mental suffering should be considered to be different from physical or psychological suffering when it comes to proper indications for euthanasia. In this section, we will discuss these arguments and examine their validity. Four types of arguments will be considered: arguments relating to the competence of the person requesting euthanasia, the type of suffering, the (non-)diagnosability of the condition, and the (in)curability of the condition.

6.4.1 Competence

First, it might be questioned whether mental suffering as defined above actually occurs very frequently. Perhaps many people who claim to suffer from tiredness of life or loss of meaning, and want to have their life ended, are actually suffering from an undiagnosed clinical depression. Following our use of the concepts, that would make their suffering *psychological* suffering rather than mental suffering, for depression is a diagnosable condition. Having a desire to die is one of the indications for diagnosing depression according to the most recent Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association 2013).

Since depression might negatively impact competence, this could constitute a reason for doubting the competence of those claiming to suffer from tiredness of life. If the competence of such persons would indeed be questionable, this would constitute a decisive reason for refusing these persons euthanasia as one of the most commonly cited justifications for euthanasia is patient autonomy. Indeed, according to the Belgian and Dutch euthanasia laws, euthanasia should not be considered when there is any doubt about a person's competence.

When a person thus claims to suffer mentally, for example from loss of dignity or tiredness of life, there are two possibilities. First, there might indeed be no diagnosable physical or psychological cause or, second, the person might actually be suffering from an undiagnosed depression (or other psychological condition). In the latter case, as mentioned above, what at first sight seemed to be mental suffering is actually psychological suffering with a diagnosable cause. However, although suicidality can be associated with depression, *it is not in itself proof of a person's incompetence*. This has been acknowledged, for example, by the Dutch Association of Psychiatry when revising a guideline on dealing with a suicide request by a patient suffering from a psychiatric illness:

> Suicidality is not by definition a psychopathological symptom. According to the commission it is possible that in rare cases a request for assistance in suicide, made by a psychiatric patient, is the result of a careful deliberative process. Although many death requests expressed by psychiatric patients have a temporary and thus passing character, the commission holds that in some cases a death request can be enduring and eventually become permanent. (Nederlandse Vereniging voor Psychiatrie 2009, 28; authors' translation)

If there is *no* underlying depression or psychological condition this is, equally, no reason to immediately question this person's competence. Indeed, it seems to be a widely accepted (legal and ethical) principle that there should always be a presumption in favour of competence; one is competent unless proven otherwise (see for example the UK Mental Capacity Act 2005). The competence of people with mental suffering, understood as suffering in the absence of a diagnosable condition has, to our knowledge, not been investigated as yet. Research conducted with patients suffering from a *diagnosed psychiatric illness* shows that they can make reliable self-reported quality of life judgements (Baumstarck et al. 2013) and that, although their competence is reduced at times, this need not *always* be the case (Grisso and Appelbaum 1995). Without additional research one cannot assume that the results for people who experience mental suffering (i.e. suffering *without* a diagnosable condition) would be significantly different.

A possible difference is perhaps suggested by research from Dees et al. (2011). In a qualitative study they performed with people who formulated a request for euthanasia, they found a multitude of different kinds of suffering. Interestingly, they conclude that '[o]nly patients with a psychiatric (co)diagnosis suffered unbearably all the time' (Dees et al. 2011, 727). Perhaps then, mental suffering is associated with episodes of severe suffering, while suffering from psychological sources is more continuous. If this is true, then patients who request euthanasia for mental suffering might do so in an episode of severe suffering, where the correct approach would be to wait for that episode to pass. However, it should be noted that patients have to repeat their request for euthanasia over a reasonable amount of time, so as to guarantee that choosing euthanasia is not a quick decision. Furthermore, one could argue that suffering from episodes of severe suffering can be just as burdensome as experiencing continuous suffering. Episodes of suffering, in our opinion, do not disqualify a patient from making autonomous requests.

It is also important to note that competence is task specific. Whether or not a person is competent has to be decided on a case by case basis. Somebody can be competent to make certain decisions while at the same time not being competent to make other decisions. Hence there seems to be no reason for declaring persons with mental suffering incompetent across the board. Obviously, choosing euthanasia involves consequences that are significantly more grave than the consequences of, for example, choosing to refuse recommended physiotherapy exercises, so a much higher standard of competence should apply to the former choice. Nevertheless, even though one might question whether persons with serious mental suffering can ever attain a standard of competence that is sufficiently high to make a truly voluntary request for euthanasia, this does not justify an a priori declaration of incompetence. Of course, some might maintain that *nobody* can ever be competent to request euthanasia, but such a view does not treat mental suffering as different from physical suffering or psychological suffering.

One might still claim that, although persons with solely mental suffering can be competent, physicians are not qualified to assess the competence of such persons. Indeed, in the court case against Dr Sutorius (discussed above) this was mentioned as one of the main reasons for finding him guilty (Hoge 2002). This issue has been extensively analysed by Varelius (2014), so we will only briefly address it here. In response to the claim that a physician cannot assess the unbearableness of mental suffering, it can be argued that physicians assess competence all the time, not just in the context of end-of-life decisions (Appelbaum 2007). For example, when patients refuse life sustaining treatment or request continuous sedation until death, physicians' abilities to assess competence are rarely questioned. Moreover, research from Belgium and The Netherlands shows that patients suffering from physical or psychological conditions who request euthanasia often do so not because of physical pain but rather for existential reasons such as perceived loss of dignity or fear of future suffering (e.g. Rietjens et al. 2006; Chambaere et al. 2010). In such cases physicians are allowed to assess the competence of these patients suffering from existential distress, so it may be problematic to declare the same physicians unable to assess competence when a diagnosable condition is absent. Various tools for assessing competence have been developed, which, when used, could give more weight to the assessment by making it more than a merely subjective judgement (Lamont et al. 2013).

It seems to be the case that a person's competence is often questioned in cases where the family or the health care professionals don't agree with the person's choice. However, if we want the principle of autonomy to have real force, we need to acknowledge that being competent also includes the right to make poor choices. A person's competence should thus not be questioned merely because we don't agree with her choice.

None of the above should be read as a plea for focussing exclusively on patient autonomy. It might still be argued that euthanasia should not be performed despite a person's competent request, for example, because this choice has undesirable societal implications. This may be true, but according to that line of reasoning what makes euthanasia unjustified are those additional reasons and not the lack of competence of the person.

6.4.2 *Type of Suffering*

One may wonder whether physical or psychological suffering resulting from diagnosable conditions is *by nature* different from mental suffering. This question is somewhat misleading as it can be understood in two different senses. It has long been acknowledged that suffering has a *physiological* aspect (for example the stimulation of pain nerves or the activation of certain brain regions) as well as a *psychological* aspect (the actual subjective experience of pain) (Merskey and Spear 1967). It is important to distinguish between these two dimensions of suffering. The question 'is mental suffering different from physical or psychological suffering?' can be understood as relating to the physiological level, i.e. are mental suffering and physical or psychological suffering physiologically different? However, the same question might also be read as 'is mental suffering experienced differently than physical or psychological suffering?', i.e. a question regarding the psychological dimension of suffering.

The first version of the question is clearly relevant for medical researchers, and much research has been conducted in this area. Indeed, there seem to be various differences between physical pain on the one hand and mental suffering on the other hand. First, on a conceptual level, if one adopts the IASP definition of pain mentioned earlier, mental suffering cannot be reduced to physical pain or suffering, for mental suffering cannot be clearly described in terms of tissue damage.[2]

Another relevant difference is that physical pain is one of the most frequent symptoms of disease and can usually be relieved by curing the underlying condition and/or by providing proper pain relief. For mental suffering, on the other hand, the presence of the suffering is not proof of an underlying problem but actually *is* the problem (see also Cholbi 2013a, b).

Moreover, physical suffering is often (to a certain degree) susceptible to medical interventions such as analgesics or sedatives. The treatment of this kind of suffering thus clearly requires medical expertise and the medical world is becoming increasingly good at managing pain [even though much pain is still untreated (Brennan et al. 2007)]. Insight into the physiology of physical pain has even lead to the designing of certain techniques to measure the presence and intensity of pain without involving a patient's judgement, for example by using fMRI (Wager et al. 2013). Mental suffering, on the other hand, is less responsive to *medical* interventions.

However, although there may be clear differences between physical pain and mental suffering, the differences between psychological suffering and mental suffering are significantly less clear. Like mental suffering, some kinds of psychological suffering cannot be described in terms of tissue damage. Moreover, psychological suffering is often not susceptible to medical treatments such as analgesics or sedatives.

Although the *physiological* aspects of suffering are highly fascinating, for our ethical analysis we are primarily concerned with the *psychological* dimensions (i.e. the subjective experience) of suffering. Again, insufficiently distinguishing between these dimensions can be misleading. However, looking at the experience of suffering one can find reasons for *not* considering mental suffering as relevantly different from physical or psychological suffering. For one, all suffering is in a sense mental as it involves conscious experience. The main difference between mental suffering and physical or psychological suffering is not where the suffering is *processed* (as this is the same in both cases), but where the suffering *originates*. However, origin may strike many as an irrelevant moral criterion. Moreover, physical, psychological and mental suffering frequently go hand in hand, for patients suffering from physical or psychological conditions often also experience mental suffering such as existential anguish (e.g. Dees et al. 2011).

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[2] We should mention here that the IASP definition of pain is subject to debate as it is questionable whether all types of *physical* pain can be adequately described in terms of tissue damage. However, we will not consider this issue here.

As mentioned previously, the Belgian and Dutch euthanasia laws stress that euthanasia should only be considered for suffering that is considered *unbearable*. This clearly relates to the psychological dimension of suffering, for the issue of unbearableness obviously cannot be settled on the basis of physiological data.

It is increasingly being acknowledged that medicine should not focus solely on pain, but should also be concerned with suffering in a broad sense. This is especially the case in palliative care. The founder of modern palliative care, Dame Cicely Saunders, introduced the concept of 'total pain' (Saunders 1964), which she defined as including not only physical symptoms but also mental distress and social or spiritual problems (Saunders 2001, 430). A recent review article has also shown that existential suffering has received increasing attention in palliative care in the last few decades (Boston et al. 2011). It therefore seems misleading to say that mental suffering has no place in medicine for in palliative care various types of suffering are not treated as radically different, but rather as different dimensions of 'total pain'.

6.4.3 Diagnosability

Medicine, one might claim, deals with the healing or curing of diseases and medical conditions. Since, in cases of mental suffering, as explained in Sect. 6.3 above, no medically diagnosable condition is present, this type of suffering may be said to lie outside the bounds of medicine. Patients experiencing these kinds of suffering and requesting euthanasia are not in need of a medical solution and should, the argument goes, not be helped to die by medical doctors but instead should receive help from the appropriate professionals (e.g. social workers, chaplains, etc.) to address their suffering. In fact, broadening the medical domain to include all suffering, both diagnosable and non-diagnosable, could be seen as an example of medicalization (Szasz 2007). We will return to this issue.

However, this argument can be challenged on multiple grounds. First, one might wonder whether the picture of the physician as a 'healer' is accurate. It is clear that, although curing medical conditions makes up a large part of modern medicine, it is not the only part. Modern medicine also includes, for example, disease prevention, aesthetic surgery, enhancing sport performances, etc. Showing that a certain intervention does not qualify as healing therefore does automatically imply that it has no place in medicine.

Second, one of the differences between physical suffering and mental suffering is that, while *mental* suffering is often only subjective, the condition causing *physical* suffering can often be objectively diagnosed in today's medicine, by using tools such as clinical observation, blood tests and medical imaging. However, we should bear in mind that what is diagnosed is the condition and *not* the suffering; physical *conditions* are objectively diagnosable while physical *suffering* is not or less so.

Moreover, while physical conditions might be objectively diagnosable, the differences between psychological suffering (i.e. suffering that is the result of a diagnosable psychological or psychiatric condition) and mental suffering (i.e. suffering without a diagnosable condition) are less clear. The standard tool for diagnosing the former is the Diagnostic and Statistical Manual of Mental Disorders (DSM). However, despite its objective appearance, this manual has been criticised for being subjective and leaving too much room for interpretation (Greenberg 2013), for example because the diagnostic criteria for some conditions are vague. Yet, as mentioned earlier, diagnosability is an important criterion in the Belgian euthanasia law: once diagnosed one can request euthanasia and possibly receive it (provided that all other legal criteria are met), but not so when a diagnosis is absent. The Belgian law thus presupposes that *psychological* suffering differs from *mental* suffering (in the senses of the terms used in this chapter) in ways that are relevant for decisions regarding the appropriateness of meeting euthanasia requests. However, the Belgian law does not explain why this supposed difference is of any significant moral relevance.

A final point we should like to make with regard to diagnosability is that one might question the relevance of 'diagnosability' as a moral criterion (for deciding whether a euthanasia request should be met or refused). Indeed, it might be argued that a diagnosis is no more than a label and that the presence of a label does not necessarily make suffering more severe or more real.

6.4.4 (In)Curability

Euthanasia for psychiatric conditions has been criticised by some commentators on the ground that for such conditions incurability is impossible to ascertain. Kelly and McLoughlin (2002, 279), for example, observe that:

> In the case of an individual patient, it remains extremely difficult to predict whether therapy will produce an early response, a delayed response or no response […]. It is impossible to predict which patients will undergo spontaneous remission and when this will happen. These uncertainties are far more pronounced in psychiatric practice than in medical practice, to the extent that it is essentially impossible to describe any psychiatric illness as incurable.

The same could be said to apply to mental suffering without a diagnosable condition and to count against it as an acceptable indication for euthanasia. For physical conditions it will often be easier to determine whether the condition is incurable, either because all treatment options have been depleted or the prognosis is so poor that new treatment has too little time to take effect. For psychological suffering there is often a wider array of different therapies and, as noted by Kelly and McLoughlin above, spontaneous remission can never be excluded as a possibility. For mental suffering there is not even a condition or cause to treat or cure; there is only suffering that one can attempt to reduce or take away. Since patients with only mental suffering almost always have relatively long life-expectancies (except when they are very old), as with psychological suffering, it cannot be ruled out that their suffering can be reduced over a longer period of time. For example, certain kinds of existential suffering may seem like they will never go away, but that does not mean they never will.

Moreover, what counts as an 'effective' intervention or treatment may be more easy to ascertain for physical than non-physical conditions. For example, a study of psychosocial interventions for existential suffering conducted among experts showed that they rated the effectiveness of the various interventions very differently (Hirai et al. 2003).

It has also been claimed that allowing assisted suicide and euthanasia for persons with mental suffering might actually *make* the suffering less reducable (Kissane and Kelly 2000). Even merely discussing the possibility of assisted dying might be understood by the person as admitting that the situation is hopeless. This might demoralise the person and make reducing mental suffering more difficult.

This is indeed a serious concern. When treatment is still reasonably possible or likely, helping and caring certainly appear to be better options than euthanasia or PAS. However, in our view it would be too demanding to require a physician to be *absolutely* certain that no cure or hope is possible. Even with somatic diseases such as cancer, there may be a remote possibility that a miracle cure is found or that another course of chemotherapy might (though very unlikely) have some positive effect. We think the existence of these small chances does not disqualify a patient as a candidate for euthanasia. In such cases, although one cannot say the chances of curing are 0 %, they approximate 0 %. This is relevant for mental suffering, for in some cases it may be highly unlikely that relief of the person's mental suffering will ever be achieved, and some might argue that this is a sufficient reason to meet a euthanasia request from that person.

6.5 Reasons for Caution

In the previous sections we have discussed various arguments for making a distinction between suffering originating from diagnosable conditions (whether physical or psychological) and suffering without a diagnosable condition (mental suffering) when deciding on the acceptability of a euthanasia request. We found that strictly distinguishing between the two may often be problematic. Nevertheless, in our view, there are several reasons to be cautious regarding euthanasia for mental suffering. In this section we will briefly comment on two reasons we believe to be highly relevant: first, considerations regarding proportionality; and second, issues regarding the involvement of physicians in euthanasia for persons with mental suffering.

6.5.1 Proportionality

Autonomy is one of the primary principles in medical ethics. If persons with mental suffering can be considered to be competent (which we would submit is often the case), then this would constitute a reason for *considering* their requests seriously, even their requests to die. Indeed, it is often said that people themselves are the best judge of whether their life is worth living. However, other principles are also at stake, for example proportionality. Killing someone (even at their request) is arguably the most far-reaching act a physician can perform, and it can thus only possibly be justified for proportionately grave reasons. We believe that, in almost all cases, less extreme responses will be possible to address feelings of loneliness, loss of hope, and other examples of mental suffering.

Moreover, even if there would be some individual cases where providing euthanasia could be a proportionate response, we believe much can be said in favour of maintaining as a general rule that euthanasia should not be allowed in cases of mental suffering. We would argue that abolishing such a rule would entail unacceptably high risks. It is unclear how a policy allowing for the granting of euthanasia requests from persons with mental suffering could be properly monitored and controlled. Moreover, allowing the euthanasia law to be broadened may also affect peoples' attitudes and expectations towards the law. In this way, what starts out as a 'right to die', risks evolving into a 'duty to die' [see for example an interview with Baroness Warnock in 2008 (Beckford 2008)] Furthermore, there is much more room for error in cases of (undiagnosable) mental suffering than in cases of (diagnosable) physical or psychological suffering. Allowing euthanasia for mental suffering could also change our perspective on medicine by creating or encouraging the view that physicians are mere executors of peoples' requests.

6.5.2 *Involvement of Physicians*

As mentioned in the introduction, the main question at issue in this chapter is not whether people with mental suffering have a right to die, but rather whether it would be acceptable for medical professionals to meet a euthanasia request from a person with (only) mental suffering. Even if the person is able to make a competent request and even if her mental suffering is both real and unbearable, there might be good reasons for concluding that the answer is no.

Indeed, it can be argued that allowing euthanasia (or PAS) to be used for mental suffering would open the door to *medicalization* in areas where this is totally undesirable. Some commentators even question whether we should consider mental health problems to be medical problems (Szasz 2007, 8). In our view, diagnosed mental health problems can indeed constitute a medical problem (e.g. certain types of depression or mood disorders), but we should be wary of going so far as to regard mental suffering as such (e.g. tiredness of life and loss of hope or purpose in life) as a medical problem.

Loneliness and tiredness of life are not medical problems, hence one may rightly ask why it should be the task of physicians to solve such problems. We should not expect the medical profession to solve problems that are non-medical in nature. Even more importantly, by regarding existential suffering as a health problem, we are failing to see the real tragedy of why people are experiencing these kinds of suffering. Frequently, such suffering is the result of social isolation and alienation resulting in feelings of profound loneliness, abandonment and uselessness. These widespread *societal* problems require a societal, economic and political response rather than a medical solution.

Of course, most proponents of euthanasia for mental suffering would not advocate euthanasia as an alternative to societal, economic and political responses, but rather as a last resort option when mental suffering cannot be overcome in any other way. However, this argument has no practical relevance to the debate, for in our current societies the efforts made and resources spent to tackle social isolation and alienation are blatantly insufficient. We believe our current failure to address these societal problems cannot serve as an argument in favour of euthanasia for mental suffering.

The conclusions that should be drawn from these considerations are up for debate. For example, although Szasz (2007) problematizes the medicalization involved in allowing medical professionals to perform euthanasia in cases of mental suffering, this leads him to conclude that these people could be helped by non-medical professionals. In The Netherlands the late Huib Drion (Emeritus Professor of Law) suggested in the 1990s that elderly people should get access to a suicide pill (for example through a machine in the wall) so that when they consider their life to have become unbearable, they could use this pill (Drion 1991). In this way, these people could end their life themselves, *without* involving medical professionals. Suggestions such as this are highly problematic for other reasons which we cannot elaborate upon here, as our focus is on the acceptability of persons with mental suffering having their life ended by a physician at their request (i.e. euthanasia as defined in the Belgian and Dutch euthanasia laws).

Of course, it might be argued that physicians should be involved, not because mental suffering constitutes a medical problem, but because physicians are often most knowledgeable of safe and effective ways to end life. Should anything go wrong, physicians are also able to respond in the most adequate way. However, we feel that involving a physician would at least create a strong impression that mental suffering does represent a medical condition. Moreover, in our view this would reduce the physician to a mere instrument, someone who is merely present because he has the practical skills to perform euthanasia in the most effective way.

Clearly, medical professionals have an important role to play in the detection of undiagnosed and sometimes preventable mental health conditions. Research shows that, for example, depression is underdiagnosed (Mitchell et al. 2009). However, once again, what is at issue here is the question as to whether euthanasia should be used to address suffering *in the absence of a diagnosable condition*. Involving medical professionals to address this kind of suffering would, in our view, probably represent the worst conceivable example of a medicalization of socio-economic problems.

6.6 Concluding Remarks

The ethical acceptability of euthanasia for mental suffering is a controversial issue. With regard to persons whose suffering is (only) mental, questions arise regarding their competence, the extent to which the presence and the intensity of their suffering can be ascertained and measured, the relevance of the absence of a diagnosis, and whether or not the suffering can be alleviated.

We hope our discussion has shown that it is problematic to claim that mental suffering is *completely* different from other types of suffering. People with mental suffering can be competent, their suffering may be unquestionably real and in some cases reasonably claimed to be unrelievable. Therefore, we would submit that, if one accepts euthanasia for patients with physical and psychological suffering, this makes it difficult to a priori refuse it for patients with only mental suffering. Nevertheless, we believe that in practice it is highly unlikely that euthanasia would ever be a proportionate response to mental suffering, and that allowing it would amount to an unacceptable medicalization of problems that are not medical in nature.

References

American Nurses Association (ANA). 2013. Position statement: Euthanasia, assisted suicide, and aid in dying. http://www.nursingworld.org/euthanasiaanddying. Accessed 7 July 2014.

Appelbaum, Paul S. 2007. Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine* 357: 1834–1840.

Beckford, Martin. 2008. Baroness Warnock: Dementia sufferers may have a 'duty to die.' *Telegraph*, 18 September. Available at: http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html. Accessed 1 June 2015.

Boston, Patricia, Anne Bruce, and Rita Schreiber. 2011. Existential suffering in the palliative care setting: An integrated literature review. *Journal of Pain and Symptom Management* 41: 604–618.

Bourdieu, Pierre. 1999. *The weight of the world: Social suffering in contemporary society*. Cambridge: Polity Press.

Brennan, Frank, Daniel B. Carr, and Michael Cousins. 2007. Pain management: A fundamental human right. *Anesthesia and Analgesia* 105: 205–221.

Cassell, Eric J. 1994. The nature of suffering and the goals of medicine. Oxford: Oxford University Press.

Chambaere, Kenneth, Johan Bilsen, Joachim Cohen, Bregje D. Onwuteaka-Philipsen, Freddy Mortier, and Luc Deliens. 2010. Physician-assisted deaths under the euthanasia law in Belgium: A population-based survey. *Canadian Medical Association Journal* 182: 895–901.

Cholbi, Michael J. 2013a. Kantian paternalism and suicide intervention. In *Paternalism: Theory and practice*, eds. Christian Coons, and Michael E. Weber, 115–133. Cambridge: Cambridge University Press.

Cholbi, Michael J. 2013b. The terminal, the futile, and the psychiatrically disordered. *International Journal of Law and Psychiatry* 36: 498–505.

Cohen, Joachim, Isabelle Marcoux, Johan Bilsen, Patrick Deboosere, Gerrit van der Wal, and Luc Deliens. 2006. European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Social Science and Medicine* 63: 743–756.

Dees, Marianne, Myrra Vernooij-Dassen, Wim Dekkers, and Chris van Weel. 2010. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-Oncology* 19: 339–52.

Dees, Marianne, Myrra Vernooij-Dassen, Wim Dekkers, Kris C. Vissers, and Chris van Wee. 2011. 'Unbearable suffering': A qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics* 37: 727–734.

Drion, Huib. 1991. Het zelfgewilde einde van oudere mensen. *NRC Handelsblad*, 19 October. http://retro.nrc.nl/W2/Tegenspraak/Drion/artikeldrion.html. Accessed 26 August 2014.

Greenberg, Gary. 2013. *The book of woe: The DSM and the unmaking of psychiatry*. New York: Blue Rider Press.

Grisso, Thomas, and Paul S. Appelbaum. 1995. The MacArthur treatment competence study. III: Abilities of patients to consent to psychiatric and medical treatments. *Law and Human Behavior* 19: 149–174.

Gündel, Harald, Mary-Frances O'Connor, Lindsey Littrell, Carolyn Fort, and Richard D. Lane. 2003. Functional neuroanatomy of grief: An FMRI study. *American Journal of Psychiatry* 160: 1946–1953.

Hendin, Herbert. 1998. *Seduced by death: Doctors, patients, and assisted suicide*. New York: W.W. Norton & Company.

Hirai, Kei, Tatsuya Morita, and Tetsua Kashiwagi. 2003. Professionally perceived effectiveness of psychosocial interventions for existential suffering of terminally ill cancer patients. *Palliative Medicine* 17: 688–694.

Huxtable, Richard, and Maaike Möller. 2007. Setting a principled boundary"? Euthanasia as a response to 'life fatigue. *Bioethics* 21: 117–126.

Inghelbrecht, Els, Johan Bilsen, Freddy Mortier, and Luc Deliens. 2009. Nurses' attitudes towards end-of-life decisions in medical practice: A nationwide study in Flanders, Belgium. *Palliative Medicine* 23: 649–658.

Joffe, Walter G., and Joseph Sandler. 1967. On the concept of pain, with special reference to depression and psychogenic pain. *Journal of Psychosomatic Research* 11: 69–75.

Karine, Baumstarck, Laurent Boyer, Mohamed Boucekine, Valérie Aghababian, Nathalie Parola, Christophe Lançon, and Pascal Auquier. 2013. Self-reported quality of life measure is reliable and valid in adult patients suffering from schizophrenia with executive impairment. *Schizophrenia Research* 147: 58–67.

Kelly, Brendan D., and Declan M. McLoughlin. 2002. Euthanasia, assisted suicide and psychiatry: A Pandora's box. *The British Journal of Psychiatry* 181: 278–279.

Kissane, David W. 2012. The relief of existential suffering. *Archives of Internal Medicine* 172: 1501–1505.

Kissane, David W., and Brian J. Kelly. 2000. Demoralisation, depression and desire for death: Problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian and New Zealand Journal of Psychiatry* 34: 325–333.

Kouwenhoven, Pauline S.C., Natasja J.H. Raijmakers, Johannes J.M. van Delden, Judith A.C. Rietjens, Maartje H.N. Schermer, J.M.W. van Ghislaine, Margo J. Thiel, Suzanne Trappenburg, Bea J. van de Vathorst, Cristiano van der Vegt, Heleen Weyers Vezzoni, Donald G. van Tol, and Agnes van der Heide. 2012. Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach. *Palliative Medicine* 27: 273–280.

Lamont, Scott, Yun-Hee Jeon, and Mary Chiarella. 2013. Assessing patient capacity to consent to treatment: An integrative review of instruments and tools. *Journal of Clinical Nursing* 22: 2387–2403.

Mee, Steven, Blynn G. Bunney, Christopher Reist, Steve G. Potkin, and William E. Bunney. 2006. Psychological pain: A review of evidence. *Journal of Psychiatric Research* 40: 680–690.

Merskey, Harold, and Nikolai Bogduk (eds.). 1994. *Classification of chronic pain*, 2nd ed. Seattle: IASP Press.

Merskey, Harold, and Frank G. Spear. 1967. The concept of pain. *Journal of Psychosomatic Research* 11: 59–67.

Mitchell, Alex J., Amol Vaze, and Sanjay Rao. 2009. Clinical diagnosis of depression in primary care: A meta-analysis. *The Lancet* 374: 609–619.

Murata, Hisayuki, and Tatsuya Morita. 2006. Conceptualization of psycho-existential suffering by the Japanese Task Force: The first step of a nationwide project. *Palliative and Supportive Care* 4: 279–285.

Nederlandse Vereniging voor Psychiatrie. 2009. *Richtlijn omgaan met het verzoek om hulp bij zelfdoding door patiënten met een psychiatrische stoornis*. Utrecht: de Tijdstroom.

Onwuteaka-Philipsen, Bregje D., Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J.F. de Jong-Krul, Johannes J.M. van Delden, and Agnes van der Heide. 2012. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: A repeated cross-sectional survey. *The Lancet* 380: 908–915.

Rietjens, Judith A.C., Johannes J.M. van Delden, Agnes van der Heide, Astrid M. Vrakking, Bregje D. Onwuteaka-Philipsen, Paul J. van der Maas, and Gerrit van der Wal. 2006. Terminal sedation and euthanasia. *Archives of Internal Medicine* 166: 749–753.

Rurup, Mette L., Martien T. Muller, Bregje D. Onwuteaka-Philipsen, Agnes van der Heide, Gerrit van der Wal, and Paul J. van der Maas. 2005. Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: An interview study. *Psychological Medicine* 35: 665–671.

Saunders, Cicely. 1964. The symptomatic treatment of incurable malignant disease. *Prescribers* 4: 68–73.

Saunders, Cicely. 2001. The evolution of palliative care. *Journal of the Royal Society of Medicine* 94: 430–432.

Savulescu, Julian. 2014. A simple solution to the puzzles of end of life? Voluntary palliated starvation. *Journal of Medical Ethics* 40: 110–113.

Szasz, Thomas. 2007. *The medicalization of everyday life: Selected essays*. Syracuse, New York: Syracuse University Press.

Varelius, Jukka. 2007. Illness, suffering and voluntary euthanasia. *Bioethics* 21: 75–83.

Varelius, Jukka. 2014. On the relevance of an argument as regards the role of existential suffering in the end-of-life context. *Journal of Medical Ethics* 40: 114–116.

Wager, Tor D., Lauren Y. Atlas, Martin A. Lindquist, Mathieu Roy, Choong-Wan Woo, and Ethan Kross. 2013. An fMRI-based neurologic signature of physical pain. *New England Journal of Medicine* 368: 1388–1397.

Court Cases And Rulings

Hoge, Raad. (2002). HR:2002:AE8772.

Laws and Legislation

Act on Euthanasia. 2002. (Belgium). Translation by Dale Kidd under the supervision of Herman Nys. *Ethical Perspectives* 9: 183–84. Online: http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59.

UK, Mental Capacity Act. 2005.

Chapter 7
Assisted Dying for Individuals with Dementia: Challenges for Translating Ethical Positions into Law

Jocelyn Downie and Georgia Lloyd-Smith

Abstract In this chapter, we explore the issue of assisted dying for individuals with dementia at the nexus of ethics and law. We set out the basic medical realities of dementia and the available data about the desire for the option of assisted dying in the face of dementia. We then describe law and practice with respect to voluntary euthanasia and assisted suicide in jurisdictions that permit at least some assisted dying. We conclude that, because of the peculiar ways in which some of the features of dementia interact with specific legislative provisions, less access to assisted dying for persons with dementia can be realized through the legislation than might have been intended or expected. We then describe draft assisted dying legislation that is before the federal Parliament of Canada. We conclude that, because of the peculiar ways in which some of the features of dementia interact with specific legislative provisions, more access to assisted dying for persons with dementia would be realized, if the legislation was passed as drafted, than might be intended or expected. This exercise reveals that very careful attention needs to be paid to the features of dementia if drafting assisted dying legislation in order to actually achieve the desired law reform effect (whatever that might be). The interplay of common ethical rationales for permitting assisted dying (e.g., autonomy and alleviation of suffering) with common features of dementia (e.g., loss of competence before the terminal phase of the illness, loss of the capacity to communicate before the loss of the capacity to suffer) raises challenges for translating one's ethical position on assisted dying for individuals with dementia into law.

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7.1 Introduction

Can individuals with dementia access assisted dying in jurisdictions where assisted dying is at least sometimes permitted? Should they be able to do so? These questions were raised publicly and powerfully in Canada through the recent case of Gillian Bennett (CBC News 2014), an 84-year-old woman who took her life three years after being diagnosed with dementia; her open letter (published on the purpose-built website www.deadatnoon.com) called for law reform to allow assisted dying through a living will. These questions are also being asked in many other countries around the world as they too grapple with the issue of assisted dying for individuals with dementia. In this chapter, we discuss the assisted dying laws in various countries in a way that we hope will illuminate the *status quo* and illustrate the effects of particular ways of approaching law reform in relation to these questions. The goal is not to argue for or against the decriminalization of assisted dying for persons with dementia[1] but rather to explore the implications of positions taken on various key legislative variables for access to assisted dying for individuals with dementia.

We first define our terms and then set out the medical realities that lie behind the questions asked above. Next we provide data (such as there is) about the desire for the option of assisted dying in the face of dementia. We then describe law and practice with respect to voluntary euthanasia and assisted suicide in jurisdictions that permit at least some assisted dying ("permissive jurisdictions"). We conclude that, because of the peculiar ways in which some of the features of dementia interact with specific legislative provisions, **less** access to assisted dying for persons with dementia can be realized through the legislation than might have been intended or expected. We then describe draft assisted dying legislation that is before the federal Parliament of Canada. We conclude that, because of the peculiar ways in which some of the features of dementia interact with specific legislative provisions, **more** access to assisted dying for persons with dementia would be realized, if the legislation was passed as drafted, than might be intended or expected. This exercise reveals that very careful attention needs to be paid to the features of dementia if drafting assisted dying legislation in order to actually achieve the desired law reform effect (whatever that might be). The interplay of common ethical rationales for permitting assisted dying (e.g., autonomy and alleviation of suffering) with common features of dementia (e.g., loss of competence before the terminal phase of the illness, loss of the capacity to communicate before the loss of the capacity to suffer) raises challenges for translating one's ethical position on assisted dying for individuals with dementia into law.

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[1] Recent philosophical explorations of assisted dying and dementia include Cholbi (2014), Menzel and Steinbock (2013), and Gastmans and De Lepeleire (2010).

7.2 Terminology

It is essential to be clear at the outset precisely what is meant by the terms being used. For the purposes of this paper, we have adopted most of the definitions provided by the Royal Society of Canada Expert Panel on End of Life Decision-Making (“RSC Expert Panel”)—a multi-disciplinary, international panel of experts (Schüklenk et al. 2011, 6–8):

> “Advance directives” are directions given by a competent individual concerning what and/or how and/or by whom decisions should be made in the event that, at some time in the future, the individual becomes incompetent to make health care decisions. An example is a woman who has signed a document that states that, should she fall into a persistent vegetative state, she does not wish to receive artificial hydration or nutrition. Or, as another example, a man who has signed a document that states that, when he is incompetent, he wishes his wife to make all health care decisions on his behalf. There are two kinds of advance directives: instruction directives, which establish what and/or how health care decisions are to be made; and proxy directives, which establish who is to make health care decisions.
>
> “Withholding of potentially life-sustaining treatment” is the failure to start treatment that has the potential to sustain a person’s life. An example is not providing cardiopulmonary resuscitation to a person having a cardiac arrest.
>
> “Withdrawal of potentially life-sustaining treatment” is stopping treatment that has the potential to sustain a person’s life. An example is the removal of a ventilator from a patient with a devastatingly severe head injury after a motorcycle accident with no prospect of improvement.
>
> “Potentially life-shortening symptom relief” is a suffering control medication given in amounts that may - but are not certain to - shorten a person’s life. An example is giving ever-increasing levels of morphine necessary to control an individual’s suffering from terminal cancer when the morphine is known to potentially depress respiration even to the point of causing death (but it is not known precisely how much is too much as the levels are slowly increased).
>
> “Palliative sedation” is an umbrella term used to explain intermittent and continuous as well as superficial and deep sedation. The most contested subtype of palliative sedation is known as “terminal sedation.”
>
> “Terminal sedation” is potentially life-shortening deep and continuous sedation intentionally combined with the cessation of nutrition and hydration.
>
> “Assisted suicide” is the act of intentionally killing oneself with the assistance of another. An example is a woman with advanced ALS who gets a prescription from her physician for barbiturates and uses the drug to kill herself.
>
> “Voluntary euthanasia” is an act undertaken by one person to kill another person whose life is no longer worth living to them in accordance with the wishes of that person. An example is a man bedridden with many of the consequences of a massive stroke whose physician, at his request, gives him a lethal injection of barbiturates and muscle relaxants.
>
> “Voluntary” means in accordance with the wishes expressed by a competent person or through a valid advance directive.
>
> “Non-voluntary” means without the knowledge of the wishes expressed by a competent person or through a valid advance directive.
>
> “Involuntary” means against the wishes expressed by a competent person or through a valid advance directive.

We also use two umbrella terms. First, "potentially life-shortening palliative interventions." Palliative interventions are a range of medical practices that provide some relief from pain or suffering at the end of life. There are two categories of palliative interventions that can potentially cause death: potentially life-shortening opioid use (captured under what the RSC Report calls "potentially life-shortening symptom relief"); and terminal sedation. Second, "assisted dying" which, for the purposes of this paper, we use to capture assisted suicide and voluntary euthanasia.

An additional term central to this paper but not defined by the RSC Expert Panel is "dementia." For a definition of this term, we rely on the Nuffield Council on Bioethics (2009, xvii):

> The term "dementia" describes a collection of signs and symptoms such as memory and communication problems, changes in mood and behavior, and the gradual loss of control of physical functions which, taken together, are an indication of damage to the brain as a result of the progressive degeneration of nerve cells. This can be caused by a variety of different diseases, of which Alzheimer's disease is the most common. Others include vascular dementia, Lewy body dementia, dementia related to Parkinson's disease, frontotemporal dementia, alcohol-related dementias and prion diseases.

7.3 Background Medical Realities

Before considering the issue of the legal status of assisted dying for individuals with dementia, it is important to first understand the background medical realities of dementia.

7.3.1 Incidence, Prevalence, and Demographics of Dementia

According to a 2013 systematic review of studies on the prevalence of dementia around the world, in 2010, 35.6 million people were living with dementia. It was predicted that the incidence would nearly double every twenty years resulting in 65.7 million people living with dementia in 2030 and 115.4 million in 2050 (Prince et al. 2013, 68). Dementia is clearly more common in older populations—with most regions ranging from 5 to 7 % prevalence for individuals 60 years old and above and doubling every 5.5–6.7 years (Ibid. 67). It is also more common for women than men with a 19–29 % lower prevalence for men than women in most regions of the world (Ibid. 67).

It can also be revealing to look at one country as an example of these numbers on a national versus global scale (given the considerable variability across regions of the world this allows a bit more precision) (Ibid. 66). The incidence in Canada has been predicted to rise from 103,728 new cases per year in individuals over the age of 65 in 2008 to 257,811 new cases per year in 2038. The prevalence of dementia for individuals of all ages has been predicted to rise from 1.5 % of the population to 2.8 %. Dementia is more common in women than men with a ratio of 1.36:1. It is also more common in older individuals: 7 % of individuals over the age of 65 in 2008 to 9 % in 2038; 40 % of individuals over the age of 90 in 2008 to 50 % in 2038; and 55 % of individuals with dementia being over the age of 80 in 2008 and 68 % in 2038 (Alzheimer Society 2010, 16–18). Dementia is also more common in First Nations populations than non-First Nations (7.5 per 1000 compared to 5.6 per 1000) and it "disproportionately affects younger age groups and males… in First Nations populations compared to non-First Nations (Jacklin et al. 2013, e39).[2]

7.3.2 Symptoms of Dementia

Dementia is commonly broken down into three stages: early, middle, and late.[3] The Nuffield Council on Bioethics (2009, 9) report on dementia sets out the symptoms associated with each stage in the context of Alzheimer's disease.

In the early (or mild) stage, symptoms include:

- memory loss
- difficulty learning new things
- difficulty making decisions
- disorientation and bewilderment
- social withdrawal
- losing track of the time
- becoming lost in familiar places

In the middle (or moderate) stage, symptoms include:

- more serious disorientation (e.g. difficulty distinguishing between day and night)
- becoming lost at home

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[2] The increased prevalence may be a result of a number of different factors: "higher rates of associated conditions, such as hypertension, heart disease, stroke, and diabetes, and higher smoking and obesity rates, all of which increase the risk of dementia. First Nations populations also have an increased vulnerability to the social determinants of health; most notable for dementia are lower incomes and lower levels of educational attainment. Recent studies suggest that sufferers of Post-Traumatic Stress Disorder (PTSD) are at an increased risk of dementia. As a result of the historical trauma attributed to residential school experience and the ongoing intergenerational effects, PTSD may also contribute to the overall prevalence of dementia for First Nations, Inuit and Metis people" (Jacklin et al. 2013, e39–e40).

[3] Other, more complex, scales are used by health-care professionals to identify the progression of dementia with more precision. These include, for example, the Clinical Dementia Rating (CDR) which rates dementia on a five step scale. The Global Deterioration Scale for Assessment of Primary Degenerative Dementia (or Reisberg scale) is the measure used for the progression of Alzheimer's disease and divides Alzheimer's disease into seven stages (Marcel et al. 2011).

- increasing difficulty with communication
- problems with visual perception which may have a very significant effect on their ability to function independently
- behaviour changes (including wandering and repeated questioning)

In late (or severe) stage dementia, symptoms include:

- becoming unaware of the time and place
- having difficulty recognizing relatives and friends
- having an increasing need for assisted self-care
- difficulty walking
- behaviour changes (including aggression)
- difficulties swallowing and eating
- loss of control over bodily functions
- loss of speech (including loss of capacity to report pain and suffering)

Other forms of dementia may not follow the same slow and steady exacerbation of symptoms. Rather, for example, someone with vascular dementia may experience a significant loss of function, then plateau, then some months or years later, experience another significant loss.[4]

Dementia is also associated with "unpredictable anger and aggression, depression and apathy" (The Nuffield Council on Bioethics 2009, 8).

There is obviously a range of scenarios that people may have in mind when considering the issue of assisted dying for patients with dementia. The vision you have of dementia can greatly impact your analysis of the issue. In order to better understand the range of scenarios, consider the contrasting descriptions of two women with dementia, Margo and Margot.

Margo was described in a short piece in *JAMA* in 1991. A medical student described a 55-year-old woman with Alzheimer's living in New York (Firlik 1991). She would wander away from her apartment, sometimes to be found a couple of days later in a nightgown "roaming Central Park." The author notes opaquely, "[b]ad things have happened during these excursions." Margo is described as enjoying reading, listening to music, and eating peanut butter and jelly sandwiches. She paints—although she has painted the same four concentric circles "every day, exactly the same way, for the last five years." The author claims "Margo is undeniably one of the happiest people I have known. There is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful."

Margot, by contrast, is an 82-year-old in the final stages of dementia living in British Columbia. In his description of Margot's condition in the context of a legal contest over the continuation of spoon-feeding, Justice Greyell writes:

> Mrs. Bentley has advanced Alzheimer's disease. It was clear from the petitioners' and respondents' evidence that Mrs. Bentley makes very few physical movements. She occasionally rubs the back of her hand, arm, or face. She is routinely transferred from her bed

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[4] For a review of the progression of various forms of dementia, see Alzheimer's Society (2011).

> to a wheelchair. Her eyes are closed much of the time. She has not spoken since 2010. She does not indicate through her behaviour that she recognizes her family members or any other person.[5]
>
> Mrs. Bentley grasps the hands of people who speak to her, but she does not make eye contact or appear to respond in other ways when people try to interact with her. The staff reported to Dr. O'Connor that Mrs. Bentley conveys when she is in pain by moaning and tightening her facial muscles. She is being given a small amount of hydromorphine regularly to address any pain she may be in.[6]

7.3.3 Decision-Making Capacity and Dementia

Decision-making capacity is often compromised in patients with dementia. Berghmans et al. distinguish four standards or criteria for capacity: "(i) the capacity to make and express a choice; (ii) the capacity to understand relevant information; (iii) the capacity to evaluate the character of the situation and possible consequences; and (iv) the capacity to handle information rationally" (Berghmans et al. 2004, 255). Each of these abilities can be compromised by dementia.

The assessment of capacity can be particularly difficult in the context of dementia. First, "cognitive fluctuations" occur in patients with dementia, e.g., in 12 % of patients with Alzheimer's disease (Trachsel et al. 2014). The specific timing of the assessment can therefore have a significant impact on the findings. Second, the results of the assessment can be dependent upon whether the assessor is familiar with the particular ways in which asking the questions and supporting the patient's decision-making can impact upon the ability of the patient to perform (Kim et al. 2002).

Difficulties aside, there is some data re: the incidence of incapacity in persons with dementia. For example, one pooled study found that 54 % of 1425 patients with Alzheimer disease were incapable (95 % CI, 28–79 %) (Sessums et al. 2011, 422). One study of 48 patients with very mild to moderate Alzheimer disease found 40 % to be competent to make an Alzheimer treatment decision. This study also suggested the following relationship between the stage of the disease and incapacity: very mild very likely to be competent; moderate and severe very likely to be incompetent; and mild and early moderate in a grey zone (Karlawish et al. 2005, 1516).

Of course, great care needs to be taken with these statistics as they report on small numbers and, more significantly, are not specific to end of life decisions. Some relate to the capacity to make decisions to enter a research trial, some to respond to hypothetical treatment scenarios, and some to actual disease treatment decisions. Nonetheless, the conclusion relevant to the purposes of this paper can

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[5] *Bentley v Maplewood Seniors Care Society* (2014) at para 18.

[6] Ibid. at para 27.

be drawn with confidence and that is that there are some individuals with dementia who clearly have the decision-making capacity needed for all decisions about assisted dying, some who have the capacity for some but not other decisions about assisted dying, some whose capacity is in flux for some or all such decisions (i.e., coming and going at different times of the day or across spans of time), and some who have no capacity for any such decision-making.

7.4 The Desire for the Option of Assisted Dying in the Face of Dementia

Not surprisingly, against these background medical realities, some individuals with dementia wish to have the option to access assisted dying at some point in the progression of their disease and some individuals who do not have dementia would like the option of access to assisted dying to be available should they develop dementia.

A 2014 "systematic review of the international literature data on attitudes of health professionals, patients, carers and the public" (Tomlinson and Stott 2015) found studies revealing the following attitudes among the public, for example:

- 10 % of 447 American adults found physician-assisted suicide to be an acceptable option for people with mild dementia (citing Cicirelli 1998)
- 24 % of 1960 Dutch adults were in favour of allowing physician-assisted suicide for people with mild dementia (citing Kouwenhoven 2013)
- Over half of a 725-person sample from the United Kingdom indicated that they would want physician-assisted suicide to be an option for themselves (59.5 %) or their partner (57.4 %) if they had severe dementia (citing Williams et al. 2007)
- 50 % of the public sampled in the Netherlands (1998), Finland (2002), and the UK (2007) were in favour of allowing euthanasia in cases of severe dementia (citing Ryynänen et al. 2002; van Holsteyn and Trappenburh 1998; Williams et al. 2007)
- 77 % of the public sampled in the Netherlands in 2013 were in favour of allowing euthanasia in cases of severe dementia (citing Kouwenhoven et al. 2013)

Obviously, there is a wide range of support revealed here and few conclusions can be drawn on the basis of them. However, it does seem reasonable to at least conclude that some individuals in some countries want to have the option of legal access to assisted dying for themselves in the face of dementia and some want that option to be available to others. So three important questions are whether individuals with dementia legally have access to assisted dying anywhere in the world, whether people with dementia living in permissive jurisdictions actually take advantage of access to assisted dying, and what lessons can be taken from permissive (or potentially permissive) jurisdictions with respect to how to make assisted dying legally accessible to individuals with dementia or how to ensure that it is not (depending on the desired result).[7]

7.5 Legal Status of Assisted Dying for Individuals with Dementia in Permissive Jurisdictions

7.5.1 Netherlands

In the Netherlands, the *Termination of Life on Request and Assisted Suicide* (*Review Procedures*) *Act* (*2002*) (The Dutch Act) establishes criteria for access to legally permissible assisted suicide and euthanasia. Under s. 2 of the Dutch Act:

1. In order to comply with the due care criteria … the attending physician must:
    - (a) be satisfied that the patient has made a voluntary and carefully considered request;
    - (b) be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
    - (c) have informed the patient about his situation and his prospects;
    - (d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
    - (e) have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in (a)–(d) above;
      and
    - (f) have terminated the patient's life or provided assistance with suicide with due medical care and attention.[8]

Under Article 2.2 of the Dutch Act,

> If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the attending physician may comply with this request. The due care criteria referred to in subsection 1 apply mutatis mutandis.

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[7] A distinct, but critically important, question is whether individuals with dementia are adequately protected at the end of life and are not having potentially life-sustaining treatment withheld or withdrawn or having potentially-life-shortening palliative interventions administered without their consent (or authorization from a substitute decision-maker) or without their knowledge (or without the knowledge of their substitute decision-maker). This must remain the topic for another paper. Although not specific to dementia, readers interested in unilateral decision-making are directed to Downie et al. (2014).

[8] Netherlands, *Termination of Life on Request and Assisted Suicide* (Review Procedures Act) (2002).

Therefore, physicians are legally allowed to perform euthanasia on, or provide for assisted suicide by, patients capable of making a "voluntary and carefully considered request" and to perform euthanasia on incapable patients based on an advance directive from the patient written at the time when they were still capable as long as the other requirements for due care are met.

Two main issues have been raised with the law as it plays out in the context of dementia. First, in the context of requests for euthanasia in early stages of dementia, questions have been raised about whether suffering of capable individuals in anticipation of increasingly severe dementia can meet the unbearable suffering criterion. Second, it has been suggested that it is difficult for physicians to ascertain whether a patient's suffering is "unbearable" without being able to communicate with the patient (Rietjens et al. 2009). Patients with advanced dementia lose their ability to communicate the extent of their suffering to a physician. This makes it difficult for physicians to assess whether the suffering is unbearable (and it is the physician who must make this assessment under the Dutch law).

Regional Review Committee decisions are illuminating with respect to how the law is being interpreted in relation to these concerns.

In relation to what kinds of suffering count, the Committee noted:

> What makes their suffering unbearable is often their awareness of the deterioration in their personality, functions and skills that is already taking place, coupled with the realisation that this will get worse and worse and will eventually lead to utter dependence and total loss of self. Already being aware of their disease and the prognosis may cause patients great and immediate suffering. In that sense, 'fear of future suffering' is a realistic assessment of the prospect of further deterioration. (Regional Euthanasia Review Committees 2010, 15)

In relation to the issue of how to determine suffering when the patient can no longer communicate, the Committee noted that the nature of a patient with dementia's suffering can be determined not only from statements written when competent but also from body language and contemporaneous oral statements (Legemaate and Bolt 2013, 456).[9] In a case in 2011, physicians performed euthanasia on a woman with advanced dementia. The Regional Review Committee noted:

> It is true that just before the termination of her life the patient was no longer able to properly express the unbearable nature of her suffering in words; however the physician and the consultants had received the very strong impression from her body language and verbal responses that the patient felt that her suffering was unbearable, having previously described it as such. The physician considered that that impression was reinforced by the fact that just before the euthanasia was carried out the patient, even if imperfectly, had on a number of occasions expressed the wish to die. (Regional Euthanasia Review Committees 2011 in Legemaate and Bolt (2013, 456))

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[9] Methods are being developed to assess pain in persons with dementia. See for example, Lichtner et al. (2014). However, "there are a considerable number of pain assessment tools available for use with the elderly cognitive impaired population. However there is limited evidence about their reliability, validity and clinical utility. On the basis of this review no one tool can be recommended giving the existing evidence" (Ibid., 138).

This case caused considerable controversy and has been the subject of a vigorous debate. The Royal Dutch Medical Association responded with guidelines cautioning physicians about the difficulty of dementia cases and asking them to "act with extreme caution and restraint (KNMG 2011, 7)." The Regional Review Committee (2010) has said that "in the case of people suffering from dementia, 'the response must in general be one of extra caution'" (Regional Review Committee 2010 in Legemaate and Bolt 2013, 455).

In sum, euthanasia or assisted suicide for individuals with dementia is permissible (under strict conditions) for early through to end stage dementia. However, because of the way the Dutch Act is drafted, it is thought to be difficult to meet the conditions in the context of dementia and the practice is uncommon for early dementia and very rare for end stage dementia.

7.5.2 Belgium

The Belgian legislation on euthanasia (*2002*) (The Belgian Act) states that euthanasia is not illegal if a physician follows the specific conditions and procedures set out in the statute.[10] As noted by Justice Smith in *Carter v Canada (Attorney General)*, "Section 3(1) of the Belgian Act provides that a physician who performs euthanasia does not commit a criminal offence when he or she ensures that ["il s'est assuré que"]:

(b) the request is voluntary, well-considered, repeated and not the result of external pressure [the request must also be in writing (s. 4)]; and

(c) the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident."[11]

While the Belgian Act does not expressly permit physician-assisted suicide, the Federal Control and Evaluation Commission (the body with oversight of assisted dying in Belgium) has accepted that assisted suicide is also legal if a doctor follows the conditions and procedures established under the Act.[12] Assisted suicide is subject to the same requirements as euthanasia.

In cases of individuals with dementia, if they are still capable of a voluntary, well-considered and repeated request and their constant and unbearable physical or mental suffering cannot be alleviated, euthanasia and assisted suicide can legally be provided if the other criteria are also met. However, as with the Dutch Act, the scope of this provision is unclear as it is the physician's assessment that is determinative and it is not clear what will be considered to constitute sufficient suffering in the context of dementia.

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[10] Belgium, *The Belgian Act on Euthanasia of May, 28th* (2002), s 4, § 2, 184

[11] *Carter v Canada (Attorney General)* (2012) at para 509.

[12] Ibid. at para 508.

In cases in which a patient is no longer capable, a physician may legally perform euthanasia based on an advance directive if:

- the patient suffers from a serious and incurable disorder, caused by illness or accident;
- the patient is no longer conscious;
- and this condition is irreversible given the current state of medical science.[13]

The legislation also requires that the advance directive was made at least five years before the start of the incapacity.[14]

Euthanasia on patients with dementia on the basis of an advance directive is therefore illegal in Belgium if the patient is still conscious. Unconsciousness is obviously far later in the disease process than the point at which many people with dementia would be requesting euthanasia even through an advance directive. That said, euthanasia is available to individuals with dementia through an advance directive at the point of unconsciousness where the patient is seen by the physician to suffer from a serious and incurable disorder (which dementia is) and the condition is irreversible (which dementia is) and the person completed the advance directive at least five years before the start of his or her incapacity.

7.5.3 Luxembourg

In Luxembourg, a physician will not be prosecuted for euthanasia or assisted suicide when:

1. the patient is a capable and conscious adult at the time of their request;
2. the request is made voluntarily, after reflection and, if necessary, repeated, and does not result from external pressure;
3. the patient is in a terminal medical situation and shows constant and unbearable physical or mental suffering without prospects of improvement, resulting from an accidental or pathological disorder;
4. the patient's request for euthanasia or assisted suicide is made in writing.[15]

In addition, a physician will not be prosecuted for euthanasia in accordance with an advance directive where the physician observes:

- that they are afflicted by a severe and incurable accidental or pathological disorder,

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[13] Belgium, *The Belgian Act on Euthanasia of May, 28th* (2002), s 4, § 2, 184.

[14] "La déclaration ne peut être prise en compte que si elle a été établie ou confirmée moins de cinq ans avant le début de l'impossibilité de manifester sa volonté." Belgium, *The Belgian Act on Euthanasia of May, 28th* (2002), s 4, § 1, 183.

[15] Luxembourg *Euthanasia and Assisted Suicide: Law of 16 March* (2009), art 2.1, 37.

- that they are unconscious, and
- that the situation is irreversible according to science at the time.[16]

While not a condition for access under the law, the National Commission for Control and Assessment (NCCA) is required to request confirmation of the wishes expressed in the advance directive at least once every five years from the date of registration.[17]

These requirements probably prevent many patients with dementia from accessing assisted dying. First, for those in early stages of dementia, they will fail to meet the requirement of a "terminal medical situation." For those in late stages of dementia, they will not be competent. They will then need to rely on an advance directive to achieve their goals but this will only be possible when they are unconscious (again, as in Belgium, much later than many people with dementia may want their advance directive to be acted upon). In addition, if they have been incompetent for more than five years, it is possible that a healthcare provider might (mis)interpret the requirement of NCCA confirmation of the patient's wishes every five years to mean that their advance directive will no longer be valid for the purposes of requesting euthanasia.

7.5.4 Switzerland

In Switzerland, euthanasia is always illegal while assisting suicide is illegal if was done for selfish motives.[18] Assisted suicide is not restricted to individuals with a terminal illness or a specific kind or level of suffering. However, it is restricted to individuals who voluntarily administer the drugs themselves and are competent. Under Article 111f of the Swiss Penal Code, assisting the death of an individual who lacks mental capacity constitutes homicide because, in that case, suicide is not considered to be the result of a free decision. Therefore, assisted suicide is legal for competent patients with dementia (hence largely in the early stages of dementia but not later).

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[16] Ibid., art 4(1).

[17] Luxembourg Ministries of Health and Social Security 2010, 20. Note the difference here between the Belgian and Luxembourgian requirements. In Belgium, the advance directive must have been made at least five years before the start of the incapacity. In Luxembourg, that restriction is not present. As long as the patient is competent, she can create a valid advance directive.

[18] Switzerland, *Swiss Criminal Code*, SR 311.0, art 115 (1937, amended 2015).

7.5.5 Oregon

Oregon was the first American state to pass legislation that legalized physician assisted dying in certain circumstances. The *Death with Dignity Act* (the Oregon Act) allows a physician to prescribe medication for the purpose of ending the patient's life only when a patient is capable (defined as having the ability to make and communicate health decisions) and is suffering from a terminal disease (death within six months).[19] This precludes individuals with dementia from accessing assisted suicide (unless they have a separate illness that will be in its terminal phase before the dementia has caused a loss of capacity). In early stages of dementia when a patient may still be deemed capable, they will not satisfy the requirement of being terminally ill. In a more advanced stage of dementia when their condition might be considered terminal, they will no longer be capable of making and communicating health decisions.

7.5.6 Washington State/Vermont

The legislation passed in Washington State[20] and Vermont[21] is based on the Oregon Act. Both Acts include the criteria of competence and terminal illness that, taken together, prevent patients with dementia from accessing assisted suicide (unless they have a separate illness that will be in its terminal phase before the dementia has caused a loss of capacity).

7.5.7 Montana

In Montana, assisted suicide has been made legal by a decision of the Supreme Court that recognized that the consent of a mentally competent, terminally ill patient can constitute a statutory defence to a charge of homicide against an aiding physician.[22] As in the other states, this decision only makes assisted suicide legal for mentally competent, terminally ill patients and therefore assisted suicide is not available for patients with dementia (unless they have a separate illness that will be in its terminal phase before the dementia has caused a loss of capacity).

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[19] Oregon, *Death with Dignity Act* (1997).

[20] Washington State, *Death with Dignity Act* (2009).

[21] Vermont, *An Act Relating to Patient Choice and Control at End of Life* (2013).

[22] *Baxter v Montana* (2009).

7.5.8 New Mexico

In the 2014 case of *Morris v New Mexico*,[23] an Albuquerque trial court recognized a patient's fundamental right to receive their physician's assistance in death only if the patient is mentally competent and terminally ill. As in Oregon, these criteria would preclude individuals with dementia from accessing assistance (unless they have a separate illness that will be in its terminal phase before the dementia has caused a loss of capacity). This decision has been appealed by New Mexico Attorney General Gary King but the appeal has yet to be heard.

7.5.9 Colombia

In 1997, the Colombian Constitutional Court considered a challenge to the criminal law provisions that prohibit euthanasia but reduce the sentence when certain conditions are met:

> He who kills another person out of compassion, to put an end to intense suffering caused by physical injuries or grave or incurable illness, will be punished with imprisonment of 1 to 3 years.[24]

This provision was challenged on the grounds that, by providing for a lesser penalty for euthanasia, the Criminal Code violated the Constitution (specifically, the rights to life and equality). In May 1997, the Court found, first, that the lesser penalty attaching to euthanasia does not violate the Constitution.[25] The Court also found that "whenever a medical doctor or physician performed such an act [euthanasia under the conditions in the Code], in the presence of informed consent, no criminal sentence, conviction or penalty could result, in observance that it is a lawfully justified conduct."[26] The Court grounded its decision in the values of autonomy, human dignity, and solidarity.

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[23] *Morris v New Mexico* (2014).

[24] Exhibit D referred to in the Affidavit of Sabine Michalowski sworn (or affirmed) 20 September 2011 in *Carter v Canada* (2012).

[25] The majority of the Court did not address the constitutionality of the assisted suicide provision. ("Incitement to suicide or assisted suicide. He who effectively incites another person to commit suicide, or provides effective assistance for its commission, will be punished with imprisonment of two to six years. The incitement or assistance are directed towards putting an end to intense suffering caused by physical injuries or grave or incurable illness, it will be punished with imprisonment of one to two years.") Michalowski (2009, 197).

[26] Statement made by Carlos Gaviria Diaz (author of the majority decision), May 20, 1997, Exhibit F, Affidavit of Sabine Michalowski, *supra* note 24.

The Court called on the Parliament to establish a regulatory regime to guide the practice of euthanasia. Despite a number of attempts (as recently as 2013), Parliament has been unable to pass such legislation (Colombia Reports 2013).

As a consequence of this decision, it appears that euthanasia in the face of intense suffering caused by "physical injuries or grave or incurable illness" (either dementia itself or coincident with dementia) without consent from the individual (but not against the wishes of the individual) would be a crime but could be subject to a lesser penalty than that applied to other forms of homicide. It also appears that euthanasia performed by a physician in the face of intense suffering caused by "physical injuries or grave or incurable illness" (either dementia itself or coincident with dementia) would have a complete defence (Michlowski 2009, 184).[27]

7.5.10 England and Wales

In England and Wales, while the act of assisting suicide remains illegal, prosecutors make decisions about whether or not to prosecute depending on the circumstances of each case under a specific set of prosecutorial charging guidelines. In 2010, the Director of Public Prosecutions issued guidelines that set out 16 criteria that would be taken into consideration when deciding whether or not to prosecute an individual for assisting suicide.[28] The list of 16 factors in favour of prosecution includes "the victim did not have the capacity to reach an informed decision to commit suicide." When the individual had reached a "voluntary, clear, settled and informed decision" and the individual was acting with compassion, these factors will weigh against prosecuting the individual for assisting suicide. Assisted suicide in cases of late dementia would clearly be limited by the competency requirement. Another factor in favour of prosecution is when "the victim was physically able to undertake the act that constituted the assistance him or herself." This might preclude assisted suicide for individuals with early dementia able to perform the suicide themselves.

7.5.11 Quebec

In Canada, both assisted suicide and euthanasia are criminal offences under the *Criminal Code*.[29] However, in Quebec, "*An Act respecting end of life care*" estab-

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[27] For a rich discussion of the law in Colombia, see Michalowski (2009).

[28] Director of Public Prosecutions, England and Wales (2010)

[29] *Criminal Code* (1985).

lishes a right to "medical aid in dying"[30] for patients who: are of full age and capable of giving consent to care; are at the end of life; suffer from a serious and incurable illness; are in an advanced state of irreversible decline in capability; and experience constant and unbearable physical or psychological pain. While the possibility of allowing requests for medical aid in dying to be made through advance directives was explicitly considered by the Quebec National Assembly, it was not included in the final version of the Act. Indeed, the Act states that "in such directives the person may not request medical aid in dying."[31] Therefore, individuals with dementia are not likely to be able to access medical aid in dying under the Quebec legislation—they will usually either be competent but not meet the "end of life" requirement or meet the "end of life" requirement for access but no longer be competent. Of course, there may be circumstances in which the individual has dementia, is still competent, and is "at the end of life" due to some condition other than the dementia and, in those circumstances, they could qualify for access.

7.6 Access in Permissive Jurisdictions

One might reasonably wonder what the rates of assisted dying for people with dementia are in countries in which there is some level of permission or tolerance. There is some data available on this:

- In the Netherlands, euthanasia or assisted suicide in patients with dementia has been steadily increasing since 2009 (12 in 2009, 25 in 2010, 49 in 2011, 42 in 2012, 97 in 2013).[32] In their Annual Report 2010, the Regional Review Committees noted that all of the 25 patients with dementia who received euthanasia were at an early stage of the disease and were competent to make autonomous decisions at the time of their death (Regional Euthanasia Committees 2010). In 2011, the Regional Review Committees reviewed the first case of a patient with advanced stage dementia. This case involved a 64-year-old woman who had written an advance directive in which she expressed her desire to die rather than go to a nursing home. The Regional Review Committees found that the physician met all due care requirements because she was experiencing unbearable suffering and continued to express her desire to die (Legemaate and Bolt 2013, 456).

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[30] Section 3: "(3) 'End-of-life care' means palliative care provided to end-of-life patients and medical aid in dying." "(6) 'Medical aid in dying' means care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relive their suffering by hastening death." Section 4: "Every person whose condition requires it has the right to receive end-of-life care." *An Act Respecting End-of-Life Care* (2014), ss 3–4.

[31] Ibid., s 51.

[32] See collection of Regional Euthanasia Review Committees Annual Reports available online at http://www.euthanasiecommissie.nl/archiefjaarverslagen.asp.

Post-2011, the majority of patients with dementia who received euthanasia or assisted suicide were in the early stage of dementia and still competent.

- A recent study of end-of-life decisions in individuals dying with dementia in Belgium revealed no cases of euthanasia being provided but in 1.3 % of 361 cases, there was an ungranted request for euthanasia (Chambaere et al. 2015, 293).
- In Switzerland, the Federal Statistical Office reported that 0.3 % of the cases of assisted suicide between 1998 and 2009 involved individuals with dementia (Swiss Federal Statistical Office 2012). “Exit Deutsche Schweiz,” a Swiss right to die organization, provided suicide assistance to four individuals with early-stage dementia in 2010 (Gather and Vollmann 2013). It has been reported that in 2013, a British man with early stage dementia chose to end his life at the Swiss Dignitas clinic (Stevens 2013).
- There are no official reports of physician-assisted suicide deaths of patients with dementia in Oregon (Oregon Public Health Division 2011). However, Gather and Vollmann note that “some neuropsychiatric diseases placed in the category of ‘other illnesses’, are definitely, or at least potentially, accompanied by dementia during the course of the disease (including Huntington’s disease, corticobasal degeneration)” (Gather and Vollmann 2013, 445). Therefore it is possible that someone could be terminally ill (as a result of something other than dementia) and be at an early stage of dementia (and therefore still competent) and access physician-assisted suicide.
- There have been no reported cases of physician-assisted suicide deaths of patients with dementia in Washington.
- It has been reported that, in practice, some Colombian physicians will euthanize unconscious patients when families state that the patient had expressed desires not to be kept alive after all hope of recovery was gone (Ceaser 2008).
- Clive Seale’s study in the UK involving 2869 doctors treating an estimated 4106 patients with dementia reported no “ending of life without explicit request of the patient” or voluntary euthanasia deaths in patients with dementia (Seale 2009,198).

7.7 Lessons to Be Learned from Permissive Jurisdictions

Thus it can be seen that assisted dying is permitted for individuals with dementia to varying (from zero to limited) degrees in the various countries in the world that have somewhat permissive regimes with respect to assisted dying. Jurisdictions that at first glance might seem to allow for access to assisted dying for individuals with dementia are often less permissive than they at first appear. For those seeking to have assisted dying available to persons with dementia, reflecting on the experiences in permissive jurisdictions can reveal what positions should be taken (or avoided) on key legislative variables in order to ensure that the access desired is the access achieved.

7.7.1 *Suffering*

Two aspects of suffering are relevant here. First, what kind of suffering is required for access? Physical only? Or also psychological? Or also existential? Second, who determines whether the patient's suffering is of the nature and to the level required for access? The patient contemporaneously? The patient through an advance directive? The patient's substitute decision-maker? A physician?

Requiring that suffering be physical only will restrict access for many individuals with dementia. Frequently the suffering of individuals with dementia is caused not by physical pain but rather by such emotions as fear, frustration, and grief over loss of self and relationships.

Requiring that physicians determine that the patient is suffering to the level required by the law restricts access for individuals with severe dementia as they are unlikely to be able to communicate about their suffering. For individuals at the late stages, only those who are demonstrating suffering through non-verbal means will have access. Yet, individuals can be in unbearable pain and especially other forms of suffering without manifesting that through nonvoluntary or involuntary bodily indicators.

To be responsive to the specifics of dementia re: kinds of suffering, permissive legislation would need to explicitly acknowledge that suffering can be physical or psychological and that either of these kinds of suffering can be experienced to the level required. Suffering doesn't need to be physical to be agonizing.

To be responsive to the specifics of dementia re: detection of suffering, permissive legislation would need to not require a finding of contemporaneous suffering where the individual is incompetent. Once the patient is incompetent, it is possible that a physician could be able to determine that that patient is suffering (e.g., through involuntary physical manifestations of pain).[33] However, it is not possible for a physician to determine that a patient is not suffering. We simply cannot know whether someone is not suffering exquisitely when they are no longer capable of competent communication—reflecting on anaesthetic awareness and locked-in syndrome and individuals who have been misdiagnosed as being in a persistent vegetative state (rather than minimally conscious) should give us pause in presuming we can reliably observe suffering (Deschepper et al. 2013, 1505–1506). We can know with some confidence that a person is in physical pain (there will sometimes be very reliable evidence of physical pain). But we cannot know with any confidence that a person is not suffering (absence of evidence of suffering is not evidence of absence of suffering).

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[33] For a review of pain assessment tools for persons with dementia, see Lichtner et al. (2014).

7.7.2 Consciousness

The requirement that patients be unconscious delays access for individuals with dementia long past the time when most would have wanted to have assisted death. Dementia alone does not cause unconsciousness. Rather, unconsciousness in the context of dementia is the result of some complication (e.g., urinary tract infections, pneumonia, dehydration), and patients usually die within a matter of days of onset of unconsciousness. Yet individuals with dementia who want an assisted death are likely to want it well before they are imminently dying. They may want it when, for example, they have lost the capacity to recognize their loved ones or to communicate and yet they can live for months or years having lost those capacities.

It is also not at all clear what the moral significance of unconsciousness is. It isn't linked to competence which correlates with autonomy and so is linked directly to the moral principle of respect for autonomy. It isn't linked to the presence of suffering which correlates with the moral justification of alleviating suffering. So consciousness as a requirement precludes some individuals with dementia from accessing assisted dying without any of the values underlying permissive legislation being protected or promoted.

7.7.3 Five Years Before Onset

The requirement that an advance directive be written at least five years before the onset of the loss of capacity, restricts access for individuals with rapid-onset dementia or individuals who did not think to write their advance directive long before any sign of dementia. The goal that presumably motivates the five-year requirement can be accomplished by insisting on competence when completing an advance directive (no matter when the completion is temporally relative to the onset of dementia). Five years is underinclusive if ensuring competence is the goal. If ensuring competence is not the goal, then it is not clear what the goal of the five year requirement could be.

7.7.4 Five Yearly Confirmation

Requiring confirmation at least once every five years restricts access for individuals who are incompetent for more than five years. Individuals can live for more than five years after dementia has robbed them of competence for end of life decision-making. The goal that presumably motivates the five-year confirmation requirement can be accomplished by insisting on confirmation every five years while competent. This prevents an individual writing a directive when very young, forgetting about it, changing her mind but not documenting the change. It makes sense to take steps to ensure that a person hasn't changed her mind while competent but not to insist on such non-ambivalence through incompetence.

7.7.5 Competence and Terminal Illness

Restricting access to assisted dying to those who are terminally ill and competent creates a Catch-22—the closer to death one needs to be, the less likely one is to be competent. This is particularly acute for individuals with dementia—while still competent, they are not yet terminally ill yet once terminally ill, they are no longer competent. To be responsive to the specifics of dementia re: the inverse relationship between competence and the terminal phase of the disease, the permissive legislation would need to either allow individuals to request assisted dying through advance directives (to allow it at end stage) or allow individuals to access assisted dying while not yet terminally ill (to allow it at early stage).

7.8 Lessons to Be Learned from a Potentially Permissive Jurisdiction

In contrast to the legislation in Europe that may have prevented more access than intended or expected with respect to persons with dementia, the Bill that is presently before the federal Parliament in Canada, may allow more access than intended or expected. Arguably, because of the way it has been worded, it may allow access to persons with dementia through contemporaneous consent (early stage) or through advance directives (all stages). Consider Bill C-581 in relation to each of the elements shown earlier to have created barriers to access for persons with dementia in currently permissive jurisdictions.[34]

7.8.1 Consciousness

There is no discussion of consciousness in the Bill.

7.8.2 Five Years Before Onset/Every Five Years

The Bill's only temporal restriction is that "at least fourteen days must elapse between the time the assisting physician, the person making the request for assisted death or the witnesses, as the case may be, signed the request and the time the request is carried out."[35] This limit would not pose any significant barrier in the context of dementia.

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[34] Bill C-581 (2014).

[35] Ibid., s 3 [creating s. 241.1(9)].

7.8.3 Terminal Illness

The Bill does not limit access to assisted dying to those who are terminally ill. Rather, as noted above, a person must only "have been diagnosed by a physician as having an illness, a disease or a disability (including disability arising from traumatic injury) that causes physical or psychological suffering that is intolerable to that person and that cannot be alleviated by any medical treatment acceptable to that person or the person must be in a state of weakening capacities with no chance of improvement."[36]

7.8.4 Suffering

Suffering under Bill C-581 is determined by the person seeking assisted death (not the physician as, e.g., in the Netherlands) as the person must "have been diagnosed by a physician as having an illness, a disease or a disability (including disability arising from traumatic injury) that causes physical or psychological suffering that is intolerable to that person and that cannot be alleviated by any medical treatment acceptable to that person."

Note, also, that suffering is not limited to physical suffering and so could include the suffering of early stage dementia.

Furthermore, and most significantly, access to assisted death is not limited to those who are suffering as the conditions in subsection (c) (only one of which must be met because of the use of the term "or" instead of "and") include "or the person must be in a state of weakening capacities with no chance of improvement."

Therefore, a person could, in principle meet the suffering condition in Bill C-581 in early, mid, or late stages of dementia.

7.8.5 Competence

Unlike other permissive legislation, the Bill does not require competence to **access** assisted dying. Rather, it only requires competence to **make a request**. The only competence requirement is that the individual is "of sound mind and capable of fully understanding the information provided to him or her under subsection (6)"[37] at the time of the request. This is extremely significant. If the Bill required individuals to be competent for access to assisted dying, then assisted dying would (obviously) not be available to any incompetent individuals (whether they had valid

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[36] Ibid., s 3 [creating s. 241.1(3)(c)].

[37] Ibid., s 3 [creating s. 241.1(3)(d)].

advance directives or not). However, since the Bill only requires that individuals be competent when the request is made, then assisted dying could be available to some incompetent individuals: i.e., those who requested assisted dying through a valid advance directive completed while competent.

The logic of this argument is as follows: provincial/territorial advance directives legislation allows individuals to request in advance of incompetence that which would be legal for them to request when competent; Bill C-581 would make assisted dying legal; therefore, individuals could request assisted dying through advance directives. This conclusion could, of course, be avoided by the inclusion of a further premise—that assisted dying is legal only for individuals who are competent at the time of access. But that premise is not included in the Bill.

In sum, under Bill C-581, individuals with dementia could access assisted dying in at least two ways. First, at an early stage, they may "have been diagnosed by a physician as having an illness, a disease or a disability (including disability arising from traumatic injury) that causes physical or psychological suffering that is intolerable to that person and that cannot be alleviated by any medical treatment acceptable to that person." Requests for assisted dying by individuals qualifying on these grounds would have to be made contemporaneously (i.e., not through an advance directive). Second, even more remarkably, at early, mid, or late stages, they may "be in a state of weakening capacities with no chance of improvement." Individuals qualifying on this ground can meet the conditions for eligibility to make a request by being "of sound mind and capable of fully understanding the information provided to him or her under subsection (6)" at the time of either a contemporaneous request or a request made through an advance directive.

It is not clear whether this level of access was intended—that will come clear during any debate on the Bill. Bill C-581 will then come to be seen as either a Bill that learned the lessons taught by the legislation in the permissive jurisdictions and achieved the goal of allowing for some access for people with dementia or as yet another example of inadvertent consequences of drafting without working through all of the implications for persons with dementia (this time, unlike the existing permissive jurisdictions reviewed earlier, being more permissive than less).

7.9 Conclusion

In sum, it can be seen that dementia creates its own special challenges for legislation on assisted dying. It can be the source of great fear, sadness, frustration, and loss and a consequential desire for access to assisted dying. It involves symptoms and the progression of disease that makes it unusual with respect to the lack of correlation between meeting the common legal conditions for access and meeting the actual conditions for desire for assisted death. Countries that have moved toward permissive regimes with respect to assisted dying have ended up permitting access to fewer people than perhaps intended or expected. As Canada considers legislation that would take it into the realm of the permissive, it may end up permitting access to more people than intended or expected. The goal of this paper has been to demonstrate the peculiar ways in which some of the features of dementia interact with specific legislative provisions so that legislators in the future will draft their legislation such that it permits access to exactly (all and only) the people intended.

References

Alzheimer's Society. 2010. Rising tide: The impact of dementia on Canadian society. http://www.alzheimer.ca/media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf. Accessed 28 April 2015.

Alzheimer's Society. 2011. The progression of Alzheimer's disease and other dementias. http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=133. Accessed 28 April 2015.

Bennett, Gillian. 2014. Dead at noon. http://www.deadatnoon.com/. Accessed 18 August 2014.

Berghmans, Ron, Donna Dickenson, and Ruud Ter Meulen. 2004. Mental capacity: In search of alternative perspectives. *Health Care Analysis* 12: 251–263.

CBC News. Suffering with dementia, dies leaving right-to-die plea, (21 August 2014), online: http://www.cbc.ca/m/touch/news/story/1.2742440.

Ceaser, Mike. 2008. Euthanasia in legal limbo in Colombia. *The Lancet* 371: 290–291.

Chambaere, Kenneth, Joachim Cohen, S. Lenzo Robijn, Kathleen Bailey, and Luc Deliens. 2015. End-of-life decisions in individuals dying with dementia in Belgium. *Journal of the American Geriatric Society* 63: 290–296.

Cholbi, Michael J. 2014. Kant on euthanasia and the duty to die: Clearing the air. *Journal of Medical Ethics*. doi:10.1136/medethics-2013-101781.

Cicirelli, Victor G. 1998. Views of elderly people concerning end-of-life decisions. *Journal of Applied Gerontology* 17: 186–203.

Colombia Reports. 2013. Euthanasia Bill Runs Out of Time in Colombia's Senate http://colombiareports.co/colombia-euthanasia-bill-runs-out-of-time-in-senate

Deschepper, Reginald, Steven Laureys, Said Hachimi Idrissi, Jan Poelaert, and Johan Bilsen. 2013. Palliative sedation: Why we should be more concerned about the risks that patients experience an uncomfortable death. *Pain* 154: 1505–1508.

Director of Public Prosecutions, England and Wales. 2010. Policy for prosecutors in respect of cases of encouraging or assisting Suicide" by the Crown Prosecution Service. London: DPP. http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf. Accessed 28 April 2015.

Downie, Jocelyn, Lindy Willmott, and Benjamin P. White. 2014. Cutting the Gordian knot of futility: A case for law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment. *New Zealand Universities Law Review* 26: 24–59.

Firlik, Andrew D. 1991. A piece of my mind: Margo's logo. *JAMA* 265: 201.

Gastmans, Chris, and Jan De Lepeleire. 2010. Living to the bitter end? A personalist approach to euthanasia in persons with severe dementia. *Bioethics* 24: 78–86.

Gather, Jakov, and Jochen Vollmann. 2013. Physician-assisted suicide of patients with dementia: A medical ethical analysis with a special focus on patient autonomy. *International Journal of Law and Psychiatry* 36: 444–452.

Jacklin, Kristen M., Jennifer D. Walker, and Marjory Shawande. 2013. The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health*: e39-e44.

Karlawish, Jason H., David J. Casarett, Bryan D. James, Sharon X. Xie, and Scott Y.H. Kim. 2005. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. *Neurology* 64: 1514–1519.

Kim, Scott Y., Jason H. Karlawish, and Eric D. Caine. 2002. Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry* 10: 151–165.

KNMG (Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst) 2011. Position paper: The role of the physician in the voluntary termination of life. http://knmg.artsennet.nl/Publicaties/KNMGpublicatie/Position-paper-The-roleof-the-physician-in-the-voluntary-termination-of-life-2011.htm. Accessed 29 April 2015.

Kouwenhoven 2013. Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach. In Palliative Medicine, ed. Pauline SC, Kouwenhoven et al, 27(3): 273–280 at 279.

Legemaate, Johan, and Ineke Bolt. 2013. The Dutch Euthanasia Act: Recent legal developments. *European Journal of Health Law* 20: 451–469.

Lichtner, Valentina, Dawn Dowding, Philip Esterhuizen, S. Closs, Andrew F. Long, Anne Corbett, and Michelle Briggs. 2014. Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. *BMC Geriatrics* 138.

Luce, John M., and Ann Alpers. 2000. Legal aspects of withholding and withdrawing life support from critically ill patients in the United States and providing palliative care to them. *American Journal of Respiratory and Critical Care Medicine* 162: 2029–2032.

Luxembourg 2010. Ministries of Health and Social Security, Euthanasia and Assisted Suicide: Law of 16 March 2009: 25 questions 25 answers. http://www.sante.public.lu/publications/sante-fil-vie/fin-vie/euthanasie-assistance-suicide-25-questionsreponses/euthanasie-assistance-suicide-25-questions-reponses-en.pdf

Menzel, Paul T., and Bonnie Steinbock. 2013. Advance directives, dementia, and physician-assisted death. *Journal of Law, Medicine, and Ethics* 41: 484–500.

Michlowski, Sabine. 2009. Legalising active voluntary euthanasia through the courts: Some lessons from Colombia. *Medical Law Review* 17: 183–218.

Nuffield Council on Bioethics. 2009. Dementia: Ethical issues. http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf. Accessed 29 April 2015.

Marcel G. M. Olde Rikkert, et al. 2011. Validity, reliability, and feasibility of clinical staging scales in dementia: A systematic review. *American Journal of Alzheimer's Disease & Other Dementias* 26(5):357–365.

Oregon Public Health Division. 2011. "Oregon's Death with Dignity Act Annual Reports". http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx. Accessed 29 April 2015.

Prince, Martin, Renata Bryce, Emiliano Albanese, Anders Wimo, Wagner Ribeiro, and Cleusa P. Ferri. 2013. The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's and Dementia* 9: 63–75.

Regional Euthanasia Review Committees. *Annual Reports*, online:http://www.euthanasiecommissie.nl/archiefjaarverslagen.asp.

Regional Euthanasia Review Committees. 2010. *Annual report 2009*. http://www.rtde.eu/node/19. Accessed 29 April 2015.

Rietjens, Judith A.C., Paul J. van der Maas, Bregje D. Onwuteaka-Philipsen, Johannes J.M. van Delden, and Agnes van der Heide. 2009. Two decades of research on euthanasia from the Netherlands. What have we learnt and what questions remain? *Journal of Bioethical Inquiry* 6: 271–283.

Ryynänen, Olli-Pekka, Markku Myllykangas, Markku Viren, and Harri Heino. 2002. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. *Public Health* 116: 322–331.

Schüklenk, Udo, Johannes J.M. van Delden, Jocelyn Downie, Sheila McLean, Ross Upshur, and Daniel Weinstock. 2011. *The Royal Society of Canada Expert Panel: End-of-life decision making*. Ottawa: Royal Society of Canada. https://rsc-src.ca/en/expert-panels/rsc-reports/end-life-decision-making. Accessed 29 April 2015.

Seale, Clive. 2009. End-of-life decisions in the UK involving medical practitioners. *Palliative Medicine* 23: 198–204.

Sessums, Laura L., Hanna Zembrzuska, and Jeffrey L. Jackson. 2011. Does this patient have medical decision-making capacity? *JAMA* 306: 420–427.

Sterckx, Sigrid, Kasper Raus, and Freddy Mortier (eds.). 2013. *Continuous sedation at the end of life: Ethical, clinical and legal perspectives*. Cambridge: Cambridge University Press.

Stevens, John. 2013. Man, 83, becomes first Briton to choose Dignitas assisted suicide because he had dementia. *Mail Online* (31 May 2013), http://www.dailymail.co.uk/news/article-2333133/Man-83-Briton-Dignitas-assisted-suicide-dementia.html.

Swiss Federal Statistical Office, "Cause of death statistics 2009: Assisted suicide and suicide in Switzerland", 2012, online: http://www.bfs.admin.ch/bfs/portal/en/index/themen/14/22/publ.html?publicationID=4732.

Tomlinson, Emile, and Joshua Stott. 2015. Assisted dying in dementia: A systematic review of the international literature data on the attitudes of health professionals, patients, carers and the public, and the factors associated with these. *International Journal of Geriatric Psychiatry* 30: 10–20.

Trachsel, Manuel, Helena Hermann, and Nikola Biller-Andorno. 2014. Cognitive fluctuations as a challenge for the assessment of decision-making capacity in patients with dementia. *American Journal of Alzheimer's Disease and Other Dementias* ePub June 18:1–4.

van Holsteyn, Joop, and Margo Trappenburg. 1998. Citizens' opinions on new forms of euthanasia: A report from the Netherlands. *Patient Education and Counseling* 35: 63–73.

White, Ben P., Lindy Willmott, and Michael Ashby. 2011. Palliative care, double effect and the law in Australia. *Internal Medicine Journal* 41: 485–492.

Williams, Nia, Charlotte Dunford, Alice Knowles, and James Warner. 2007. Public attitudes to life-sustaining treatments and euthanasia in dementia. *International Journal of Geriatric Psychiatry* 22: 1229–1234.

Willmott, Lindy, Ben White, and Jocelyn Downie. 2013. Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand. *Journal of Law and Medicine* 20: 907–924.

Court Cases and Rulings

Baxter v Montana, 2009 MT 449, 224 P (3d) 1211 (Mont Sup Ct 2009).

Bentley v Maplewood Seniors Care Society, 2014 BCSC 165.

Carter v Canada (Attorney General), 2012 BCSC 886.

Morris v New Mexico, No. D-202-CV 2012-02909 (N Mex Dist Ct 2014).

Laws and Legislation

Belgium, Loi Relative à l'Euthanasie, BS 2002, http://eol.law.dal.ca/wp-content/uploads/2015/06/Belgian-Euthanasia-Act.pdf, translated in Dale Kidd, "The Belgian Act on Euthanasia of May, 28th 2002" (2002) Ethical Perspect 9(2–3): 182–188, http://eol.law.dal.ca/wp-content/uploads/2015/06/Euthanasia-Act.pdf.

Bill 52 (Quebec), *An Act respecting end-of-life care*, SQ 2014, c2.

Bill C-581 (Canada), "*An Act to amend the Criminal Code (Physician-assisted Death)*" First Reading, March 27, 2014, Second Session, Forty-first Parliament.

Criminal Code, RSC 1985, c C-46.

Luxembourg, *Euthanasia and Assisted Suicide*: *Law of 16 March* 2009, (Luxembourg 2010). http://www.sante.public.lu/publications/sante-fil-vie/fin-vie/euthanasie-assistance-suicide-25-questions-reponses/euthanasie-assistance-suicide-25-questions-reponses-en.pdf.

Netherlands, Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002). http://www.euthanasiecommissie.nl/Images/Wet%20toetsing%20levensbeeindiging%20op%20verzoek%20en%20hulp%20bij%20zelfdoding%20Engels_tcm52-36287.pdf.

Oregon, *Death with Dignity Act*, Or Rev Stat, §§ 127.800–127.995 (1997) http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/statute.pdf.

Switzerland, *Swiss Criminal Code*, SR 1937 (amended 2015), 311.0, http://eol.law.dal.ca/wp-content/uploads/2015/06/Penal-Code.pdf.

Vermont, *An Act Relating to Patient Choice and Control at End of Life* 18 Vt Stat Ann § 77 (2013). http://legislature.vermont.gov/assets/Documents/2014/Docs/ACTS/ACT039/ACT039%20As%20Enacted.pdf.

Washington State, *Death with Dignity Act*, Wash Rev Code tit 70 § 70.245 (2009) http://app.leg.wa.gov/rcw/default.aspx?cite=70.245.

Chapter 8
Clinical Ethics Consultation and Physician Assisted Suicide

David M. Adams

Abstract In this paper I attempt to address what appears to be a novel theoretical and practical problem concerning physician-assisted suicide (PAS). This problem arises out of a newly created set of circumstances in which persons are hospitalized in jurisdictions where PAS, though now legally available to patients, remains morally contentious. When moral disagreements over PAS come to divide physicians, patients, and family members, it is quite likely they will today find their way to the hospital's consulting *ethicist*, a member of an emerging group of professionals charged with the responsibility (so we are told) of resolving moral conflict in the clinic. What can or should an ethics consultant do to fulfill this mandate in such circumstances? I argue that the now predominant conception of clinical ethics consultation is importantly deficient in that it provides no final guidance to ethicists on how they should respond in such cases. The ethicist may only recommend—or assist others to reach—solutions to moral disagreements falling within the limits of established norms. Since the normative landscape of PAS appears to be changing, whether it falls within these limits is unsettled. I conclude that the accepted goals of ethics consultation require a revised and expanded conception of the ethicist's role in cases involving PAS. I close by outlining what that revised understanding would look like and the further questions it raises.

8.1 Introduction

In this paper I attempt to address what appears to be a novel theoretical and practical problem concerning physician-assisted suicide (PAS). That problem arises out of a newly created set of circumstances in which persons are hospitalized in

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jurisdictions where PAS, though now legally available to patients, remains morally contentious. When moral disagreements over PAS come to divide physicians, patients, and family members, it is quite likely they will today find their way to the hospital's consulting *ethicist*, a member of an emerging group of professionals charged with the responsibility (so we are told) of resolving moral conflict in the clinic. What can or should an ethics consultant do to fulfill this mandate in such circumstances? The burden of my argument will be that the now predominant conception of the ethicist's role is incapable of satisfactorily answering this question and that therefore a fresh understanding of the ethicist's competence and commission needs to be developed.

I turn first to the nature of the problem, illustrated by the following case.

8.2 The Problem

Mr. Smith is a 79-year-old man suffering from end-stage COPD. He has dealt with recurrent pneumonia and has been hospitalized several times in the past eight years with respiratory failure. During his most recent hospitalization Mr. Smith required endotracheal intubation and ventilatory support, though he was subsequently successfully weaned off the respirator. The patient completed an advance healthcare directive after discharge; the directive requests no attempt at resuscitation in the event of cardiac arrest. Mr. Smith has become increasingly frail in the last three months, though cognitively he is still intact. Five days ago his wife found him down on the floor of their home with labored breathing. Brought to the hospital by ambulance, he was intubated emergently upon arrival, diagnosed with a fresh case of pneumonia, and placed on a regimen of IV antibiotics. The pulmonologist and critical care specialist caring for Mr. Smith believe he can again be weaned and returned home, though they admit his prognosis is extremely poor. He is entering the terminal phase of his illness, they believe, and will almost certainly be dead in less than six months.

Mr. Smith has been in the ICU since his admission; he is tired but awake and alert. He communicates in writing with his wife, adult daughter, and treating physicians. Two days ago the hospital's clinical ethics consultation service was contacted with a request to meet with the patient, family and treatment team. Mr. Smith has conveyed in writing to all concerned that he detests being hospitalized and wishes to go home to die. He insists he "has had it living with COPD" and can't bear the thought of enduring even one more intubation. Weak yet restless, Smith hates his growing dependence upon machines—and other people—for the maintenance of his failing body.

Mr. Smith lives in a state that permits PAS by law and he has indicated his desire to leave the hospital—against medical advice, if necessary—to seek PAS. He has researched the law and concluded he satisfies the requisites it specifies (for example, that the patient have a terminal illness). Though the patient's daughter and his long-time primary care physician are reluctantly supportive of his resolve to end his life in this way, his wife and other treating physicians are strongly opposed, believing it would be wrong both for the patient to cause his death and for them to support such an outcome. Mr. Smith responds angrily: "Don't you have any compassion? It's pointless to go on." His wife doubts this entreaty expresses Smith's real reasons for requesting assisted death, however, suspecting he actually wants to rid his family of a burden that will only grow more onerous with time. Smith's doctors refuse to credit either of the forgoing reasons for pursuing death, believing the promotion of health, not the appeasement of existential distress or alleviation of hardship, to be the true and only good of medicine. The pursuit of that good is incompatible with intending death, even a death that is undeniably foreseeable. Better management of his symptoms is the answer, they say, urging him to re-consider.

Mr. Smith's wife and daughter page the hospital's consulting ethicist, posing a stark question: Is it ethical for her father to obtain PAS? "None of us can agree on whether it is right for him to do this," the daughter confides. "We need your help. Can you tell us if PAS is ethical in a case like this?"

Two recent developments in the practice of healthcare are converging in a way that makes cases of the foregoing sort inevitable. The emergence of clinical ethics consultation, evolving out of previously established hospital ethics committees, coincides with renewed debate over—and incremental legal expansion of—physician-assisted death. In addition to their contemporaneity, the practice of ethics consultation and continuing disputes over PAS share in the considerable uncertainty each occasions. The forms such uncertainty takes, upon which I shall elaborate in this paper, come together in cases like that of Mr. Smith, and in ways making a straightforward answer to the daughter's questions extraordinarily difficult to obtain. Yet some kind of response from the ethicist is surely called for and expected, both by the members of Mr. Smith's family and also by the involved physicians, the patient himself, and (presumably) the hospital for which the ethicist works. What is the ethicist to say?

It is important to be clear at the outset what the involved parties here are (and are not) asking. They are not asking about the *legality* of PAS: all parties to the Smith case understand that assisted suicide is lawful in their state. Moreover, and as they realize, if the law were all that mattered the disputing parties could clear up their disagreement by consulting an attorney. There would be no need of an ethicist. But they quite sensibly realize the legality of a practice does not settle its moral status. Nor are the parties in the Smith case asking for the ethicist to *make a decision for* Mr. Smith on whether he should seek PAS. All concede that the patient (so long as decisional capacity is retained) has the final say in this. The issue is not who has the right to decide on the clinical course of action to be taken. The issue is *what decisions may rightfully be made*. The question is about the moral status of the choices open to Mr. Smith, and about the choice for PAS in particular. Finally, Mr. Smith's family members are not inquiring about *general public attitudes* toward assisted suicide. The patient and his family members can reasonably be assumed to appreciate that opinions on this issue are divided. They want to know what is, in fact, the moral status of PAS. Is it allowable in this case or not?

What then should an ethics consultant say to the family of Mr. Smith? This is the question I shall tackle. My answer will unfold in two stages. At the first stage, I argue that the now predominant conception of clinical ethics consultation—what it should aim to achieve and how it should do so—is importantly deficient, in that it provides no final guidance to ethicists on what they should say to Mr. Smith's family. To support this claim, I begin in Sect. 8.3 by summarizing briefly the conception of clinical ethics consultation widely accepted and practiced in America and (increasingly) in some other parts of the world. Since as we shall see this predominant theory makes the ethicist's advice a function of how law, professional standards, scholarly literature, and prevailing practice currently view assisted suicide, I set out in Sect. 8.4 a detailed summary of the current state of affairs regarding PAS. I then seek to show (in the remaining sections of the paper) that this predominant conception of ethics consultation necessarily fails to satisfy its own stated goals in cases turning on contentious and unsettled areas of bioethical concern such as PAS. I conclude that the accepted goals of ethics consultation require a revised and expanded conception of the ethicist's role in cases involving PAS. I close by outlining what that revised understanding would look like and the further questions it raises.

8.3 Ethics Consultation

Many hospitals in the U.S. now have some form of ethics consultation service, developed to address ethical concerns regarding patient care (Fox et al. 2007).[1] Put most generally, clinical ethics consultants deal with moral conflicts arising in the care of the sick. The kinds of moral conflict addressed by clinical ethicists typically involve difficult decisions. Would it be best to attempt resuscitation of a critically ill patient with a terminal disease? What should be done for an individual with fast-spreading cancer that cannot be stopped? Should a feeding tube be withheld in a patient with end-stage disease who can no longer swallow? Naturally, it is of preeminent importance to know how hospital ethicists ought to respond when approached about these and related moral concerns.

The most influential conception of the goals and aims of ethics consultation, emerging in the last fifteen years, is set forth in a series of documents developed and disseminated by the American Society for Bioethics and Humanities (ASBH), most particularly the *Core Competencies for Health Care Ethics Consultations*

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[1] While European countries for some time lagged behind the U.S. in this regard, things appear to be changing, particularly in the nations of Eastern Europe. See the contributions from many European clinical ethicists in Schildmann et al. (2010). See also McLean (2009), Reiter-Theil (2001), and Nagao et al. (2008).

(ASBH 1998).[2] The first edition of the *Core Competencies* report endorsed a methodology for ethics consultation it called *ethics facilitation*, the overarching aim of which is to resolve moral disagreement by "facilitating the building of consensus among the involved parties" within "a range of morally acceptable options" (ASBH 1998, 8). This theory of ethics consultation was an outgrowth of work published by clinical ethicists going back to the 1980s.[3] The theories and ideas expressed in this early work have now coalesced into a widely-accepted view.[4] On this understanding, ethics consultation is indicated in situations of moral "uncertainty or conflict" (ASBH 2011, 4) where the goal is to "identify, analyze, and resolve ethical problems" (Dubler et al. 2009, 25) by assisting disputing parties to find consensus within a range of "morally acceptable options" (ASBH 1998, 6).[5] Ethics consultants are to assist in "the building of morally acceptable shared commitments" bounded by "societal values, law, and institutional policy" (ASBH 1998, 7); no acceptable consensus resolution of a conflict in the clinic may "fall outside the boundaries of widely accepted ethical and legal norms" (ASBH 2011, 7). Imagine, for example, that Mr. Smith specifically refuses in writing any further mechanical ventilation, yet his family and physicians entirely ignore this instruction and orally intubate him. Such a course of action would be an obvious "violation of the patient's right of medical self-determination" (ASBH 1998, 6). Clearly acknowledged rights and widely accepted standards and principles set "boundaries that must be respected in ethics consultation" (ASBH 1998, 4).

The ASBH Clinical Ethics Credentialing Project recently summarized, by way of re-affirming, the basic features of this predominant understanding of ethics consultation:

> The task of the [clinical ethics consultant] is to identify, clarify, and analyze the ethical issues in the case and the interests and rights of patients, family members, providers, and administrators, and—where they clash—to facilitate or mediate a 'principled resolution': a plan that falls clearly within accepted ethical principles, legal stipulations, and moral

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[2] Summaries of the report also appeared in Aulisio and Arnold (2000), Aulisio et al. (2003). This document was subsequently revised. See ASBH (2011).

[3] See, e.g., Ackerman (1987), Thomasma (1987), Glover et al. (1986), and Veatch (1987).

[4] There is "general consensus in the field," according to the revised *Core Competencies* Report, "that 'ethics facilitation' is the best model for HCEC [health care ethics consultation]" (American Society for Bioethics and Humanities 2011, 6). The model of ethics consultation defended in the *Core Competencies* has been adopted by any number of hospitals, including the Veterans Health Administration (VHA). See Veterans Health Administration *Integrated Ethics*. It is also arguably embraced by the American Medical Association, which advises that "where there is a dispute, the [ethics] consultant's role is one of negotiation and resolution." See American Medical Association (2012, 2).

[5] See also Aulisio and Arnold (2008, 422): The role of the ethics consultant "is to help the clinicians, patients, and families arrive at a decision that optimally respects and promotes the values of the appropriate decision-makers—most often the values of the once competent but now incompetent patient—within the bounds of medically acceptable options." The ethicist facilitates the building of a "principled ethical resolution" of a moral problem by "helping involved parties identify a range of ethically acceptable options, and providing an ethical justification for each option" (Tarzian and ASBH Core Competencies Update Task Force 2013, 5).

> rules defined by ethical discourse, legislatures, and courts and that facilitates a clear plan for future interventions (Dubler et al. 2009, 28).[6]

For convenience, I will refer to this as the *received view* of ethics consultation.

As I have elsewhere argued, the distinctive feature of ethics consultation on the received view is the notion that whatever consensus plan is finally adopted is necessarily *constrained*: the collective reflection and deliberation that constitute the ethics consultation process are to be guided along particular dimensions and conducted in a way that rules out appeal to certain kinds of considerations and reasons (Adams 2009). And it is the ethics consultant's responsibility to ensure that the consensus is in this way ethically justified, guiding deliberations among a circumscribed set of allowable medical choices. I use the expression 'allowable' (and its converse, 'disallowable') throughout—as opposed to 'permissible' and 'impermissible'—as the latter terms, suggesting *moral* permissibility, appear too restrictive: for on the received view morality is not the only source of normativity from which the constraints upon consensus formation are to be drawn. Rather, ethicists must "ensure that identified options comport with relevant bioethics, medical, and scholarly literature, and with laws, pertinent institutional policies, and current [ethics consultation] practice standards" (Tarzian and ASBH Core Competencies Update Task Force 2013, 5). In deciding whether a given clinical course of action is allowable, the ethics consultant is ascertaining what I will call the *normative status* of a general practice or of a particular decision.

On the received view then the ethicist is to seek resolution of bioethical disputes among parties who presumably hold widely divergent moral and non-moral beliefs (for example, concerning the worth of human life, the meaning of suffering, the finality of death) by specifying as initial conditions normative boundaries demanding the disputants select from among a limited range of allowable resolutions. The boundaries of the allowable are drawn by standards deriving from several sources of normativity: statutes and regulations, widespread institutional policies, prevailing standards of professional practice, and positions adopted in the bioethics literature. Clearly, this theory of ethics consultation will work only if it is possible in each case reliably to identify the allowable choices; and answering the question posed by Mr. Smith's daughter requires that we discern what these designated sources of normativity say about the allowability of assisted suicide. As we shall see, this is not as straightforward a matter as the theory assumes.

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[6] This model is the centerpiece of a nascent movement to standardize the training of clinical ethicists by, for example, specifying minimum qualifications for consultants and establishing uniform curricula for credentialing programs. See Dubler et al. 2009; Tarzian 2015. For further support of the facilitated consensus model see Aulisio et al. (1999), Aulisio and Arnold (2000, 2008), DeRenzo (1994), and (Dubler 2011).

8.4 The 'Allowability' of PAS

My contentions in this section will be two. First, I will try to show that despite careful examination of the available evidence, the normative status of PAS remains indeterminate with respect to the sources of normativity the clinical ethicist is supposed to consider. Second, I will claim that the (unstated) assumption of the received view—that determinate answers to questions about the normative status of various clinical choices will be forthcoming—is false in just those cases, like PAS, where ethical guidance on deeply controversial matters is most needed. I begin by looking at what each of the normative sources singled out by the received view says about PAS.

8.4.1 Law

The first source of norms meant to constrain deliberations about the allowability of a given clinical course of action is law. The most salient legal fact in the case of Mr. Smith is of course that he resides in a state that allows PAS and has legislation in place detailing the procedures for obtaining access to it. It is also important, though, to situate Mr. Smith's legal rights within a larger jurisprudential context.

The legal landscape of PAS, both in the U.S. and elsewhere, is changing. While as recently as the mid-1990s, no American jurisdictions allowed PAS by law, five (as of the time of this writing) now do so.[7] Three of these states (Oregon, Washington, and Vermont) have legal protocols in place specifying criteria and procedures for obtaining access to PAS, approved either by ballot initiative (Oregon and Washington) or legislative enactment (Vermont). Courts in both Montana and New Mexico have ruled that PAS is not illegal in those states, but currently no set of enabling procedures is in place. Since the early 1990s (and in addition to the three states noted above), ballot initiatives undertaking to legalize PAS have been voted on in California, Maine, Massachusetts, and Michigan. Though all were defeated, the margins in the first three states were close.[8] Support among state legislators for the legalization of PAS, while not yet sufficiently widespread to win large-scale passage of proposed bills, appears nonetheless to be growing. According to the Death with Dignity National Center, bills proposing legislation similar to that currently in place in Oregon, Washington, and Vermont

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[7] See data from Pro/Con.org. Retrieved July 3, 2014 from (http://euthanasia.procon.org/view.resource.php?resourceID=000132) and (http://www.procon.org/headline.php?headlineID=005198). For the text of the recent court ruling in New Mexico, see http://agoodgoodbye.com/wp-content/uploads/2014/01/199446010-Physician-aid-in-dying-Ruling.pdf.

[8] See information at Patients Rights Council. Retrieved July 3, 2014 from http://www.patientsrightscouncil.org/site/failed-attempts-usa/.

have since 2013 been introduced in Connecticut, Hawaii, Kansas, New Hampshire, New Jersey, and Pennsylvania.[9]

It is reasonable to suppose that the forgoing numbers reflect changing attitudes apparent in public opinion surveys. Three polling organizations recently surveyed Americans on the subject of PAS and reported similar results. A survey published in late 2013 by the Pew Research Center found that 62 % of Americans now say a person suffering great pain with no real hope of improvement should have a right to commit suicide; a majority (56 %) say the same of those with an incurable illness.[10] According to the same survey, nearly half of Americans polled (47 %) approve of laws permitting physicians to prescribe a lethal dose of drugs to a terminally ill patient. A BBC/Harris Poll indicated 70 % of Americans believe terminally ill patients in great pain and with no chance of recovery should have the right to choose to end their lives.[11] A 2013 Gallup poll found that 70 % of Americans responded favorably when asked if doctors should be allowed to "end the patient's life by some painless means"; 51 % approved of doctors acting to "assist the patient to commit suicide."[12] Majorities supporting PAS (though by smaller percentages) were reported by two other polls.[13] A recently published study of shifts in American attitudes regarding PAS over a number of decades concluded that "Americans who reported that physician-assisted suicide should be legal rose from 37 % in 1947 to 61 % in 1999" and "during these years, those who agreed that physician-assisted suicide should be allowed were invariably in the majority" (Allen et al. 2006).

Increasing legislative and popular support for PAS is evident as well in other countries. A bill to allow "voluntary assisted dying" was introduced in Tasmania in

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[9] Retrieved July 3, 2014 from http://www.deathwithdignity.org/advocates/national. See also, "'Aid-In-Dying' Movement Takes Hold in Some States," *New York Times*, Feb. 7, 2014. Retrieved July 10, 2014 from http://www.nytimes.com/2014/02/08/us/easing-terminal-patients-path-to-death-legally.html?_r=0. The text of the Connecticut bill is representative. See State of Connecticut General Assembly Bill 1138, January, 2009 Session. Retrieved July 3, 2014 from http://www.cga.ct.gov/2009/TOB/S/2009SB-01138-R00-SB.htm.

[10] See "Views on End-Of-Life Medical Treatments," Pew Research Religion and Public Life Project, November 21, 2013. Retrieved July 3, 2014 from http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/.

[11] "Large Majorities Support Doctor Assisted Suicide for Terminally Ill Patients in Great Pain," January 25, 2011. Retrieved July 3, 2014 from http://www.harrisinteractive.com/NewsRoom/HarrisPolls/tabid/447/mid/1508/articleId/677/ctl/ReadCustomDefault/Default.aspx.

[12] "U.S. Support for Euthanasia Hinges on How It's Described." Retrieved July 24, 2014 from http://www.gallup.com/poll/162815/support-euthanasia-hinges-described.aspx.

[13] A HuffingtonPost/YouGov poll from 2013 reported that 50 % of Americans say it should be legal for a doctor to assist the terminally ill in suicide. "Assisted Suicide Legalization Supported by Half of Americans," June 23, 2013. Retrieved July 10, 2014 from http://www.huffingtonpost.com/2013/05/22/assisted-suicide-legalization_n_3314849.html. An NPR-Truven Health Analytics survey pegged the number of Americans in favor of assisted suicide at 55 %. "Americans Support Physician-Assisted Suicide for Terminally Ill," December 28, 2012. Retrieved July 10, 2014 from http://www.npr.org/blogs/health/2012/12/27/168150886/americans-support-physician-assisted-suicide-for-terminally-ill.

2013; a bill modeled after the Oregon Death With Dignity Act was proposed in Scotland in the same year.[14] A French ethics advisory body in late 2013 recommended legalization of "medical assisted suicide,"[15] and a poll from 2011 showed that a majority of Canadians support the legalization of PAS[16]; at least some reports show similar numbers among Europeans in twelve nations.[17] Luxembourg legalized PAS in 2009 (joining Belgium, the Netherlands, and Switzerland). In early 2015 the Supreme Court of Canada invalidated laws in the country banning assisted suicide.[18]

These changes in law and attitudes suggest if nothing else that Mr. Smith, his family members and physicians should not regard the lawfulness of PAS in their state as anomalous, despite representing at least for now a minority legal view.

8.4.2 Institutional Policy

The received view directs the ethicist's attention to institutional or organizational policy as a further source of guidance concerning the range of allowable medical options within which parties to an ethical disagreement must choose. Not surprisingly, shifting legal conditions in respect of PAS are bringing with them changes in institutional arrangements. Naturally, most hospitals and healthcare facilities are located in jurisdictions that do not (as yet, at any rate) recognize PAS; these institutions may thus be presumed to lack policies supporting the practice. Organizational policy on end-of-life care is of course common, and it is not unusual to find facilities with protocols concerning withdrawal of treatment or use of palliative care that incorporate boilerplate language of the following sort: "nothing in this Policy and Procedure shall be construed to condone, authorize, or approve mercy killing, assisted suicide, or euthanasia."[19] Nonetheless, hospitals in states sanctioning PAS are beginning to formulate protocols and plans in anticipation of

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[14] For the text of the bill, see http://www.scottish.parliament.uk/parliamentarybusiness/Bills/69604.aspx.

[15] See "French Panel Recommends Legalizing Assisted Suicide for Terminally Ill," Deutsche Welle, December 16, 2013. Retrieved July 1, 2014 from http://www.dw.de/french-panel-recommends-legalizing-assisted-suicide-for-terminally-ill/a-17300805.

[16] See "67 % of Canadians Support Legalizing Assisted Suicide: Poll," National Post, December 29, 2011. Retrieved July 1, 2014 from http://news.nationalpost.com/2011/12/29/67-of-canadians-support-legalizing-assisted-suicide-poll/.

[17] See "Large Europe Majorities for Assisted Suicide," Reuters, Nov. 30, 2012. Retrieved July 1, 2014 fromhttp://www.reuters.com/article/2012/11/30/us-euthanasia-europe-survey-idUSBRE8AT0EG20121130.

[18] See Pope (2009). See also Lewy (2011). See "Canada Court Strikes Down Ban on Aiding Patient Suicide," *New York Times,* Feb. 6, 2015. Retrieved July 23, 2015 from http://www.nytimes.com/2015/02/07/world/americas/supreme-court-of-canada-overturns-bans-on-doctor-assisted-suicide.html?_r=0.

[19] Taken from policy statement on "End of Life Care," San Antonio Regional Hospital, Upland, CA. Copies available from author.

patient requests for assistance in dying. Laws in the three states with a regulatory framework for assisted suicide contain similar provisions regarding the participation of healthcare providers. None impose a duty upon a doctor, nurse, or hospital to provide access to PAS, though each insists that a facility electing not to provide assisted suicide must promulgate policies making this stance clear.[20] What data is available from Oregon and Washington—states with the longest record of implementation with respect to PAS—show that some hospitals and medical centers are supporting access to PAS, while others (notably, Catholic facilities) are not.[21] The Washington State Hospital Association responded to the change in that state's law by formulating model policies both for facilities electing to participate and those opting not to do so.[22] In a much discussed piece in the *New England Journal of Medicine* a group of physicians at the Seattle Cancer Care Alliance—a consortium of the Fred Hutchinson Cancer Research Center, the University of Washington School of Medicine, and Seattle Children's Hospital—described the implementation of their policy for PAS (Loggers et al. 2013). This protocol was apparently modeled on guidelines developed by Oregon Health & Science University Hospitals & Clinics in Portland.[23] A study of hospice programs in Oregon found that while most refuse to participate "directly" or "actively" in PAS—by, for example, procuring or administering medications to end life—a majority do provide information about the Death With Dignity law, refer patients for further assistance, and furnish bereavement support (Campbell and Cox 2010). Lastly, it is

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[20] Relevant provisions of the Washington Death with Dignity Act are illustrative. See Revised Code of Washington, Sec. 70.245.190: "Only willing health care providers shall participate in the provision to a qualified patient of medication to end his or her life in a humane and dignified manner… A health care provider may prohibit another health care provider from participating under [the law] on the premises of the prohibiting provider if the prohibiting provider has given notice to all health care providers with privileges to practice on the premises and to the general public of the prohibiting provider's policy regarding participating…" Retrieved July 3, 2014 from http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245. See also Oregon Death with Dignity Act, Oregon Revised Statutes, Sec. 127.885 §4.01, (4) and (5a); and Vermont Statutes Annotated, Title 18 chapter 113, sec. 1.

[21] See "Healthcare Facilities Scrambling to Deal with Dignity Act," *Seattle Times,* Feb. 2, 2009. Retrieved July 3, 2014 from http://seattletimes.com/html/health/2008696811_death02m.html. See also "Island Hospital Readies Plan for Death with Dignity Act," *Skagit Valley Herald*, Feb. 26, 2009. Retrieved July 3, 2014 from http://www.goskagit.com/news/island-hospital-readies-plans-for-death-with-dignity-act/article_70db5389-2bd9-52d0-91ca-e6420b12bfb6.html?mode=jqm; "Death with Dignity at WGH," *Whidbey News Times*, March 3, 2009. Retrieved July 3, 2014 from http://www.whidbeynewstimes.com/news/40682408.html; "Grace Cottage Opts Out of Assisted Suicide Law—For Now," *Battleboro Reformer*, June 22, 2013. Retrieved July 3, 2014 from http://www.reformer.com/localnews/ci_23515442/grace-cottage-opts-out-assisted-suicide-law-now. "Cancer Center Goes Public with Assisted Suicide Protocol," *Amednews.com,* April 22, 2013. Retrieved July 3, 2014 from http://www.amednews.com/article/20130422/profession/130429973/2/.

[22] See "Death With Dignity Act," Washington State Hospital Association. Retrieved July 3, 2014 from http://www.wsha.org/0302.cfm.

[23] "Cancer Center Goes Public with Assisted Suicide Protocol," *Amednews.com*, April 22, 2013. Retrieved July 3, 2014 from http://www.amednews.com/article/20130422/profession/130429973/2/.

worth noting that research in countries where PAS is legally tolerated shows a broad and growing number of institutions formulating guidelines and policies on assisted suicide. One Dutch study revealed that 70 % of all healthcare facilities in the Netherlands had a written policy statement on assisted suicide, with the percentage of hospitals having such guidelines rising to 80 % (Passman et al. 2009).

Mr. Smith resides in one of the states where PAS is regulated by statute. Thus, while almost certainly some hospitals or clinics in his state do not allow PAS to be conducted under their auspices, it is likely that with some effort Mr. Smith would be able to locate a facility whose policies permit its physicians and nurses to assist him in obtaining the death he seeks.

8.4.3 Professional Standards of Practice

Professional standards of practice constitute a further source of guidance concerning the range of allowable options, according to the received model of ethics consultation. Such norms are evident from an inspection of generally promulgated practice guidelines and organizational codes of ethics, and are largely reflected in widespread clinical practice.

The clear majority of American medical organizations and societies of healthcare professionals are on record as being opposed to the practice of PAS, though this stance is by no means unanimous; and some such bodies have explicitly refused to take a position on the allowability of PAS. The most prominent organizations, such as the American Medical Association, the College of Physicians, and the American Nurses Association have voiced long-standing opposition to assisted suicide.[24] Other associations including the American Society of Pain Management Nursing, the American Medical Directors Association, and the American College of Medical Quality join them.[25] At odds with these views is the position of the American Public Health Association, which "supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death…" (APHA 2008). More nuanced is the view of the Hospice and Palliative Nurses Association. While maintaining that it "opposes the legalization of assisted suicide," the organization recognizes that "nurses have important roles in supporting patients requesting [PAS]" and, when working in states where PAS is legal, must "guard against communicating a negative judgment" on patients who elect to pursue it (HPNA 2011).

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[24] See American Medical Association (2012), Opinion 2.211. Available at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page?. See also American College of Physicians (2012), "Care of Patients Near the End of Life: Physician-Assisted Suicide and Euthanasia"; American Nurses Association (2013).

[25] See American Society for Pain Management Nursing (2003), American Medical Director's Association (1997), American College of Medical Quality (2000).

Perhaps most notable is the growing number of societies adopting what amounts to a neutral stance on the moral status of PAS. Emblematic of this stand is the position staked out by the American Academy of Hospice and Palliative Medicine (AAHPM). Speaking of "physician assisted death" (PAD) the AAHPM "takes a position of 'studied neutrality' on the subject of whether PAD should be legally regulated or prohibited," and cautions its physician members to "carefully scrutinize" requests for assisted suicide and proceed with "great caution before instituting PAD…" (AAHPM 2007). The American Academy of Physician Assistants argues that though "liberalization of assisted suicide could have unintended consequences, so too could absolute restriction on assisted suicide" (AAPA 1997). While the AAPA does not advocate PAS, it offers "decriminalization with well-defined guidelines" as one solution and insists that "the ethical, compassionate, well-intentioned provider who discusses voluntary self-termination" with a capable patient must not be subject to legal liability (AAPA 1997). The American Pharmacists Association "supports informed decision-making based upon the professional judgment of pharmacists, rather than endorsing a particular moral stance on the issue of physician-assisted suicide," but "opposes laws and regulations which mandate or prohibit the participation of pharmacists in physician-assisted suicide" (APA 2004). The American Society of Health-System Pharmacists affirms the "right of a pharmacist to participate or not in morally, religiously, or ethically troubling therapies," while insisting pharmacists must apprise patients of "all legally available treatment options" (ASHSP 1999). Concerning PAS, the National League for Nursing adheres to the "belief that a single position on the part of this organization would not be helpful at this time" (NLN 1999). Among hospice nurses and social workers surveyed in Oregon, 95 % indicated that their hospice agency should either support a patient's choice for PAS, or at least remain neutral (see Miller et al. 2004). Some prominent ethicists, such as Timothy Quill, encourage the adoption of such a neutral position (Quill and Cassell 2003). State medical societies in jurisdictions sanctioning PAS by law appear as well to be opting for this neutral view, neither opposing nor supporting PAS. The Oregon Medical Association states that its members "may choose whether to participate" in PAS, and it has made available checklists and forms to be used by doctors helping their patients under the state's Death with Dignity legislation (OMA 2011). The Vermont Medical Society refers the public and its members to a policy adopted in 2003. According to the Society, that policy "does not support laws for or against physician assisted suicide."[26] The Washington State Medical Association has posted a "Physician's Guide" to that state's "Death with Dignity Law" containing information and links to documents, but with neither condemnation nor endorsement of assisted suicide (WSMA 2009). In May 2015, the California Medical Association dropped its opposition to PAS in the face of widespread support for

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[26] See Vermont Medical Society (2003). The text of the Society's policy states "there should be no laws concerning physician-assisted suicide."

proposed legislation that would legalize PAS in the state. The CMA is the largest state-wide medical association to adopt a position of neutrality.[27]

Though he is undertaking to obtain PAS in a state recognizing it by law, it is reasonable to suppose Mr. Smith will encounter resistance to his plan by practitioners whose attitudes have been shaped in part by professional opposition to assisted suicide, though he and his family may well find local organizations of healthcare providers unopposed to his intentions.

8.4.4 The Bioethics Literature

The received view insists that agreements facilitated with or recommendations given by a clinical ethicist must "comport with the bioethics literature" and "other relevant scholarly literature," in addition to statutes, judicial opinions, and pertinent institutional policies (ASBH 2011, 6). This presumably means looking for positions broadly supported in published bioethics research. It may appear surprising to assume any body of literature as voluminous as that in bioethics to speak as if with one voice on any subject, though it is in fact possible to identify some widely endorsed views. For example, bioethics scholars now overwhelmingly support the proposition (defended extensively by the 1983 President's Commission) that decisionally capable patients have a right to refuse unwanted medical treatment of whatever kind (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983). But predictably, matters are by no mean so clear respecting PAS. Since it looks for positions generally supported in the scholarly literature, the received view assigns some weight to the distribution of professional opinion on matters like assisted suicide. It is therefore relevant to make two observations about that literature in this connection. It is large. And it is deeply split, as a brief (but far from exhaustive) list of prominent bioethicists on opposing sides of the PAS question attests. Among those arguing in support of PAS are Angell (1982), Battin (2005), Brock (2004), Caplan (2012), Dworkin and Frey (1998), Dworkin et al. (1997) (along with Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson), Kamm (1998), Miller and Truog (2012), Quill (2008), Singer (2005) and Sumner (2011). The ranks of those opposing PAS include Arras (1998), Bok (1998), Callahan (2002), Cohn and Lynn (2002), Dorff (1998), Kass (2002), Marquis (1998), Meilaender (2005), and Pellegrino (2002). Unsurprisingly, this "bioethics literature" enunciates no overall position respecting PAS. Pursuant to it, assisted suicide is both inconsistent and fully compatible with the aims of medicine; both absolutely distinct from and decidedly no different than death following removal of life-sustaining interventions; both too dangerous to the vulnerable ever to permit

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[27] See "CMA changes stance on physician aid in dying, takes neutral position on end of life option act." Retrieved July 23, 2015 from http://www.cmanet.org/news/detail/?article=cma-changes-stance-on-physician-aid-in-dying.

and acceptably safe when properly regulated; both a dignified way to alleviate misery and a dehumanizing ploy to silence suffering by eliminating the sufferer; both a necessary means to address intolerable pain and an unnecessary overreaction to inadequate palliative treatment. A recent editorial in the *New England Journal of Medicine* is emblematic of the current state of the PAS literature, with the two contributors taking entirely opposing positions on whether assisted suicide should be permitted (Boudreau and Sumerville 2013; Biller-Andorno 2013).

We can therefore be confident that Mr. Smith, his family, and physicians could consult the scholarship and there find a wealth of arguments, objections, and counter-arguments respecting PAS, though without any prospect of discovering what the "bioethics literature," as a corporate body, says about the allowability of PAS.

8.5 The Unsettled Status of PAS

Let me recap my argument thus far. Confronted with a man determined to forgo further treatment for his disease and leave the care of his doctors to seek assisted suicide, his family and care providers are troubled and divided over the ethics of PAS. Having been contacted by the patient and his family, the clinical ethicist prepares to follow the prevailing conception of the ethicist's role, endeavoring to facilitate a dialogue with the disputing parties over the options open to them. The ethicist recognizes this discussion must be confined to courses of action allowed by the combined operation of several sources of normativity. The ethicist in our case thus undertakes an investigation, the fruits of which we can assume are summarized in the analysis of Sect. 8.4.

But what now is the ethicist to say to the question he or she was originally asked: Is PAS ethical in Mr. Smith's case? On the received view this question must be re-formulated: Does PAS fall within the range of allowable options open to Mr. Smith? The question plainly assumes a clear answer will be forthcoming. Just as obviously, however, this assumption is untenable. The only reasonable conclusion to draw from the foregoing investigation is that current laws, policies, professional standards, and relevant literature, when taken together, say nothing definitive about the normative status of PAS. There simply is no settled answer reflecting the aggregate input of the sources of normativity upon which the allowability of a course of action is supposed to depend. As we saw, some jurisdictions (including Smith's) unequivocally permit PAS by law; and while laws in the great majority of jurisdictions forbid it, the number that do is slowly decreasing, perhaps a reflection of the fact that majority public opinion appears now supportive of PAS. Proposals to permit assisted suicide are regularly being introduced in legislatures both in the U.S. and elsewhere. Institutional policies generally track the law, but as observed above there is evidence of such policies being modified to accommodate PAS in jurisdictions where it is legal. Many professional bodies still prohibit healthcare providers from participating in PAS, though some organizations have adopted positions of "studied neutrality," while others encourage their members to act as their conscience dictates. The bioethics literature is quite simply all over the place, reflecting deep divisions of opinion among scholars about the permissibility of PAS and the wisdom of its legalization.

It may be tempting to suppose that this state of irresolution—the lack of a settled normative status—is a singular result, a consequence of the uniquely divisive nature of the debate over assisted death. But to suppose this would be a mistake. Feeding tubes for infants with "incompatible with life" anomalies; use of palliative sedation; organ donation "after circulatory determination of death"; hemodialysis for octogenarians suffering from end-stage conditions; deactivation of implanted pacemakers—there are many disputed practices and procedures in clinical biomedicine. As William Winslade and I have argued, PAS is far from the only controversial matter currently dividing bioethicists, members of the medical profession, and the wider public in a way that leaves its normative status unsettled. (Adams and Winslade 2011). Naturally, some of these contentious issues may become normatively settled over time; and it is equally possible that some now settled areas of moral, professional, and legal agreement may become destabilized and eventually break down. (We may be witness to the beginnings of such destabilization with recent challenges to the notion of "death by neurological criteria" or brain death.)[28]

There are at least two general reasons for thinking that proper identification of what I am calling the normative status of difficult medical choices is not likely to be the straightforward matter it is presumed to be on the received view. First, and as we have seen, whether a clinical choice is allowable is supposed to be a function of several sources of normativity acting together. Yet the received view says nothing about how this overall sum is supposed to be arrived at or how the results vouchsafed by these sources are to be combined when they pull in different directions. Nor, second, does it assign comparative weights to the various sources of normativity to which it directs the ethicist's attention. When, for example, two or more sources of normativity give conflicting answers, which is to take priority? These seem to be serious deficiencies, and it is not immediately clear how proponents of the received view could easily rectify them.

8.6 The Role of the Clinical Ethicist

We arrive then at this question: How is the ethicist to respond when the normative status of a clinical course of action he or she has been called upon to clarify is unsettled? What ought to be expected of a hospital ethicist when questioned

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[28] See, e.g., "Jahi McMath Case Renews Moral Debate Over Brain Death Diagnoses," National Catholic Register, January 14, 2014. Retrieved August 21, 2014 from http://www.ncregister.com/daily-news/jahi-mcmath-case-renews-moral-debate-over-brain-death-diagnoses/-ixzz-3B4Ma64GQ. See also Miller and Truog (2014).

about the normative status of a contentious practice such as PAS? I have argued that the conceptual resources of the received view neither isolate the normative status of PAS nor enable the ethicist in Smith's case correctly to discover it. (Indeed, if I am right there is nothing definitive to discover.) Yet at the same time we are told that clinical ethics consultants are ethics *experts* equipped with knowledge allowing them to offer "expert opinions, at least ones consistent with established ethical standards" (Tarzian and ASBH Core Competencies Update Task Force 2013, 5). Such avowals surely give rise to an expectation that ethicists will have something to say about puzzlement over the normative status of particular clinical decisions. But what could it mean for someone to give expert ethics input regarding a disputable moral matter such as PAS? We seem to have reached something of an impasse.

There are at least two ways to address this impasse. I will reject the first and endorse the second. To begin with, we could imagine an ethicist responding to questions about the allowability of PAS by first informing the patient and other involved parties that their disagreement cannot be resolved because the normative status of assisted suicide remains indeterminate. The ethicist then indicates that by so informing them she has discharged her responsibilities and can be of no further service. Now, in what sense hospital ethicists are experts is an issue far too large to take up here. But in whatever such expertise exactly consists, it is surely abandoned by an ethicist acting in the manner just described. We can see this by contrasting the ethicist's response with a similar one by a different kind of specialist. Suppose Mr. Smith has a brain tumor. A neurosurgeon is consulted and talks with the patient and his family. "My job," says the specialist, "is to present you with a range of potential treatments, including possible surgical options based upon my neurosurgical expertise and training. Having studied the situation carefully, however, I believe there is no clear answer to which surgical option is best. Therefore, I can be of no further help to you." Surely something is badly amiss here, and the patient had better find another surgeon. For plainly the expertise of the neurosurgeon must consist in at least this much: instead of signing-off the case, he should engage further with the patient, laying out the considerations for and against possible treatment modalities with the aim of arriving along with the patient at agreement upon a treatment that seems best supported in his or her particular case.

I want to suggest that something similar must be true where an ethics expert or specialist confronts uncertainty over the allowability of practices like assisted suicide. The basic idea would be that in situations where the range of allowable choices is not clear the ethicist should engage the disputing parties in a process of moral inquiry and deliberation with the aim of help them *determine for themselves what ought to be regarded as allowable*. The ethicist does this by inviting them to participate in a deeper moral inquiry—evaluating arguments, probing distinctions, questioning assumptions—thereby working toward the goal of articulating reasons and arguments that could function as a shared basis for agreement. In this way the ethicist can assist the parties to resolve their moral disagreement on the basis of ethically well-informed deliberations. This suggestion seeks to take seriously the alleged expertise of the consultant—his or her status as an ethics specialist. A medical specialist is called into a case with the expectation he or she will provide the requesting parties with a more detailed account of the medical options open to them, permitting the attending physician and patient (or surrogate) to make a better, more informed and carefully reasoned choice. In the same way, when disagreement occurs concerning the normative status of a moral choice, the allowability of which is unsettled, the consulting ethicist should help those involved arrive at a better understanding of the contested moral territory and of the reasons that can be advanced for and against treating a given choice as allowable.

Thinking about ethics consultation in unsettled cases as an engagement in moral inquiry and deliberation underscores the need to reconsider the basic goal of clinical ethics consultation and, along with that, the nature of the ethicist's expertise. It also points up questions for further investigation. The received view instructs the ethicist in Mr. Smith's case to *resolve* value uncertainty and conflict. On the face of it this is indeed a tall order—for given the normatively unsettled state of affairs regarding assisted suicide it is not entirely clear what could count as success in fulfilling it. It hardly makes sense to expect Mr. Smith's ethicist to settle definitively the long-running debate over the morality of assisted suicide (or, indeed, of any other normatively unsettled bioethical issue). The immediate need is of course to clear up the conflict between Mr. Smith, members of his family, and the treating team. If the source of their antagonism were poor communication or interpersonal friction, then the obvious goal would be to address that tension with the aid of a social worker, ombudsperson, or perhaps a therapist; should they be of a particular religious background and their differences were over the interpretation of scripture as it relates to end-of-life decisions, the intervention of a chaplain would be called for. But none of these matters appear to be what is chiefly at stake in the case of Mr. Smith.

The root of dissension in Smith's case, we are to suppose, is *moral disagreement*. Since the normative status of PAS is unsettled and the contending parties have appealed to deeply contested ideas—for example, about causing death, the aims of medicine, the duty to alleviate suffering—the only meaningful goal of an ethics consultation can be to ensure that whatever decision is arrived at—either by the group as a whole or by Mr. Smith acting on his own—is the *best ethically informed* decision possible under the circumstances. The ethicist should help the parties achieve a deeper understanding of what their respective moral beliefs and commitments entail, how they conflict, and the reasons that can be given to support or contest them. For the work of the ethicist to be genuinely a form of *ethics* consultation (as opposed to pastoral counseling, psychotherapy, or dispute resolution) it must include an examination of the parties' moral beliefs and convictions. Mr. Smith's physicians are generally opposed to his plans to seek PAS. Do they believe all cases of intentionally assisting to bring about the death are wrong? If so, how do they defend intentionally removing critically ill people from life-sustaining interventions? Does discontinuing such interventions count as taking a life? Mr. Smith thinks others are failing to honor a duty of compassion by refusing to assist him. But is this a duty to relieve suffering irrespective of the means involved? Would compliance with such a duty bring Smith's doctors into conflict with another duty, to refrain from causing harm? Mr. Smith's wife seemingly distinguishes amongst reasons for pursuing assisted suicide. Yet which reasons are licit and which not? The patient's plea underscores his suffering. But if suffering is an "afflicted state of being" (Cassell 2004), are all of the ways in which an individual suffers equally the business of medicine to address? Most of the doctors insist that healing the sick is their primary moral duty. What does it mean, though, to heal an obviously dying man? Smith himself evidently sees PAS as a release from a dehumanizing ordeal. Does assisted suicide put an end to such debasement or serve as its tragic culmination? Naturally, many more equally weighty and challenging questions lie just beneath the surface of the confusion caused by Smith's declared intention to end his life. But perhaps enough has been said to demonstrate the salience of such serious moral questions and the need straightforwardly to confront them—or at least some of them—as indispensible to disciplined reflection on a factious issue. Such reflection affords at least some assurance that whatever decision is reached is informed by the best moral reasons and arguments the parties can identify.

The role I have just sketched for ethics consultation in unsettled cases is a richer and more convincing conception of the consultant's ethics expertise than is accepted by the received view; for on that view such expertise is confined to knowledge of what is and isn't generally accepted or allowed, and the ethicist's role limited to relating the implications of well-established options for the case at hand. This attenuated understanding of ethics and its relevance to controversies in the clinic is problematic for two reasons. First, it is unhelpful in just those cases where ethical reflection is most needed. When what is generally accepted cannot with confidence be discovered, attention needs to turn more fundamentally to reflection on what *should be* regarded as allowed—and this requires careful reconstruction and evaluation of competing arguments, analysis of critical distinctions, and interrogation of pivotal assumptions. Second, to insist that only those medical options the acceptability of which is broadly recognized should be supported by an ethicist—in other words, that principles and distinctions embedded in law, policy, and practice must be respected—is to embrace a conservatism inconsistent with serious moral reflection and careful moral reasoning. Return once more to Smith's case. His doctors assert that actions taken when death is intended are distinct from conduct foreseeably leading to a patient's demise. Is this distinction truly tenable? Unquestionably, it is frequently cited in codes of ethics and hospital policies. But moral reasoning that is rigorous and discerning cannot begin by assuming that because certain judgments have gained traction in professional codes and bioethical discussion they are supportable by the best arguments. It is likely the case that the best ethically informed decision about PAS—or about any other practice whose normative status remains unsettled—will be the product of a wide-ranging discussion, one that not only examines but challenges claims or ideas largely accepted.

8.7 Conclusion

The received view of ethics consultation fails to accomplish its stated goal of resolving the conflict dividing Mr. Smith, his family, and doctors. This is because genuine moral disagreements, like that over PAS, lack the settled normative status indispensible on the received view to the attenuated role assigned to the ethicist. In addition, there appears to be no accepted procedure for deriving clear conclusions about the normative status of a given clinical practice or decision from a set of disparate and imprecise normative sources. I have tried to illustrate each of these concerns in the forgoing, though it should be clear that many questions remain. What, for instance, should an ethicist report about the normative status of assisted suicide in a jurisdiction *not* currently extending it legal recognition? Is the illegality of a practice a decisive reason for concluding it is disallowed? Suppose that despite the law, the state's medical societies and major medical centers come out in support of PAS. What then is its normative status? Could a clinical decision be widely viewed as (morally) impermissible yet remain allowable because it is both legal and supported by a significant body of bioethical scholarship? (Might certain forms of abortion be an example?)

I have argued that moral disagreement over particular medical decisions occurring in contexts where legal, professional, and institutional practices are at odds over the acceptability of those decisions, requires a new understanding of the aims of ethics consultation—a conception of the consulting ethicist's role differing markedly from how that role is constructed under what I have called the received view. The revised understanding of ethics consultation I have sketched is by no means complete, however, either in its theoretical underpinnings or in its practical applications. A number of further questions await investigation, among which are these. Is an ethicist a "moral authority," in the way (for example) a neurosurgeon is an authority in operating on the brain? May an ethicist give moral advice reflecting his or her own moral judgment, as opposed simply to reporting what is generally regarded as acceptable or unacceptable? What responsibility does the ethicist have to share minority positions—views dissenting from established standards or scholarly consensus? If as I suggest ethics expertise consists in helping others to reason better about the moral questions confronting them, what does this imply about the training of clinical ethics consultants? Must they, for example, be moral philosophers? If the parties to a clinical moral disagreement aim to resolve their differences by reaching a consensus to which they are collectively bound, how must they justify their decision? Ought they, for example, reach agreement (assuming they can) only by appeal to reasons that all can accept?

These questions need to be taken up and carefully discussed by bioethicists before a revised conception of ethics consultation along the lines I have proposed can be developed, and before more effective ways of responding to unsettled bioethical disputes can be implemented. I have not undertaken that work in this paper, but I hope here at least to have begun the conversation.

References

Ackerman, Terrence F. 1987. The role of an ethicist in health care. In *Health care ethics: A guide for decision makers*, eds. Gary R. Anderson, and Valerie A. Glesnes-Anderson, 309–320. Gaithersburg: Aspen Publications.

Adams, David M. 2009. Ethics consultation and ‘facilitated’ consensus. *Journal of Clinical Ethics* 20: 44–55.

Adams, David M., and William J. Winslade. 2011. Consensus, clinical decision making, and unsettled cases. *Journal of Clinical Ethics* 22: 310–327.

Allen, Jen, Sonia Chavez, Sara DeSimone, Debbie Howard, Keadron Johnson, Lucinda LaPierre, Darrel Montero, and Jerry Sanders. 2006. Americans’ attitudes toward euthanasia and physician-assisted suicide, 1936–2002. *Journal of Sociology and Social Welfare* 33: 5–23.

American Academy of Hospice and Palliative Medicine (AAHPM). 2007. Statement on physician-assisted death. http://aahpm.org/positions/pad. Accessed 7 July 2014.

American Academy of Physician Assistants (AAPA). 1997/2009. End-of-life decision making. http://www.aapa.org/workarea/downloadasset.aspx?id=812. Accessed 2 August 2014.

American College of Medical Quality (ACMQ). 2000. Policy 34: Physician-assisted suicide and end of life care. http://www.acmq.org/policies/policy34.pdf. Accessed 7 July 2014.

American College of Physicians (ACP). 2012. Care of patients near the end of life: Physician-assisted suicide and euthanasia. In *Ethics manual*, 6th ed. http://www.acponline.org/runningpractice/ethics/manual/manual6th.htm-euthanasia. Accessed 7 July 2014.

American Medical Association (AMA), Council on Ethical and Judicial Affairs. 2012. *Code of medical ethics,* Opinion 2.211. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page? Accessed 2 July 2014.

American Medical Director’s Association (AMDA). 1997. Position statement on care at the end of life. http://www.amda.com/governance/resolutions/p97.cfm. Accessed 7 July 2014.

American Nurses Association (ANA). 2013. Position statement: Euthanasia, assisted suicide, and aid in dying. http://www.nursingworld.org/euthanasiaanddying. Accessed 7 July 2014.

American Pharmacists Association (APA). 2004. Policy: Physician-assisted suicide. http://www.pharmacist.com/policy/physician-assisted-suicide-13. Accessed 7 July 2014.

American Public Health Association (APHA). 2008. Patients’ rights to self-determination at the end-of-life, Policy 20086. http://www.apha.org/advocacy/policy/policysearch/default.htm?id=1372. Accessed 7 July 2014.

American Society for Bioethics and Humanities (ASBH). 1998. *Core competencies for health care ethics consultation.*

American Society for Bioethics and Humanities (ASBH). 2011. *Core competencies for health care ethics consultation*, 2nd ed.

American Society for Pain Management Nursing (ASPMN). 2003. Position statement on assisted suicide. http://www.aspmn.org/pdfs/assistedsuicide.pdf. Accessed 7 July 2014.

American Society for Bioethics and Humanities (ASBH). 2010. Clinical Ethics Consultation Affairs (CECA) Committee Report to the Board of Directors. Certification, accreditation, and credentialing of clinical ethics consultants. http://www.asbh.org/uploads/files/cecacareport101210.pdf. Accessed 24 July 2014.

American Society of Health-System Pharmacists (ASHSP). 1999. Statement on pharmacist’s decision-making on assisted suicide. http://www.ashp.org/DocLibrary/BestPractices/EthicsStSuicide.aspx. Accessed 7 July 2014.

Angell, Marcia. 1982. The quality of mercy. *The New England Journal of Medicine* 306: 98–99.

Arras, John D. 1998. Physician assisted suicide: A tragic view. In *Physician assisted suicide: Expanding the debate*, eds. Margaret Pabst Battin, Rosamond Rhodes, and Anita Silvers, 279–300. New York: Routledge.

Aulisio, Mark P., and Robert M. Arnold. 2000. Health care ethics consultation: Nature, goals, and competencies. *Annals of Internal Medicine* 133: 59–70.

Aulisio, Mark P., and Robert M. Arnold. 2008. Role of the ethics committee: Helping to address value conflicts or uncertainties. *Chest* 134: 417–424.

Aulisio, Mark P., Robert M. Arnold, and Stuart J. Younger. 1999. Moving the conversation forward. *Journal of Clinical Ethics* 10: 49–56.

Aulisio, Mark P., Robert M. Arnold, and Stuart J. Younger. 2003. *Ethics consultation: From theory to practice*. Baltimore: The Johns Hopkins University Press.

Battin, Margaret Pabst. 2005. *Ending life: Ethics and the way we die*. Oxford: Oxford University Press.

Biller-Andorno, Nikola. 2013. Physician-assisted suicide should be permitted. *New England Journal of Medicine* 368: 1451–1452.

Bok, Sissela. 1998. Physician-assisted suicide. In *Euthanasia & physician assisted suicide: For and against*, ed. Gerald Dworkin, Raymond G. Frey, and Sissela Bok, 128–139. Cambridge: Cambridge University Press.

Boudreau, Donald J., and Margaret A. Somerville. 2013. Physician-assisted suicide should not be permitted. *New England Journal of Medicine* 368: 1450–1451.

Brock, Dan W. 2004. Physician assisted suicide as a last resort option. In *Physician-assisted dying: The case for palliative care and patient choice*, eds. Timothy E. Quill and Margaret Pabst Battin, 130–149. Baltimore: The Johns Hopkins Press.

Callahan, Daniel. 2002. Reason, self-determination, and physician-assisted suicide. In *The case against assisted suicide*, eds. Kathleen Foley and Herbert Hendin, 52–68. Baltimore: The Johns Hopkins University Press.

Campbell, Courtney S., and Jessica C. Cox. 2010. Hospice and physician-assisted death. *Hastings Center Report* 40: 26–35.

Caplan, Arthur. 2012. Massachusetts should legalize physician-assisted suicide. Harvard Law Petrie-Flom Center. http://blogs.law.harvard.edu/billofhealth/2012/11/02/art-caplan-ma-should-legalize-physician-assisted-suicide/. Accessed 25 July 2014.

Cassell, Eric T. 2004. When suffering patients seek death. In *Physician-assisted dying: The case for palliative care and patient choice*, eds. Timothy E. Quill and Margaret Pabst Battin, 75–89. Baltimore: The Johns Hopkins Press.

Cohn, Felicia, and Joanne Lynn. 2002. Vulnerable people: Practical rejoinders to claims in favor of assisted suicide. In *The case against assisted suicide*, eds. Kathleen M. Foley, and Herbert Hendin, 238–260. Baltimore: The Johns Hopkins University Press.

DeRenzo, Evan G. 1994. Providing clinical ethics consultation. *HEC Forum* 6: 384–389.

Dorff, Elliott N. 1998. *Matters of life and death: A Jewish approach to modern medical ethics*. Philadelphia: Jewish Publication Society.

Dubler, Nancy N. 2011. A 'Principled Resolution': The fulcrum for bioethics mediation. *Law and Contemporary Problems, Summer* 2011: 177–200.

Dubler, Nancy N., Mayris P. Webber, and Deborah M. Swiderski. 2009. Charting the future: Credentialing, privileging, quality, and evaluation in clinical ethics consultation. *Hastings Center Report* 39: 23–33.

Dworkin, Ronald, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson. 1997. Assisted suicide: The Philosophers' Brief. *The New York Review of Books* 27: 41–47.

Dworkin, Gerald, and Raymond G. Frey. 1998. The nature of medicine. In *Euthanasia and physician assisted suicide: For and against*, eds. Gerald Dworkin, Raymond G. Frey, and Sissela Bok Dworkin, 6–16. Cambridge: Cambridge University Press.

Fox, Ellen, Sarah Myers, and Robert A. Pearlman. 2007. Ethics consultation in United States hospitals: A national survey. *American Journal of Bioethics* 7: 13–25.

Glover, Jacqueline J., David T. Ozar, and David C. Thomasma. 1986. Teaching ethics on rounds: The ethicist as teacher, consultant, and decision-maker. *Theoretical Medicine* 7: 13–32.

Hospice and Palliative Nurses Association (HPNA). 2011. Position statement: Legalization of assisted suicide. https://www.hpna.org/DisplayPage.aspx?Title1=PositionStatements. Accessed 7 July 2014.

Kamm, Frances M. 1998. Physician-assisted suicide, euthanasia, and intending death. In *Physician assisted suicide: Expanding the debate*, eds. Margaret Pabst Battin, Rosamond Rhodes, and Anita Silvers, 28–62. New York: Routledge.

Kass, Leonard R. 2002. ‘I will give no deadly drug’: Why doctors must not kill. In *The case against assisted suicide*, eds. Kathleen Foley and Herbert Hendin, 17–40. Baltimore: The Johns Hopkins University Press.

Lewy, Guenter. 2011. *Assisted death in Europe and America*. Oxford: Oxford University Press.

Loggers, Elizabeth Trice, Helene Starks, Moreen Shannon-Dudley, Anthony L. Back, Frederick R. Appelbaum, and F. Marc Stewart. 2013. Implementing a death with dignity program at a comprehensive cancer center. *New England Journal of Medicine* 368: 1417–1424.

Marquis, Don. 1998. The weakness of the case for legalizing physician assisted suicide. In *Physician assisted suicide: Expanding the debate*, eds. Margaret Pabst Battin, Rosamond Rhodes, and Anita Silvers, 267–278. New York: Routledge.

McLean, Sheila A.M. 2009. Clinical ethics consultation in the United Kingdom. *Diametros* 22: 76–89.

Meilaender, Gilbert. 2005. *Bioethics: A primer for Christians*, 2nd ed. Grand Rapids: William B. Eerdmans Publishing Co.

Miller, Franklin G., and Robert D. Truog. 2012. *Death, dying, and organ transplantation*. Oxford: Oxford University Press.

Miller, Lois L., Theresa A. Harvath, Linda Ganzini, Elizabeth R. Goy, Molly A. Delorit, and Ann Jackson. 2004. Attitudes and experiences of Oregon hospice nurses and social workers regarding assisted suicide. *Palliative Medicine* 18: 685–691.

Miller, Franklin G., and Robert D. Truog. 2014. Bioethics and the dogma of brain death. *Bioethics Forum*, 3 Feb 2014. http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=6769&blogid=140. Accessed 21 August 2014.

Nagao, Noriko, Mark P Aulisio, Yoshio Nukaga, Misao Fujita, Shinji Kosugi, Stuart Youngner, and Akira Akabayashi. 2008. Clinical ethics consultation: Examining how American and Japanese experts analyze an Alzheimer’s case. *BMC Medical Ethics* 9. http://www.biomedcentral.com/content/pdf/1472-6939-9-2.pdf. Accessed 16 July 2014.

National League for Nursing (NLN). 1999. Life-terminating choices: A framework for nursing decision-making. http://www.nln.org/aboutnln/info-suicide.htm. Accessed 7 July 2014.

Oregon Medical Association (OMA). 2011. ‘PAS patient form’ and ‘PAS compliance checklist.’ http://www.theoma.org/. Accessed 7 July 2014.

Pasman, H. Roeline W., Johanna E. Hanssen-de Wolf, Berniek A.M. Hesselink, Agnes van der Heide, Gerrit van der Wal, Paul J. van der Maas, and Bregje D. Onwuteaka-Philipsen. 2009. Policy statements and practice guidelines for medical end-of-life decisions in Dutch health care institutions: Development in the past decade. *Health Policy* 92: 79–88.

Pellegrino, Edmund D. 2002. Compassion is not enough. In *The case against assisted suicide*, ed. Kathleen M. Foley, and Herbert Hendin, 41–51. Baltimore: The Johns Hopkins University Press.

Pope, Thaddeus M. 2009. Legal briefing: Medical futility and assisted suicide. *Journal of Clinical Ethics* 29: 274–286.

President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1983. Deciding to forego life-sustaining treatment. https://repository.library.georgetown.edu/handle/10822/559344. Accessed 29 April 2015.

Quill, Timothy E. 2008. Physician-assisted death in the United States: Are the existing ‘last resorts’ enough? *Hastings Center Report* 38: 1–22.

Quill, Timothy E., and Christine K. Cassel. 2003. Professional organizations’ position statements on physician-assisted suicide: A case for studied neutrality. *Annals of Internal Medicine* 138: 208–211.

Reiter-Theil, Stella. 2001. Ethics consultation in Germany: The present situation. *HEC Forum* 13: 265–280.

Schildmann, Jan, John-Stewart Gordon, and Jochen Vollmann (eds.). 2010. *Clinical ethics consultation*. Surrey: Ashgate Publishing.

Singer, Peter. 2005. Decisions about death. *Free Inquiry* 25. https://www.secularhumanism.org/index.php/cont_index_25. Accessed 17 July 2014.

Sumner, L.W. 2011. *Assisted death: A study in ethics and law*. Oxford: Oxford University Press.

Tarzian, Anita J. and ASBH Core Competencies Update Task Force. 2013. Health care ethics consultation: An update on core competencies and emerging standards from the American Society for Bioethics and Humanities' Core Competencies Update Task Force. *American Journal of Bioethics* 13: 3–13.

Tarzian, Anita J. and Lucia D. Wocial. 2015. A code of ethics for health care ethics consultants. *The American Journal of Bioethics* 15: 38–51.

Thomasma, David C. 1987. Legitimate and illegitimate roles for the medical ethicist. In *Clinical medical ethics: Exploration and assessment*, eds. Terrence F. Ackerman, Glenn C. Graber, Charles H. Reynolds, and David C. Thomasma. Lanham: University Press of America.

Veatch, Robert M. 1987. The medical ethicist as agent for the patient. In *Clinical medical ethics: Exploration and assessment*, ed. Terrence F. Ackerman, Glenn C. Graber, Charles H. Reynolds, and David C. Thomasma. Lanham: University Press of America.

Vermont Medical Society (VMS). 2003. Physician assisted suicide. http://www.vtmd.org/physician-assisted-suicide-likely-top-priority-2011. Accessed 7 July 2014.

Washington State Medical Association (WSMA). 2009. Physicians' guide to health law: The Death with Dignity Act. https://www.wsma.org/doc_library/LegalResourceCenter/RulesRegulatoryInformation/Rules_Washington_Physicians_Guide_DWDA_20120511-1.pdf. Accessed 7 July 2014.

Chapter 9
License to Kill: A New Model for Excusing Medically Assisted Dying?

Richard Huxtable and Jonathan Ives

9.1 Introduction: A View to a Kill

Gaylin et al. (1998, 2140) have suggested that physician-assisted dying:

> touches medicine at its very moral center; if this moral center collapses, if physicians become killers or are even merely licensed to kill, the profession – and, therewith each physician – will never again be worthy of trust and respect as healer and protector of life in all its frailty.

Are Gaylin et al. right to be concerned, or should doctors be "licensed to kill"? The idea of a "licence to kill" conjures the image of James Bond, the fictional British spy, whose adventures are featured in an internationally-renowned series of books and films. We deploy a Bondian metaphor throughout this paper, which is linked to the analogy we use to moot a new direction, and we hope, in doing so, that readers will not think that we are belittling the serious topic with which the paper is concerned. Opinions understandably differ on this complex, sensitive phenomenon and specifically about the appropriateness of such killing. All too often the disputants reach a familiar crossroads: one fork points towards permission, in view of the alleged justifiability of the practice, the other towards prohibition, in view of its alleged unjustifiability. As this volume suggests, new directions of travel are needed, which are capable of leading us away from these well-trodden and entrenched paths.

In this chapter, therefore, we seek to forge and explore a different path. Our exploratory model builds on an analogy with armed response police units as

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they operate in England, and specifically with situations in which such officers are found to have killed someone in the course of their duties. Rather than confer immunity prospectively (as proponents of assisted dying often seek) or deny immunity completely (as opponents insist), our policy would provide a potential retrospective excuse.

We start by surveying the main features of the debates to date. We first look to the advocates of assisted dying, who argue that there are obligations to respect autonomous choices and to relieve suffering, which suggest that assistance in dying is justifiable. We then, however, encounter the opponents. Opponents will typically point to the intrinsic value of human life, arguing that life should never intentionally be shortened. They also argue that, in principle and in practice, a policy of permission is dangerous, since it will lead us onto slippery slopes. Finally, as Gaylin et al. suggested, opponents will argue that doctors should not be involved in any such policy because it will erode trust in the profession. In many of the permissive laws that are proposed, as well as in many of those already in operation, doctors are typically positioned as the providers of assistance in dying. Opponents fear the affront to the integrity of medicine that such a development poses.

Each set of arguments has a long history and continues to command substantial support; indeed, the to-and-fro of argument, counter-argument and counter-counter-argument appears to be unrelenting. Yet, despite this history, we still appear to lack a definitive, principled answer to the euthanasia question. In the absence of such an answer, we look to alternative ways forward. One such route would lead us to assess the prospects for consensus. Whilst we detect some areas of convergence, we acknowledge that the disputants are unlikely ever to agree on the fundamental question. Perhaps, instead, a compromise might indicate the way forward. The options here include the possibility of creating an excusable (but not justifiable) offence. Our proposed model takes a different line, albeit explicitly a compromise position, which acknowledges that there are good justifications both for being permissive and prohibitive, and seeks a middle way that allows us to make progress in the debate.[1]

9.2 Never Say Never Again

In current parlance, acting to end the life of a suffering individual tends to be described as "assisted dying." A multiplicity of concepts and phrases litter debates about the (ethical and legal) rights and wrongs of such a practice. References are therefore made to "euthanasia" and "assisted suicide", as well as to slogans like "death with dignity" and the "right to die". It is not always obvious that the terms capture a single practice. Indeed, sometimes neighbouring, but potentially

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[1] See, e.g., Huxtable (2012) and Ives (2014) for an exposition of the theoretical basis of the need for, and value of, compromise in genuinely dilemmatic situations.

distinguishable, practices feature in the discussions, such as the withdrawal of life-sustaining treatment or the use of drugs to relieve symptoms, which might be said to "ease the passing". Without a common referent, there is a risk that disputants will talk past one another. Unfortunately, the task of defining the practice with which we are concerned has been rather neglected.[2] Although we will occasionally return to questions of definition, we will focus on what we term "assistance in dying". For the label to be applied, the assistance will have been intentionally achieved by some positive means (such as supplying or administering a lethal medication) and it will have been provided by a particular person, specifically a medical doctor. Furthermore, this assistant—and, where there is one, the request—will have been motivated by the current or anticipated suffering of the individual who is to receive the assistance.

Perhaps "It's Over, Debbie", the article to which Gaylin et al. were responding (along with numerous others), provides an illustration of such assistance in action. The piece outlined an anonymous gynaecology resident's decision to administer morphine to a 20-year-old patient who was dying of ovarian cancer (Anonnymous 1988). Debbie, who had not slept or eaten for two days, was struggling to breathe. When the resident appeared, Debbie said only: "Let's get this over with". Debbie appeared to die minutes after the injection. Maybe this was "double effect" in action: the drug brought Debbie relief from her symptoms, but it also had the unintended secondary effect of suppressing her breathing (see, e.g., Huxtable 2007, 11–12). Or perhaps this was assistance in dying—and perhaps, in any event, that was what Debbie had sought.

Gaylin et al. propose that we should never countenance assistance in dying, at least by doctors, but others argue that we should never say "never". Proponents will usually point to one or both of two ethical arguments (see De Haan 2002). The first argument is grounded in respect for autonomy and thus in the view that life has a self-determined value (Huxtable 2007, 13–15). Many would maintain that we should allow scope for self-rule (e.g. Gillon 2003). If this is morally worthwhile, the argument runs, then we should allow autonomous individuals to decide for themselves what should, and should not, happen to them in relation not only to their lives, but also to their deaths. Proponents of the autonomy argument would therefore say that a patient like Debbie should have a wish to die granted, provided (of course) that death is autonomously sought. "Making someone die in a way that others approve, but he [himself] believes a horrifying contradiction of his life, is a devastating, odious form of tyranny", suggests Dworkin (1993, 217). Many would agree, and they do so from a variety of ethical perspectives, including deontology, consequentialism, feminism(s), and virtue ethics (e.g. Beyleveld and Brownsword 2001; Singer 1993; Biggs 1998; van Zyl 2000).

The support is not merely theoretical or abstract. Some patients appear to want the option of ending their lives early, and they will occasionally approach their

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[2] But see, e.g., Beauchamp and Davidson (1979), Wreen (1998), and Huxtable (2007).

clinicians or the courts with their requests.[3] There is also public approval, at least in some jurisdictions: in England, for example, opinion polls typically reveal a high proportion of support for a reform to the law in order to allow some form of assistance in dying.[4] Such support is usually offered for voluntary forms of assistance in dying, such as voluntary euthanasia (in which the assistant takes the final fatal step) or assisted suicide (in which the patient does so).

These latter forms of assisted dying appear most obviously premised on respect for autonomy, but the idea can also offer principled support for some of its other forms. Where the patient in question is no longer autonomous, but has made a prior request for assistance whilst autonomous, then this might count as not only *non-voluntary* (since the patient now lacks autonomy), but also *voluntary* (as the patient made an autonomous advance request) assistance in dying. Perhaps the same idea can also be stretched to encompass proxy requests, and therefore to cases in which a loved one authorises assistance in dying for the incapacitated, suffering patient, on the premise that death would be in their best interests (Singer 1993, 182–3).

Yet, there might be no need to stretch the logic of autonomy to cover these sorts of cases, since an alternative argument might provide a better moral basis. This latter argument is variously articulated in terms of beneficence, mercy, and the relief of suffering. The central idea here is that life has only an instrumental value: it is good only insofar as it can be put to use in pursuing that which makes life worthwhile (Huxtable 2007, 15–17). Where the life is sufficiently afflicted, and the quality of that life is sufficiently poor, its value may be said to diminish. In such circumstances the patient, or perhaps others acting in the patient's interest, might come to judge it better—kinder, more merciful—to end a life of suffering, rather than allow (or force) its continuation. These sorts of arguments, which tend to be consequentialist, are captured by Singer, who refers to the example of critically ill infants: "When the life of an infant will be so miserable as not to be worth living [and] there are no 'extrinsic' reasons for keeping the infant alive—like the feelings of the parents—it is better that the child should be helped to die without further suffering" (Singer 1993, 182–183; see also Doyal 2006).

As Singer implies, sometimes the autonomy and mercy arguments will work together to justify an apparent instance of non-voluntary euthanasia. Indeed, this might even be the case with voluntary euthanasia and assisted suicide. Although autonomy might be capable of doing the relevant moral work unaided, autonomy and mercy can work together to form a "joint view" on the appropriateness of consensual killing (De Haan 2002). Indeed, both grounds typically feature in those laws which permit voluntary forms of assistance in dying. As is well known, the Netherlands has the longest history, but its Benelux neighbours have recently taken similar steps, as have certain states in the USA, not least Oregon, which

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[3] E.g. the recent English ruling in R (on the application of Nicklinson and another) (2014).

[4] House of Lords Select Committee (2005); Commission on Assisted Dying (2011).

allows physician assisted suicide.[5] Respect for autonomy is a central feature of these permissive laws, and Belgium has recently extended its provision of assistance in dying to encompass competent minors (Siegel et al. 2014). Mercy, nevertheless, also plays a part, as the individuals who can avail themselves of such laws usually need to be patients (in some sense) i.e. they need to have particular medical conditions that lead to unbearable suffering. In some legal systems, the condition in question is narrowly defined: in Oregon, for example, the patient must be in the last six months of terminal illness. Elsewhere the suffering criterion is more expansive: the Dutch policy, for example, originated in somatic disease, but thereafter extended to psychiatric suffering and there has even been discussion of its ability to accommodate assistance in dying for cases of so-called “life fatigue” (Huxtable and Möller 2007; Varelius 2007).

As we have seen, the argument from mercy seems applicable not only to voluntary, but also to non-voluntary assistance in dying. Presumably the argument could even extend to *involuntary* instances of assistance i.e. to assistance in dying which is provided contrary to the wishes of the autonomous individual or without them even being consulted. No one seems to support such an extension, presumably given the affront to autonomy. Yet, it is possible to find support for non-voluntary assistance in dying, including in practice. The Dutch policy only explicitly allows for voluntary forms of assistance in dying, but a protocol openly operates in Groningen, by which euthanasia is provided to critically ill infants (Manninen 2006).

9.3 Dr – No!

These arguments in favour of assisted dying, and their deployment in practice, may leave opponents of the phenomenon shaken, but not stirred. First, the opponents are unstirred by the proclaimed moral force of the case for allowing assistance in dying, as they dispute the meaning, scope and appeal of the proponents’ appeals to autonomy and mercy (see Huxtable 2007, 24–27). The proper meaning of respect for autonomy gives some critics reason to pause. The idea is enduring something of a backlash in various contexts, from various quarters (Donchin 2001). Some critics complain that respect for autonomy should not be reduced to “I want”, with the expectation being that this translates unequivocally to “I should get”: we still need to be convinced that what “I want” is in some sense “good” and that “I” am entitled to the provision of that good. Operating alone, the logic of autonomy “is ostentatiously silent about whether death is desirable or undesirable, but insists only that each individual should make this value choice for himself” (Burt 2005, s13).[6] If that is the case, then the logic is also difficult to constrain.

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[5] For an overview of some of these laws, see Lewis and Black (2012).

[6] Sometimes proponents will point to dignity as a basis for respecting individual choice, but critics suspect that these efforts are equally misconceived (Foster 2011).

Why restrict a policy to only assisted suicide, and not also allow voluntary euthanasia, and why not also extend that logic to being able to choose the manner of death? Furthermore, why insist that there be any underlying medical condition—surely, if the autonomous choice is central, it matters not why that choice was formed, but only that it was formed autonomously (see e.g. Huxtable and Moller 2007)?

Critics even suspect that the logic of autonomy will prove self-defeating. If autonomy is a crucial value for proponents, then they will certainly need to attend to any risks that assistance in dying poses to that value. Perhaps there are such risks: maybe the very existence of an option to die will be sufficient to place pressure on people to have the option exercised in their case, which will therefore serve to threaten their autonomy (Velleman 1992). Finally, say the opponents, there is not necessarily the public appetite for assisted dying that the proponents claim there is. The surveys that reveal public support are sometimes badly phrased and badly timed, coming amidst difficult, high-profile cases (Hagelin et al. 2004). Indeed, the suggestion has been made that, when the surveys are amended to include counter-arguments, public support appears to drop (Saunders 2014).

Similar charges are levelled against the proponents' appeals to mercy. Singer spoke of ending "miserable" lives, but the qualifying criteria need to be spelled out, especially if charges of "disablism" are to be avoided.[7] Here, too, we might well ask whether something like "life fatigue" should (or should not) be considered a good ground for euthanasia? The individuals who should be empowered to make such life-ending judgments also need to be identified. We might then wonder whether and how the brakes can be put on any merciful policy: to condemn involuntary euthanasia as "murder" is simplistic (e.g. Harris 1997), since every form thereof will be murder in many jurisdictions, but the condemnation of this specific practice does at least require proponents to spell out clearly what is (and is not) to be allowed.

In addition to criticising proponents of assisted dying, the opponents also provide standalone arguments against affording doctors a licence to kill. There are three main clusters of arguments offered, which respectively refer to the intrinsic value of human life, the avoidance of slippery slopes, and the need to preserve the integrity of the medical profession. First, as will be apparent from some of the preceding points, opponents of assisted dying do not judge the value of life in self-determined or instrumental terms. Rather, they argue, life has an intrinsic value, in and of itself: life is inviolable and it should not be ended intentionally, whether by action or by omission (e.g. Keown 2002). This essentially deontological position is traditionally associated with theistic (and often Judaeo-Christian) thinking, but the same idea recurs in more secular forms, such as in the right to life. For some, respect for autonomy can only be understood in such terms: a truly autonomous choice will be one which recognises the value of life, whether that life is one's own or another's (Keown 2002, 53).

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[7] For (critical) discussion of the disability rights perspective, see Ouellette (2006).

The second argument is more consequentialist in nature, since it points to the disastrous effects that could—or logically should—follow on from endorsing assistance in dying in some form or another. Variously expressed in terms of the “thin end of the wedge” or “opening the floodgates”, there are usually two types of “slippery slopes” which are mentioned, the first logical, the second empirical or psychological. One logical objection makes a familiar claim: involuntary euthanasia follows the same logic as voluntary or non-voluntary euthanasia, insofar as they can all be premised on the poor quality of the patient’s life (e.g. Keown 2002, 70). The empirical objections, meanwhile, refer to probabilities: we are more likely in fact to be led into dangerous territory, if we make the first step of allowing some form of assisted dying. Opponents fear that life will be de-valued, and lives will be imperilled, and they draw various analogies, including with the Nazi atrocities (which are said to rest on the same judgment of worthless lives) and with terminations of pregnancy (which are said to have expanded considerably from apparently modest beginnings) (e.g. Keown 2002, 73). The move in the Netherlands, from allowing euthanasia only in cases of somatic disease, to mental health disorders, and possibly now to “life fatigue”, is an example of such a slope. As Bond is told by Dryden in the opening sequence of *Casino Royale*,[8] the first kill is always the hardest, because you feel it. The second, Bond laconically agrees as he pulls his trigger, is considerably easier.

Most apposite, perhaps, are the references to data emerging from jurisdictions that have passed measures to allow assistance in dying. As we have seen, the Dutch policy widened its scope beyond the unbearable suffering associated with terminal illness. Notably, not every instance of euthanasia in that jurisdiction appears to be entirely voluntary: not only is non-voluntary euthanasia now openly practised in that jurisdiction, but early reports suggested that 1000 (0.8 %) of the annual occurrences of “voluntary” euthanasia took place without any explicit request from the patient (see Keown 2002, 104–106). The assistants involved appear not to have been censured. More recently, as we also saw, Belgium has amended its law: the original law was only passed in 2002, but in 2014 the provisions were extended to encompass minors (Siegel et al. 2014). Citing such examples, opponents of assistance in dying argue that lines can neither be drawn in principle nor defended in practice, so the practise is best left unlawful.

Finally, the opponents point to the integrity of medicine, which would be threatened by any moves to equip doctors with a license to kill. This was a central objection from Gaylin et al., whose opposition can be linked to efforts by Kass and Pellegrino to spell out the distinctive “internal morality of medicine”. Kass (1975) sees medicine as a moral enterprise, which is orientated towards the end of health. Pellegrino (2001) takes a similarly Aristotelean approach, in which the correct function of medicine is to serve the good of the patient, which he sees as having four dimensions. Doctors should therefore seek to promote the medical good (which requires technical competence), the good as perceived by the patient

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[8] Campbell (2006).

(which requires respect for their autonomous wishes), the good for the patient as a human being, and the spiritual good. These goods ascend in order of importance: ultimately, the patient's apparent choices or perceived needs are subordinate to the spiritual good, which, on Pellegrino's account, is incompatible with assistance in dying. Such incompatibility, in turn, renders the practice incompatible with medicine's moral mission. In short, assistance in dying is contrary to the integrity of medicine, so the final answer to the euthanasia question should be: "Dr – No!"

9.4 Live and Let Die

Proponents of assisted dying take issue with each of the opponents' objections, and whilst they may agree that it is generally better to live, we also ought to let (people) die when certain conditions are met. First, they question the view that life has an intrinsic value, citing problems with its meaning, scope and appeal, similar to those the opponents had levelled against rival accounts of the value of life. Proponents of assisted dying initially criticise the concepts and distinctions on which the ethic apparently relies. The intentional ending of life is prohibited according to adherents to the intrinsic value of life, but critics suspect that "intention" is being defined too narrowly, in ways which serve the moral judgments these adherents seek to make (e.g. Rachels 1986, 92). Even if we think that Debbie's doctor did not intend to end her life, this doctor did act voluntarily and did appear to cause her death—so why not hold this doctor to moral account?

There are said to be similar problems with opponents' efforts to justify some fatal omissions (e.g. Rachels 1986, 106–150). Those opponents who cleave to the intrinsic value of life believe that they can differentiate situations of "live and let die": they therefore distinguish between acts and omissions, and then between different sorts of omissions (see, e.g., Keown 2002, 42–43). According to such arguments, life-supporting interventions can be withdrawn or withheld (i.e. the doctors can omit to treat), provided that the interventions are judged to be "futile" or more burdensome than beneficial. The proponents of assisted dying remain unconvinced, and they again argue that key terms like "futility" are being defined in ways that beg the crucial moral questions (e.g. Halliday 1997).

These problems lead some proponents to suspect that the inviolability ethic is dishonest and self-defeating. Since the approach allows doctors to withdraw allegedly futile life-support or administer symptom-relieving drugs that might incidentally (but not intentionally) shorten life, proponents insist that it tacitly embraces consequentialist (instrumentalist) judgments that some poor quality lives are best ended (e.g. Singer 1993, 210, 211). Perhaps the ethic can only be rescued by insisting on a more vitalistic stance, which would require every effort to be made to protect life (Kuhse 1987). However, supporters of the sanctity of life find this extreme just as unappealing as the opposite, consequentialist extreme (Keown 2002). Yet, even their alleged middle ground position is found to be unappealing: although the central idea commands some secular support, the sanctity of life looks like a distinctively theological notion, which will scarcely convince those who have no, or alternative, faith-based commitments (e.g. Dworkin 1993, 217).

Proponents secondly dispute the logic and likelihood of claims that, by allowing assisting dying in some cases, we will be led down a slippery slope. Some simply dismiss the alleged logic of the slippery slope argument as fallacious (e.g. Smith 2005). Others suspect that the claim merely camouflages the opponents' real objection, which is premised on the intrinsic value of life (e.g. Doyal 2006). The empirical objections and analogies are also rejected. The Nazi eugenic policies are said to be some considerable moral distance from policies advocated by those in favour of assistance in dying (e.g. Rachels 1986, 177–178). Any slide in relation to termination of pregnancy is also disputed: for example, the fact that doctors can abort disabled foetuses has not generally inclined them towards killing disabled children or adults (e.g. Singer 1993, 217 and Rachels 1993, 62–63). Furthermore, the Dutch data, including the problematic 1000 deaths, might not be all that they appear; maybe, indeed, these deaths were not non-consensual (Downie 2000). In short, advocates insist that ways can be found to pinpoint and police the necessary boundaries (e.g. Rachels 1993, 61–62).

Finally, the integrity of medicine is said to present no barrier to allowing assistance in dying. For one thing, it might be possible to create a new specialty—"thanatology", for example—whose practitioners need not be drawn from medicine's ranks (Brazier 1996). Of course, this might not be a complete response, since clinicians seem likely to be involved in some way in any state-endorsed system.[9] Yet, proponents still perceive no problem in principle with affording doctors a licence to kill, or with otherwise involving them in such a licensed system, because robust measures can always be put in place to ensure that abuses of trust are identified and appropriately dealt with, if not eliminated entirely.

In contrast to Kass et al., Miller and Brody suggest that medicine is not only about healing and promoting health, but also concerned with enabling patients to achieve dignified and peaceful deaths (Miller and Brody 1995). They deny that this latter goal begs the question about medicine's compatibility with assistance in dying (it might only refer to the need for palliative care), although they do still conclude that medicine can encompass the practice. On their account, doctors cannot be obliged to assist in dying, but they have the discretion to do so, provided that the patient has chosen this autonomously and the doctor is satisfied that this is best in the circumstances. Momeyer argues to similar effect (Momeyer 1995). Although he agrees with Kass that medicine is about healing, Momeyer rejects Kass's Hippocratic beneficence and charges him with paternalism. For Momeyer, medicine's ends are chosen by humans, not stipulated by nature. Such ends should allow room for patient autonomy. There may (but only may) be extrinsic reasons for resisting assisted dying, but neither Momeyer nor Miller and Brody believe that there is anything intrinsic to medicine which requires such opposition.

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[9] However, this is not the position in Switzerland (see Lewis and Black 2012). There is also some scholarly support for less medicalised models, e.g., Ost (2010).

One of the most significant difficulties faced by proponents, however, is to propose a legislative system that permits assisted dying and also provides adequate protections to the potentially vulnerable, so that assistance to die is only provided to those who want it and where it is the only reasonable option available. Any legislation that allows assisted dying admits the possibility—perhaps the probability—that some unwilling patients will slip through the net. This possibility alone, opponents will argue, is enough to support prohibition.

9.5 Die Another Day?

We seem to be left with an assisted dying equation: although people will tend to prefer the arguments on one particular side, neither side appears conclusively to have greater value than the other. Each side seems to offer important insights: proponents understandably proclaim the importance of self-determination and the avoidance of suffering; opponents plausibly point to the value of human life and the risks of unintended consequences; and both sides seem to make viable suggestions about the core business of medicine. Yet, the arguments on each side are also afflicted by considerable problems of meaning, scope and appeal.

The ethical battles will undoubtedly continue to be waged, and we should not be beguiled into thinking that better evidence can instigate a ceasefire (Parker 2005). Of course, the arguments that are raised continue to become ever more nuanced, and there is certainly more to these debates than our summary can convey. At the same time, however, the essential points are well-established, but the process of argument and counter-argument is unceasing. As far back as 1958, the debate about assisted dying was deemed “jaded” (Williams 1969). Perhaps this is a debate that must wait to die another day. Prior to its demise, and as this collection attests, we need to consider whether there are new directions in which assisted dying can travel.

One possibility might be to look for areas of consensus and to construct our laws and policies on such bases. Maybe this is not an unrealistic ambition, since proponents and opponents will agree about the appropriateness of many practices, although they will cast their respective ethical justifications in different terms. For example, both sides support the cessation of life-supporting treatment in particular cases, and also the use of strong painkillers and sedatives for some patients, even in the (admittedly extremely rare) case where the drugs might shorten life. Opponents of assisted dying will justify such cases by reference to acts, omissions and futility, on the one hand, and double effect, on the other; proponents, meanwhile, might reject such convoluted labels, but they will nevertheless agree with the course proposed in many such cases.

Proponents and opponents might also be united in other ways, ways which are too seldom noticed. Writing about those who support assistance in dying, Gillett referred to the moral significance of “the pause”: “a crucial element in the moral competence of a doctor is a tendency to hesitate, have misgivings or feel a ‘pause’ about certain principled medical decisions involving life and death" (Gillett 1988, 61).[10] Perhaps this pause is already present, even in proponents' arguments: notice the care with which qualifying conditions and criteria tend to be formulated, and the fact that assistance in dying is typically conceived as an exception to any general rule against killing. In short, proponents do not seek a wholesale dismantling of the ethic that prohibits the ending of life. Equally, opponents do not wholly insist that life must be preserved, no matter what. As such, even those opponents of assisted dying who support the intrinsic value of life appear mindful of the need to pause, since they allow for situations in which not every effort must be taken to prolong or protect life.

However, we should not be too optimistic about the prospects for convergence and consensus. Each side might exhibit a degree of caution, and be inclined to support some practices that are also endorsed by their opponents, but on the crucial question they still fail to reach consensus. In short, proponents still insist that assisted dying can be justified (at least in some cases), while opponents still insist the opposite. Determining a victor continues to prove difficult: jurisdictions might adopt more or less permissive policies in practice, but the principled disputes rage on. Absolutists and universalists on either side might insist that they are in the right, but their arguments will scarcely convince everyone. Closure on the justifiability—or unjustifiability—of assisted dying seems highly unlikely; as van Willigenburg commented, albeit in another context, either "there *is* no superior way of mixing values or *we* are unable to rationally trace that superior mix" (Van Willigenburg 2000, 400).

But maybe both sides are deploying the wrong conceptual category: perhaps, if we move away from notions of *justification*, and towards the concept of *excuse*, we can begin to attend to concerns on both sides. An excuse can convey a compromise, since it signals a degree of wrong-doing, albeit in the presence of factors which suggest a degree of right-doing (e.g. Austin 1956). Assisted dying might be amenable to such a policy solution: rather than judge this as justified or unjustified, it might be possible to treat it as criminal (in line with opponents) but also to ensure a suitably humane disposal by the criminal courts (in line with proponents) (e.g. Huxtable 2007).

It remains to be seen whether such a proposal is defensible or, indeed, offers enough to either side (see, e.g., Holm 2010). We will leave this proposal to one side, although there is one element thereof which merits further consideration here. In contrast to many (envisaged or operative) legal models, this sort of compromise proposal does not provide a template for conferring immunity *prospectively*. Rather, the excuse operates *retrospectively*: the alleged assistant's actions are judged against pre-ordained criteria, to ascertain whether the conditions of the excuse are satisfied, such that it should be made available in this case. This sort of approach merits further exploration, since it promises to take the assisted dying debate in a new direction. In the next section we therefore outline an alternative model, by drawing an analogy with UK armed response units.

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[10] See similarly Burt (2005) on ambivalence.

9.6 The Man with the Golden Gun

This section outlines a model of "retrospective excuse", which has the potential to accommodate permissiveness towards assisted dying, whilst maintaining both appropriate legislative safeguards and an appropriately prohibitive attitude towards killing in general. We will do this by drawing an analogy with the way in which killing is dealt with in the context of UK police armed response units, which are permitted to use lethal force in the carrying out of their duties. As we shall see, the analogy is not perfect, but it does provide food for thought, in offering a new direction to our thinking about assisted dying. We first outline the armed response model, and then use this to sketch an analogous model for doctors and assisted dying.

9.6.1 UK Armed Response

In the UK,[11] police officers do not routinely carry firearms. They are authorised to use physical force as necessary, but are subject to the same laws regarding physical assault as all UK citizens. There are, however, a special subset of police officers who are specially selected and trained in the use of, and therefore authorised (or "licensed") to carry and use, firearms. These officers are deployed when the use of lethal force may be necessary in the discharge of the police force's duty to protect the public.

Whilst the firearms officer is authorised to carry a weapon, trained in its use and educated in the circumstances in which it may be lawful to discharge it, the responsibility of any decision to shoot a person belongs to that officer alone. There is no such thing as prior authorisation or immunity, and the Nuremberg defence ("I was only following orders") cannot be relied upon. The officer who pulls the trigger must never do so on the order of someone else, but must be satisfied that it is necessary and correct to do so. Furthermore, the trigger is pulled in the knowledge that the resulting death will be investigated thoroughly, and the officer must be prepared to defend and justify his or her actions and to accept criminal sanctions if the death is consequently judged unlawful. Importantly, because no shooting, and therefore no resultant killing, is ever pre-approved, any death is automatically treated as potentially criminal and investigated as such.

Following a shooting, an investigator from the Independent Police Complaints Commission (IPCC) is appointed and called to the scene. A solicitor is called out

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[11] Our primary sources for this section are: Association of Chief Police Officers, Association of Chief Police Officers in Scotland, and National Policing Improvement Agency (2011), Accessed 15th Aug 2014, 1001 GMT. and UK Police Firearms Officers Association (see PFOA. Post Shooting Procedures (2015), Accessed 14th Aug 2014, 10:57 GMT). We would also like to acknowledge and thank M, otherwise known as Martin Cooper, who gave us invaluable advice on this section. Any mistakes are, of course, our own.

to represent any officer who has discharged a firearm. Officers involved may make written notes of the event, subject to legal advice, and witnesses to the shooting (but not participants in it) will be asked to write a statement giving their account of events. All weapons discharged will be handed over to a forensics officer, alongside anything else of forensic value. In the following few days, officers involved must meet with their solicitor and make a detailed statement about the event for the investigators. Officers may confer about times, locations, routes, but may not confer about their honestly held beliefs at the time they discharged their weapons. At this time, officers are given the opportunity to speak to a welfare counsellor.

Following the completion of individual statements, and any debriefing meetings (which would be attended by the investigator and recorded), all officers who discharged their weapon are removed (with pay) from active duty. If it was a fatal shooting, an inquest will be held. If the inquest determines that the officers acted appropriately and their use of firearms was justified, they will return to active duty. The Association of Chief Police Officers states that "[a] critical shot should only be fired when absolutely necessary in defence of a person when there is an imminent and extreme risk to life from unlawful violence. A critical shot is a shot or shots aimed to the head, if possible, or otherwise to the central nervous system or major organs".[12] If, in terms of guidelines quoted above, the inquest determines that the use of firearms was not justified, then the officer may be subject to a criminal investigation and, if found guilty, criminal sanctions.

9.6.2 *Medically Assisted Dying: The Analogous Model*

In order to develop an analogous model, we would first have to note that, in the UK, doctors are not routinely expected to carry the equipment to assist death, nor be mindful that this may be part of their job. That would not rule out, however, the creation of a subset of the profession who could be specially selected and trained in the use of lethal medication (or other methods of assisting death), who are therefore authorised (or "licensed") to assist death, and who are called upon when the use of lethal medications (for example) may be necessary in the discharge of the medical profession's duty to respect patient autonomy and alleviate suffering. In keeping with the terminology we introduced earlier, let us call this group "thanatologists". We will presume that such professionals will have voluntarily chosen to assume these duties (and, therefore, that no professional will be required to do so contrary to their conscience) (see Huxtable and Mullock 2015).

Whilst the thanatologist would be authorised to carry death-assisting equipment, would be trained in its use and educated in the circumstances in which it may be lawful to use it, the responsibility of any decision to assist a patient to die belongs to that practitioner alone. There would be no such thing as prior

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[12] Association of Chief Police Officers, Association of Chief Police Officers in Scotland, and National Policing Improvement Agency (2011), Accessed 15th Aug 2014, 1001 GMT. S2.43, p. 35.

authorisation or immunity, and the Nuremberg defence could not be relied upon. Furthermore, the assistance would be given in the full knowledge that the resulting death will be investigated thoroughly, and the thanatologist must be prepared to defend and justify his or her actions and to accept criminal sanctions if the death is consequently judged unlawful. Importantly, because no assistance to die could ever be pre-approved, any death will be automatically treated as potentially criminal, and must be investigated as such.

Following an assisted death, an investigator would be appointed and called to the scene. Those involved would have access to a solicitor, and make written notes of the events. All "witnesses", including members of the multi-disciplinary team, family members and/or friends of the patient would be asked to make statement giving their account of events. Any relevant forensic material will be handed over to forensics officers, and a post-mortem examination will be held to determine cause of death. In the following few days, the thanatologist(s) must meet with their solicitor and make a detailed statement about the event for the investigators. At this time, the thanatologiost(s) involved would be given the opportunity to speak to a welfare counsellor.

Following the completion of (an) individual statement(s), the thanotologist(s) involved would be suspended from practice (with pay) whilst an inquest is held into the death. If the inquest determines that the thanatologist(s) acted appropriately and their role in assisting a death was justified, they will return to active duty. If, in terms of whatever guidelines are used, the inquest determines that the assistance was not justified, then the thanatologist may be subject to a criminal investigation and, if found guilty, criminal sanctions. We might tentatively suggest, based on the arguments from proponents, and on the assumption that it may represent some common ground, that the following guidelines might suffice: "assistance to die should only be provided when absolutely necessary, and must be performed in the sincere and honest pursuit of humanitarian ends—those ends being to relieve intolerable suffering and act according to the demonstrable interests and/or autonomous decisions of the patient".

9.6.3 The Tightrope of Compromise?

This model represents a significant divergence from the well-trodden permissive path, because it proposes that an act of assisted dying can never be approved or justified in advance, and it also avoids the equally familiar prohibitive path, since it does allow for retrospective authorisation in some circumstances. As such, assisted in dying would only be judged lawful after the act. An act of killing is so serious, so final, and so *prima facie* reprehensible, that an individual who assists a death must do so according to their own conscience, taking full responsibility, and be prepared to be judged retrospectively. Under such a model, the state, and the law, would not sanction the act of killing before the act. The state and law would, however, outline circumstances under which an act of killing might be excusable.

Just as the criminal law accepts that actions that result in death can be lawful, for example, when acting under an honestly held belief that they were necessary for self-defence, it could accept that an action that results in death may be lawful, if it is performed in the sincere and honest pursuit of humanitarian ends—those ends being to relieve suffering and act according to the demonstrable interests and/or autonomous decisions of the patient.

We suggest that this model ought to satisfy both opponents and proponents of assisted dying on a number of contested points, which we will briefly outline.

First, because it would treat all assisted dying as potentially criminal, which must then be proven to be excusable (lawful), the model retains the message that life is to be valued. Certainly, in-roads are made into the notion that life must never be ended, but these would appear to be exceptional and would therefore capture something of Gillett's "pause".

Secondly, because the thanatologist can never be given prospective permission to end life, or immunity from criminal sanctions, the decision to assist a death is never "safe" and could never be taken lightly. The question will never be "can I do this without being prosecuted or investigated?", as would be the case if assisted dying were to be legalised in a prospective fashion. Rather, the question would be "can I excuse my action when I am investigated, and prove beyond reasonable doubt that I acted in the interests of my patient?". This ought to serve to put the brakes on any potential slippery slope, as it does not make assisted dying easy, and will ensure that the thanatologist only assists a death when s/he is certain that it is right thing to do, and can demonstrate this. It may, in fact, make assisting death so unappealing, because it is so personally risky, that it will fail to satisfy proponents of assisted dying.[13] We feel, however, that this is the correct point at which to compromise as it will ensure, as far as possible, that assisting dying never becomes comfortable. It will always be done at personal risk (just as is the case with firearms officers who make the decision to pull the trigger).

Thirdly, this model accepts that the medical profession in general should not be involved in assisted dying, but acknowledges that assisted dying is not incompatible with medicine per se, and may be in accordance with it on occasion (as has been discussed above). By creating a specialised subset, which is trained and "licensed", a clear message will be sent to the public, and to the profession, that there will remain a clear distinction between those professionals who will be involved in assisting death, and those who will not and cannot. Just as there is no good reason to mistrust all police officers simply because a small minority carry a gun and may use it, there is similarly no good reason to mistrust all doctors just because a small minority are permitted to assist death (see, e.g., Miller and Brody 1995, 14–15). That specialist subset must be rigorously selected and monitored, including psychological assessment—not just anyone should be given a "license to kill".

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[13] The practice might also remain rare because, as Stevens' (2006) research reveals, many doctors who have assisted in dying "are adversely affected emotionally and psychologically by their experiences."

9.7 Conclusion: Quantum of Solace?

We accept that not all parties will find solace in our proposed compromise. There are problems with our proposal, and a great deal more thought needs to go into it before it could be ever adopted as a policy.

The first such problem concerns the criteria against which an instance of assistance in dying should be judged, retrospectively, to be appropriate or inappropriate. We were (maybe noticeably) cautious about the qualifying criteria when we outlined our model. Perhaps assistance in dying should only be excused if it was initiated by an express, autonomous wish from the patient; or perhaps the model should accommodate proxy requests, such as those from the parents of critically ill infants or from other loved ones of incapacitated adult patients. Or maybe, more boldly still, the model should allow for these decisions to be made for incapacitated patients in the absence of such a proxy or prior request, on the basis that the worth (of the life) is not enough. We leave it to others to judge the exact qualifying criteria that might be adopted, if such a model is considered to have any merit.

Of course, if the model is endorsed, and it were to be adopted, then it will entail that some patients will be helped to die, albeit in exceptional circumstances. This would appear to offer more to proponents of assisted dying than to opponents. It effectively does allow assisted dying, and that may be too much for those who believe that life is sacrosanct and we should strive to protect and prolong life. For the less fundamentalist opponents, what we offer in our proposal is a safeguard that ought to prevent empirical/psychological slippery slopes, which maintains a high value on life, and which acknowledges the need to separate assisted dying from mainstream medical practice. We note, also, that the personal risk involved to the thanatologist is potentially so great, that it might dissuade many from ever assisting death, and this may present too large a barrier to be acceptable to proponents. We fall back, however, on the nature of compromise and the task we have been set in this volume to explore new directions. A new direction should admit the possibility of moving forward and making progress and, we would argue, making progress in this debate requires compromise. A compromise, by its very nature, means that each side gets something they want, but no side gets everything they want (see, e.g., Huxtable 2012). Our proposal fits the bill, and our hope is that it gives each side just enough of what they *need*, in order for them to accept it.

The latter point about preventing the slippery slope may fail, nonetheless, to accommodate legitimate concerns about "Bondian mavericks".[14] Momeyer (1995, 13), for example, refers to:

> the crusading, self-righteous Jack Kevorkian with his Volkswagen van, intravenous lines, face masks and tanks of carbon monoxide 'servicing' desperate strangers seeking to escape lives they no longer find endurable.

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[14] We are grateful to Genevieve Liveley, whose golden eye spotted this potential slope.

This kind of “maverick”, dedicated to the “cause” and willing to court controversy may be encouraged by our proposal, and see it as a licence to push the boundaries, which would certainly threaten the essence of our model.[15] Similarly, “villains” may be encouraged to become thanatologists and to use it to camouflage more questionable killings—one can easily imagine a character such as Harold Shipman taking such an opportunity.[16] One response may be to invoke the old adages about one bad apple and not throwing out the baby with the bathwater. There will always be rogue agents, but this is no reason to dispense with espionage altogether. A more useful response may be to note that it is precisely the idea of selection, training, assessment and ultimately “licencing” that would aim to filter out any putative thanatologist who is “suspect”. Anyone who is too keen, too quick, or just does not display the appropriate attitude would not get a license. The Platonic adage about not affording power to those who most want it springs to mind here, and we suggest that mavericks ought not be licenced in the first place, or would have their licence revoked if they display maverick tendencies. It is important, nonetheless, that this model incorporate some notion of the conscientious professional, who is correctly motivated, appropriately reflective, and will assist death as a last resort only when s/he is convinced that it is necessary and appropriate. Such a professional will also have to accept the possibility of criminal sanction, be prepared to be open and transparent, and be prepared to document and defend his or her actions at every turn.

9.8 Final Remarks: For Your Eyes Only?

The proposal we have outlined is deliberately controversial, and is offered as a thought experiment to encourage a stale debate to explore new directions and new possibilities for fruitful and defensible compromise. The proposal for compromise offered here is broadly permissive towards assisted dying, but it does not let the sky fall in on the value of life. Furthermore, it is not for your eyes only—we now turn this proposal over to the reader, to consider, discuss and respond to, in the hope that, even if the model ultimately proves unacceptable or unworkable, we have presented a new direction that is worthy of consideration.

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[15] Kevorkian is not the only ‘maverick’ of this kind; other examples include the Australian Dr. Philip Nitschke, and, in the UK, Michael Irwin, as well as Nicholas Reed and (self-appointed) “Dr” Lyons. In the 1980s, the latter pair had collaborated in a clandestine assistance-in-dying service, before they were discovered and convicted: see e.g. Huxtable (2007: 55–57, 78).

[16] Harold Shipman was a UK family doctor who, in 2000, was found guilty of murdering 15 of his patients. The subsequent judicial inquiry, examining nearly 500 of his patient’s deaths, found that he had killed 215 of his patients in total, the majority of whom were elderly women. See Smith (2002), 0917 GMT.

References

Anonymous. 1988. A piece of my mind. *JAMA* 259: 272.

Association of Chief Police Officers, Association of Chief Police Officers in Scotland, and National Policing Improvement Agency. 2011. *Manual of guidance on the management, command, and deployment of armed officers*, third edition. http://www.acpo.police.uk/documents/uniformed/2011/201111MCDofAO3.pdf.

Austin, J.L. 1956. A plea for excuses. *Proceedings of the Aristotelian Society* 57: 1–30.

Beauchamp, Tom L., and Arnold I. Davidson. 1979. The definition of euthanasia. *Journal of Medicine and Philosophy* 4: 294–312.

Beyleveld, Deryck, and Roger Brownsword. 2001. *Human dignity in bioethics and biolaw*. Oxford: Oxford University Press.

Biggs, Hazel. 1998. 'I don't want to be a burden!' A feminist reflects on women's experiences of death and dying. In *Feminist perspectives on health care law*, ed. Sally Sheldon, and Michael Thomson, 279–295. London: Cavendish.

Brazier, Margaret. 1996. Euthanasia and the law. *British Medical Bulletin* 52: 317–325.

Burt, Robert A. 2005. The end of autonomy. *Hastings Center Report, Special Report* 35: s9–s13.

Campbell, Martin. dir. 2006. *Casino Royale* [film]. UK: EON Productions.

Commission on Assisted Dying. 2011. *The current legal status of assisted dying is inadequate and incoherent*. London: Demos.

De Haan, Jurriaan. 2002. The ethics of euthanasia: Advocates' perspectives. *Bioethics* 16: 154–172.

Donchin, Anne. 2001. Understanding autonomy relationally: Toward a reconfiguration of bioethical principles. *Journal of Medicine and Philosophy* 26: 365–386.

Downie, Jocelyn. 2000. The contested lessons of euthanasia in the Netherlands. *Health Law Journal* 8: 119–139.

Doyal, Len. 2006. Dignity in dying should include the legalisation of non-voluntary euthanasia. *Clinical Ethics* 1: 65–67.

Dworkin, Ronald. 1993. *Life's dominion: An argument about abortion and euthanasia*. London: Harper Collins Publishers.

Foster, Charles. 2011. *Human dignity in bioethics and law*. Oxford: Hart.

Gaylin, Willard, Leon R. Kass, Edmund D. Pellegrino, and Mark Siegler. 1998. Doctors must not kill. *JAMA* 259: 2139–2140.

Gillett, Grant. 1988. Euthanasia, letting die and the pause. *Journal of Medical Ethics* 14: 61–67.

Gillon, Raanan. 2003. Ethics needs principles—four can encompass the rest—and respect for autonomy should be "first among equals". *Journal of Medical Ethics* 29: 307–312.

Hagelin, Joakim, Tore Nilstun, Jann Hau, and Hans-Erik Carlsson. 2004. Surveys on attitudes towards legalisation of euthanasia: Importance of question phrasing. *Journal of Medical Ethics* 30: 521–523.

Halliday, Robert. 1997. Medical futility and the social context. *Journal of Medical Ethics* 23: 148–153.

Harris, John. 1997. Euthanasia and the value of life. In *Euthanasia examined: Ethical, clinical and legal perspectives*, ed. John Keown, 6–22. Cambridge: Cambridge University Press.

Holm, Sören. 2010. Euthanasia: Agreeing to disagree? *Medicine, Health Care and Philosophy* 13: 399–402.

Huxtable, Richard. 2007. *Euthanasia, ethics and the law: From conflict to compromise*. London: Routledge-Cavendish.

Huxtable, Richard. 2012. *Law, ethics and compromise at the limits of life: To treat or not to treat?*. Abingdon: Routledge.

Huxtable, Richard, and Maaike Möller. 2007. "Setting a principled boundary"? Euthanasia as a response to 'life fatigue'. *Bioethics* 21: 117–126.

Huxtable Richard. and Mullock, Alexandra. 2015. 'Voices of discontent? Conscience, compromise, and assisted dying'. *Medical Law Review*, 23: 242–262.

Ives, Jonathan. 2014. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics* 28: 302–312.

Kass, Leonard R. 1975. Regarding the end of medicine and the pursuit of health. *Public Interest* 40: 11.

Keown, John. 2002. *Euthanasia, ethics and public policy: An argument against legalization*. Cambridge: Cambridge University Press.

Kuhse, Helga. 1987. *The sanctity-of-life doctrine in medicine: A critique*. Oxford: Clarendon Press.

Lewis, Penney, and Isra Black. 2012. *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. London: Demos.

Manninen, Bertha A. 2006. A case for justified non-voluntary active euthanasia: Exploring the ethics of the Groningen protocol. *Journal of Medical Ethics* 32: 643–651.

Miller, Franklin G., and Howard Brody. 1995. Professional integrity and physician-assisted death. *Hastings Center Report* 25: 8–17.

Momeyer, Richard. 1995. Does physician assisted suicide violate the integrity of medicine? *Journal of Medicine and Philosophy* 20: 13–24.

Ost, Suzanne. 2010. The de-medicalisation of assisted dying: Is a less medicalised model the way forward? *Medical Law Review* 18: 497–540.

Ouellette, Alicia. 2006. Disability and the end of life. *Oregon Law Review* 85: 123–182.

Parker, Malcolm. 2005. End games: Euthanasia under interminable scrutiny. *Bioethics* 19: 523–536.

Pellegrino, Edmund D. 2001. The internal morality of clinical medicine: A paradigm for the ethics of the helping and healing professions. *Journal of Medicine and Philosophy* 26: 559–579.

Rachels, James. 1986. *The end of life: Euthanasia and morality*. Oxford: Oxford University Press.

Rachels, James. 1993. Euthanasia, in T. Regan, ed. *Matters of life and death: new introductory essays in moral philosophy*, 30–68, New York: McGraw Hill.

Saunders, Peter. 2014. Support for UK assisted dying bill plummets to 43 % after hearing opposing arguments. http://www.lifesitenews.com/pulse/support-for-uk-assisted-dying-bill-plummets-to-43-after-hearing-opposing-ar. Accessed 29 Apr 2015.

Siegel, Andrew M., Dominic A. Sisti, and Arthur L. Caplan. 2014. Pediatric euthanasia in Belgium: Disturbing developments. *JAMA* 311: 1963–1964.

Singer, Peter. 1993. *Practical ethics*, 2nd ed. Cambridge: Cambridge University Press.

Smith, Stephen W. 2005. Fallacies of the logical slippery slope in the debate on physician-assisted suicide and euthanasia. *Medical Law Review* 13: 224–243.

Smith, Dame J. (2002). The shipman enquiry—first report: Death disguised. The National arc hives.http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/home.asp . Accessed 15 Aug 2014.

Stevens Jr, Kenneth R. 2006. Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians. *Issues in Law and Medicine* 21: 187–200.

UK Police Firearms Officers Association (PFOA), n.d. Post-shooting procedures. 2015. https://www.pfoa.co.uk/211/post-shooting-procedures. Accessed 29 Apr 2015.

Varelius, Jukka. 2007. Illness, suffering and voluntary euthanasia. *Bioethics* 21: 75–83.

Van Willigenburg, Theo. 2000. Moral compromises, moral integrity and the indeterminacy of value rankings. *Ethical Theory and Moral Practice* 3: 385–404.

van Zyl, Liezl. 2000. *Death and compassion: A virtue-based approach to euthanasia*. Aldershot: Ashgate.

Velleman, David J. 1992. Against the right to die. *Journal of Medicine and Philosophy* 17: 665–681.

Williams, Glanville. 1969. Euthanasia legislation: A rejoinder to the non-religious objections. In *Euthanasia and the right to death: The case for voluntary euthanasia*, ed. A.B. Downing, 134–147. London: Peter Owen.

Wreen, Michael. 1998. The definition of euthanasia. *Philosophy and Phenomenological Research* 48: 637–653.

Court Cases and Rulings

R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions [2014] UKSC 38.

Laws and Legislation

UK, House of Lords Select Committee (2005). *Assisted Dying for the Terminally Ill Bill* [*HL*], Volume I – Report, HL Paper 86-I, London: Her Majesty's Stationery Office, 125–127.

Chapter 10
Medically Enabled Suicides

Michael Cholbi

Abstract Medically enabled suicides occur when an individual (a) puts herself in a physiological condition requiring lifesaving medical care, and (b) the individual takes advantage of recognized treatment protocols (e.g., advance directives) requiring the withholding or withdrawal of care from competent patients to ensure that medical personnel enable her to die. Such suicides are likely to be attractive to those with chronic illnesses who either do not live in jurisdictions legally permitting assisted dying or who do not meet the legal requirements for assisted dying. Here I consider (and reject) two ethical objections to medical personnel refusing to participate in medically enabled suicides. The first alleges that medical care providers may not contribute to harming their patients, and so they may not contribute to their patients' suicides. The second alleges that if care providers, as a matter of personal conscience, believe that suicide is wrong, then they may not be compelled to contribute to their patient's acting wrongly by assenting to the wishes of a patient pursuing medically enabled suicide. Both dilemmas arise from the fact that while medical personnel are bound by widely accepted precepts of medical ethics to honor the competent wishes of their patients, medically enabled suicides entangle them in their patients' suicidal plans in ways that result in their contributing to those suicides. I conclude that neither dilemma should be resolved in the direction of medical personnel having the right to refrain from involvement in medically enabled suicides. Thus, while we may find medically enabled suicide distasteful or exploitative, a strong case cannot be made that medical personnel refusing to involve themselves in such suicides is ethically permissible.

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10.1 Introduction

Assisted suicide and voluntary euthanasia deviate from 'normal' death in two crucial respects. First, they are instances of self-killing, practices in which a person willfully brings about her own death. Second, they involve soliciting the aid of others to bring about one's death. The second category encompasses the first, for in soliciting another's aid to bring about one's own death, a person brings about her own death even if, as is arguably the case in voluntary active euthanasia, that person's death is caused by another person's acts instead of by her own. However, as the following example shows, it is possible for a suicidal person to involve others in her self-killing without soliciting their aid:

R. has been suicidal for nearly all of her adult life. Now in her late forties, R. was diagnosed with manic depression in her early twenties. She has been subject to a number of therapies over the past quarter century, including psychotropic drugs and ongoing counseling. Twice her symptoms have become severe enough to require hospitalization. R. has engaged in three previous suicide attempts. Two of these involved her taking large doses of over-the-counter painkillers, the third a clumsy attempt at cutting her throat.

R.'s desire to end her life of course ebbs and flows, but it is recurrent. When in her suicidal frame of mind, R. is not the slightest bit ambivalent about wanting to end her life. But one problem has been her choice of method. R. does not live in a jurisdiction where physician-assisted suicide is legally available, and even if she did, she would probably not qualify because her medical condition is neither terminal nor 'futile'. She finds her past suicide attempts a bit embarrassing: Only a coward uses methods known to be so ineffective. R. knows that guns are likely to be the most effective method, but she does not know the first thing about guns or how to get ahold of one—and even if she did, her history of hospitalization for mental illness would probably serve as a legal obstacle to obtaining a gun permit. R. is also reluctant to use violent methods or methods that would inflict physical trauma on her body because she does not want to be found in a bloody or brutalized state by her family. R. is thus in a quandary: Many of the most effective suicide methods are either unavailable or unattractive, but readily available methods are unreliable at best. Furthermore, she does not want to upset anyone through her suicide. She desires, above all else, a 'normal' death.

R.'s sister invites her to housesit while the sister and her family enjoy a vacation. R. recalls that her sister recently had the powerful painkiller oxycodone prescribed to her after major back surgery. Again feeling like life is futile, R. rummages through the medicine chest and finds the bottle of oxycodone and swallows ten times the dose suggested on the bottle. R. then calls a taxicab and directs the driver to deliver her to the nearest emergency room.

Within minutes after her arrival, R. collapses, unconscious. Hospital staff witness her collapse, find that her breathing has stopped, and ready her for emergency interventions. R. is fitted with an artificial ventilator. While her condition remains critical and her prognosis uncertain, R. can be kept alive indefinitely with the ventilator's assistance. R.'s sister, listed on R.'s admission form as her medical contact, arrives at the hospital. One hour later thereafter, medical personnel find in R.'s purse an advance directive she completed two years prior. R.'s advance directive states that she does not wish to be revived or resuscitated if her breathing or cardiovascular activity stops, nor does she wish to receive artificial lifesaving measures. The attending physicians honor the wishes stated in her advance directive and remove R.'s ventilator. R. dies within five hours of consuming the overdose of pain medication.

Assuming that R. completed the advance directive, with its 'do not resuscitate' clause, in anticipation of taking the drug overdose, then R. seemed to have knowingly and willfully implemented a plan that culminated in a death she endorsed. She seems then to have ended her life via suicide. But the example of R. is an atypical instance of suicide, a case of what I will call *medically enabled suicide.* Medically enabled suicides have four distinctive features:

1. *They are instigated by actions of a suicidal individual, actions she intends to result in a physiological condition that, absent lifesaving medical interventions, would be otherwise fatal to that individual.* In R.'s case, the painkiller overdose was aimed at putting her in a physiological state that is fatal. However, this state can nearly always be treated so as to prevent the patients' death.
2. *These suicides are 'completed' due to medical personnel acting in accordance with recognized legal or ethical protocols requiring the withholding or withdrawal of care from patients (e.g., following an approved advance directive).* R. dies in part because medical personnel honor an advance directive proscribing her receiving lifesaving care. Medically enabled suicide could also occur when competent patients refuse lifesaving care 'at the bedside'.
3. *The suicidal individual acts purposefully to ensure that medical personnel will act on these protocols.* R. filled our her advance directive recognizing that its provisions, if honored, would make it the case that her drug overdose would lead to her death.
4. *These suicides do not involve medical personnel providing aid in dying in the standard sense, either through* (a) *active voluntary euthanasia, or* (b) *assistance by means of prescriptions, etc.* Medically enabled suicides involve the participation of medical personnel, but not their "assistance," as that is standardly understood. Medical personnel, acting on protocols requiring the withholding or withdrawal of care, participate in patients' suicidal plans without consenting to participating in those plans insofar as those plans aim to end the patient's life. The patient's underlying physiological condition ends up killing her, rather than (say) the subsequent administration of a lethal medication.

The frequency of medically enabled suicides cannot be estimated with any accuracy. In the United States, nearly half a million people are treated in emergency rooms for self-inflicted injuries or harm each year (US Centers for Disease Control 2012). Recent surveys indicate that about one-third of adults have a living will or other provision for their end-of-life care. About half of all Americans indicate that there are some circumstances in which they would refuse or cease treatments even if this would result in their deaths (Pew Research Forum 2013). Of course, no reasonable inferences can be made from this data about the prevalence of medically enabled suicides. But the number of self-inflicted injuries, combined with the fact that many adults have concluded that they would sometimes prefer not to receive life sustaining treatments, suggests that medically enabled suicides, while rare, do occur. In a survey of English clinicians treating self-poisoning (reported in Kapur et al. 2010), an advance directive was mentioned in 2.5 % of cases. The case of Kerrie Wooltorton is a real life example where an advance directive came into play in the treatment of suicidal injuries (Dresser 2010; Szawarski 2013).

Regardless of how common medically enabled suicides are, they raise compelling questions at the interface of medicine and individual choice. After first clarifying the concept of medically enabled suicide and exploring some of the reasons why it might be attractive to suicidal individuals, I then investigate two apparent dilemmas that medically enabled suicides raise for medical care providers. The first alleges that medical care providers may not contribute to harming their patients, and so they may not contribute to their patients' suicides. The second alleges that if care providers, as a matter of personal conscience, believe that suicide is wrong, then they may not be compelled to contribute to their patient's acting wrongly by assenting to the wishes of a patient pursuing medically enabled suicide. Both dilemmas arise from the fact that while medical personnel are bound by widely accepted precepts of medical ethics to honor the competent wishes of their patients, medically enabled suicides entangle them in their patients' suicidal plans in ways that result in their contributing to those suicides. I conclude that neither dilemma should be resolved in the direction of medical personnel having the right to refrain from involvement in medically enabled suicides. Thus, while we may find medically enabled suicide distasteful or exploitative, a strong case cannot be made that medical personnel refusing to involve themselves in such suicides is ethically permissible.

10.2 The Concept of Medically-Enabled Suicide

Before considering the ethical obligations of medical caregivers as regards medically enabled suicides, we must first answer worries to the effect that medically enabled suicide is a conceptually suspect category.

First, are the actions of R. suicide at all? One reason for doubt is that in order for R. to die, others must act in specific ways. In this case, R. will not die unless medical personnel withdraw the ventilator in accordance with the wishes R. stated in her advance directive. Suicide is *self*-killing. But an act is not precluded from being suicidal on the grounds that should death occur, an agent besides the suicidal individual had to act in a specified way. In the phenomenon known as 'suicide by cop', an individual commits a crime in the hope that police officers will be provoked to kill her. Here the individual acts with the intention of bringing about her own death, but is not the cause of her own death (or at least is not the immediate cause of her own death.) Likewise, in medically enabled suicide, an individual initiates a plan of action whose success hinges upon another's act. Both acts are necessary conditions of her suicide succeeding in bringing about her death, but the fact that her plan of action may not be sufficient on its own to bring about her death does not imply that her action is not suicidal. Furthermore, on standard definitions, suicide is *intentional* self-killing. But acting with an intention that one bring about one's own death need not entail that one's acts are the *cause* of one's own death (Cholbi 2011a, 21–26). In cases such as R., an individual wishes to be dead, initiates a plan of action a success condition of which is (from her point of view) her own death, and dies as a result. Her actions are most coherently described as trying to die by virtue of her rational endorsement of dying as a means to her presumed end, relieving her own suffering or anguish. Medically enabled suicide thus clearly qualifies as suicide.

Some will resist the claim that such suicides are medically enabled, i.e., that they are in any way brought about by the involvement of medical personnel. After all, in acceding to the R.'s advance directive, medical personnel do not necessarily share R.'s intention. For they may not endorse the end she seeks to achieve. In examining the example of a suicidal individual "Tony," with a similar clinical history and suicidal intention as R., Salter (2014, 46) argues that such examples do not constitute "aiding or abetting suicide":

> The decision to attempt suicide (by Tony) and the decision to withdraw care (by other relevant decision makers) are two separate — although certainly connected — issues. The hospital and clinicians did not aid, or even support, Tony's original actions. They were not actors in that decision. … a subsequent, post-stabilization decision to withdraw treatment is separate from the suicidal act by the *initial* response of the medical team, which is to act contrary to the original goals of suicide. While Tony's intention to cause his own death can be assumed, this need not be the intention of the clinicians in order for treatment to be withheld. Indeed, as is the case for all treatment refusals, it is assumed that the intention is not death, but instead to *not prolong* death or to *relieve* pain and suffering …Thus, the clinicians' initial response to the suicidal patient and their divergent intentions sufficiently dissociate a decision to withdraw treatment from the original suicide attempt.

Salter is certainly correct that in such cases, clinicians do not aid or abet suicide inasmuch as they do not provide care with the intention of helping patients end their own lives. However, the partition between that intention and intentions such as relieving pain, etc., is more porous than Salter recognizes. For one need not intend what another intends in order to act knowingly so as to enable their intention to be realized. The cashier forced to turn over money at gunpoint does not share the thief's intention of robbing the merchant. Yet in turning over the money, he does help the thief succeed in this intention. (This does not entail that the cashier is rightfully blamed when the thief makes off with the money.) Similarly, Salter's argument does not enable clinicians to fully dissociate themselves from patients' suicidal intentions, leaving them with 'clean hands' in cases such as these. Perhaps they ought not be blamed for their patients' suicide, but that does not mute the ethical questions concerning their non-consensual involvement in them.

A more complex worry occurs when medically enabled suicide happens not as a result of ceasing life sustaining treatment but as result of never starting it. Suppose that R.'s advance directive had been discovered *before* the introduction of the mechanical ventilator, and medical personnel honor the directive. Might one argue that in this case, medical personnel do not enable R.'s suicide simply because involvement in her suicide requires them to act, and in this instance, the directive mandates that they *not* act? My opponent might rest this argument on the premise that medical personnel do not act to bring about her death but merely let R. die.

This conclusion is not plausible though. Action cannot be equated with behavior. And while it is true that in this case, there may not be discrete bodily movements that count as medical personnel not introducing the ventilator to R., their omission nevertheless counts as an act. For to refrain from doing what would otherwise be obligatory is an act—a mental act of choice. To deny this seems to invite sophistical conclusions. A bad Samaritan cannot assert that his not helping was not a wrongful act because he did not act, i.e., there is not some identifiable bodily movement that counts as his 'inaction.' Rather, he enables the death of the individual whom he opts not to help just as medical personnel enable R.'s suicide: by rationally choosing not to perform an act.

A final conceptual worry regarding medically enabled suicide is that it cannot be suicide because it is not a species of killing at all. One might argue that in R.'s case, she was not killed by anyone. Because R. was provided the ventilator, her suicidal act (her effort to kill herself) was interrupted by the actions of medical professionals. According to some physicians and medical ethicists, the subsequent removal of the ventilator results in R. dying from untreated respiratory failure. *No person* kills R. Rather, untreated respiratory failure kills her. Since R. is not killed by anyone, she does not kill herself and therefore cannot count as an instance of suicide.

This argument rests on the contentious claim that in removing R.'s ventilator, her doctors were not killing her but merely allowing her to die. I find this distinction implausible, an ethical shibboleth to sustain the fiction that doctors may not kill their patients (Miller et al. 2010). However, I will not contest that here. Instead, I draw attention to the apparent false dichotomy presupposed in this objection: Either R. is killed by someone (herself or someone else) or she is killed by her underlying condition. This objection seems to presuppose that if underlying respiratory failure kills the patient, then no one killed the patient. This presupposition reflects a crude picture of causation and the role of human agency in causation. For what distinguishes non-natural deaths is precisely a kind of dual causality: In cases of suicide or homicide, there are always two 'killers,' the individual who sets in motion a causal chain intending to lead to a person's death, and the condition within that causal chain that proves fatal. Both the agent who kills and the condition that kills can be said the kill the person. In R.'s case, it is true both that R. killed herself (with medical professionals enabling this) and that untreated respiratory failure kills her. Indeed, it was R.'s intention in fashioning her advance directive and then taking the overdose that the withdrawal of treatment would kill her. She intended to kill herself by putting herself in a condition that would kill her once medical professionals responded appropriately to her advance directive. That the causal chain from her overdose to her death was interrupted by medical interventions does not make it any less the case that she killed herself. This is apparent when we envision a parallel case of homicide: Suppose that, in the course of an attempted robbery, R. was viciously attacked by a physician who just happened to have a portable mechanical ventilator. R.'s injuries are grievous enough that she will die without the ventilator. The physician fits R. with the ventilator and her condition stabilizes. Rummaging through the victim's pocket, the physician finds an advance directive, mandating that mechanical ventilation not be administered. The attacking physician complies with the directive and R. dies as a result. No one would deny here that the physician killed R., despite its also being true that an underlying condition created by the physician killed R. Likewise, there is no basis for claiming that R. (in our original case) was not killed by anyone because her underlying physiological condition killed her.

10.3 The Attractions of Medically Enabled Suicide

Again, I make no assertion that medically enabled suicides are common. But it does represent a conceptually coherent category, and I would not be surprised if its numbers are significant and growing.

Why might someone seek out medically enabled suicide, and more specifically, why might someone opt for medically enabled suicide rather than suicide *simpliciter*? What is gained via a suicidal act intended to engage with medical care providers? These questions can be answered by noting that medically enabled suicide occupies a middle ground between more orthodox acts of suicide and the forms of assisted dying—physician-assisted suicide or voluntary euthanasia—available in a few jurisdictions (Dresser 2010). For while medically enabled suicide involves medical personnel in the death of an individual, it does not occur with the consent of those personnel. Hence, the attractions of medically enable suicide become more apparent when we consider the attractions of assisted dying.

First, many suicidal persons are deeply concerned for the effects that their deaths will have on others (Cholbi 2011b). In fact, according to Thomas Joiner's well-developed theory of the causes of suicide, most suicidal persons are moved to end their lives from an essentially altruistic motive, the belief that they are burdensome to others (Joiner 2007). Most suicidal individuals also want to spare their loved ones the trauma of discovering their corpses or of encountering a badly damaged or brutalized corpse. Yet some of the most effective methods for ending one's life (notably, guns) do tend to leave a damaged or brutalized corpse, and in many jurisdictions they are difficult to obtain in any case. Assisted suicide or euthanasia, because they are pre-arranged and use hygienic lethal methods, avoid such traumas. Moreover, assisted dying, while controversial, is also likely to be less psychologically distressing than ordinary suicide. Given the stigma of suicide, including popular beliefs associating suicide with madness or irrationality (Joiner 2010), individuals who wish to die have strong motivations to normalize their life-ending choices in ways that give those choices a patina of societal approval. By "medicalizing" patient self-killing, assisted suicide and euthanasia render self-killing less deviant, particularly in societies where over half of all people die in hospitals or other medically licensed facilities (US Department of Health and Human Services 2010, 43). Assisted suicide or euthanasia are less secretive or clandestine than standard suicides. Assisted suicide and euthanasia thus enable patients to have deaths with more of the features of a "good death": peacefully, with family members and loved ones at one's bedside. Finally, assisted suicide and euthanasia remove uncertainty regarding death as an outcome. Fortunately or not, many suicide methods, such as cutting or overdoses of over-the-counter medications, are not especially effective in bringing about death. The methods and techniques deployed for assisted suicide and euthanasia sometimes fail to end a patient's life swiftly and without complication. One study of assisted dying in the Netherlands found that complications occur up to 16 % of assisted suicides or euthanasias. Rarely, however, do these complications postpone a patient's death to a later date (Groenwoud et al. 2000). In contrast, ordinary suicide has a 'success rate' (i.e., a suicide attempts actually kills the suicidal person) in the single digits (World Health Organization 2006). Of course, the explanations for why suicide attempts prove not to be lethal are diverse. A medically enabled suicide in which an individual chooses a method with the very low probability of being lethal is not more likely to kill that individual than when an individual chooses that same method for a standard, non-medically enabled suicide. But a medically enabled suicide does circumvent one factor that prevents some suicidal acts from resulting in death, namely, medical interventions. Medically enabled suicides, by removing one significant barrier to a suicide attempt's being lethal, have a greater likelihood of killing the suicidal individual.

Thus, because assisted suicide or euthanasia essentially medicalize the process of self-inflicted death, they offer suicidal patients a number of advantages over standard attempts at suicide. A death that is less traumatic, more conventional, more transparent, and more certain will be more desirable for most suicidal individuals. But of course, few suicidal persons live in the half dozen or so nations or five U.S. states that legally permit assisted suicide or voluntary active euthanasia. And even if a suicidal person lives in one of these jurisdictions, she is not likely to meet the legal criteria for assisted dying. R., suffering from bipolar disorder, does not suffer from a condition that is standardly classified as terminal, nor would her condition be judged futile (Cholbi 2013). Indeed, given that the vast majority of suicidal persons suffer from mental disorders (Joiner 2007, 192–202) rather than conditions such as cancer, few would satisfy the criteria to be eligible for assisted suicide or euthanasia. Finally, few suicidal patients will want to subject their care providers to legal risk, but at the same time, they may have difficulty identifying physicians willing to assist in their suicides, especially given (again) that they are not likely to be suffering from a condition that is terminal or medically futile. In most jurisdictions where assisted dying is available, the involvement of medical personnel is voluntary. The number of personnel involved in assisted dying is sometimes minute. In Oregon, whose Death with Dignity Act provides a legal protocol for assisted suicide wherein physicians can write prescriptions for lethal medications, only about 60 physicians generally write such prescriptions in a given year (Oregon Health Authority 2014). In a state with an active physician population of nearly 11,000 (Association of American Medical Colleges 2013, 191), that entails that only 0.5 %, or one in 200, of physicians have agreed to write such prescriptions. Consequently, even patients legally eligible for aid in dying may be unable to identify willing medical partners.

Assisted suicide or voluntary euthanasia thus offer considerable advantages to suicidal individuals, but also present considerable obstacles. My suggestion is that medically enabled suicides represent the next best alternative for many patients. Medically enabled suicide enables suicidal individuals to compel the engagement of medical personnel with their suicidal plans, but unlike in assisted suicide or euthanasia, without securing medical personnel's *assent to* their suicidal plans. Medically enabled suicide also allows individuals to have a 'normal,' even 'good' death, in a culturally sanctioned clinical setting. Their deaths are less violent and more tranquil. Medically enabled suicides are culturally sanitized, cleansed of many of the popular negative associations with suicide. Suicidal individuals may also be able to exploit the ambiguity, both emotional and legal, of their courses of death. Their families and loved ones are less likely to associate their deaths with 'suicide,' given that it occurs in a care facility under the observation of medical personnel.

For patients like R., medically enabled suicide represents a viable middle ground between ordinary suicide—often more uncertain, dangerous, and psychologically harrowing—and a fully supervised 'medical' death. This is not to say that medically enabled suicide is without risk. For instance, an individual like R. may, due to ignorance or carelessness, take a fatal dose of a drug, thus resulting in an ordinary, rather than a medically enabled suicide. Still, the strong deference to patient choice regarding medical treatment seems to allow suicidal individuals to pursue a medically supervised, though not medically sanctioned, suicide.

10.4 Dilemma 1: Self-determination Versus Harming the Patient

But should medical personnel who are aware that they are being enmeshed in a medically enabled suicide assent to doing so? One rationale for their having a right not to participate in the care of someone with a clear intention to engage in medically enabled suicide stems from the claim that medical personnel should not knowingly harm their patients:

(1) For a patient to end her life is a harm to a patient.
(2) Medical personnel may not knowingly contribute to harming a patient.
(3) So medical personnel may now knowingly contribute to ending a patient's life.

Therefore, medical personnel may not medically enable a patient's suicide.

This argument is valid: (3) is a proper inference from (1) and (2), and the conclusion is inferred from (3) (along with the definition of suicide). However, the soundness of the argument is questionable.

To begin, (1) assumes that suicide is a harm to patients. Suicide can harm individuals by killing them, but it does not designate a class of harms. Rather, suicidal acts (should they succeed in killing a person) are harmful only if death is harmful. According to the most widely accepted account of the possible harms of death, the comparativist account, whether death is a harm to an individual at a given time is determined by comparing (a) the overall well-being contained in the individual's life if she dies at that time with (b) the overall well-being contained in the life the individual would have had if she had not died at that time (more specifically, the overall well-being her life would have had if she had died at the next most likely time for her to die) (Feldman 1991). In other words, death is bad for us when, on balance, we would have enjoyed more intrinsic goods by surviving longer. According to comparativism, was R.'s death bad for her? Of course, this is a complex question, requiring us to think about the course of her life thus far, her likely future well-being, and the overall shape of the life she had with that of the life she would have had. Our concern here is not with what the correct answer is in R.'s case, or in any particular case. Rather, our concern is with the universal proposition implied in (1)—that suicide is always a harm to an individual. Clearly, if the comparativist account is correct, that will be a contingent matter. And it seems plausible to suppose that at least sometimes a person's dying prematurely due to suicide results in her having a better (albeit shorter) life overall than the life she would have had if she had continued to live.

As for (2), it is clearly not true in its unqualified form. For one, there will be many risky medical treatments for which it is not apparent whether medical personnel are knowingly contributing to harming patients. Or at the very least, whether they contribute knowingly to harming a patient can only be judged in retrospect. Furthermore, medical personnel are clearly not barred from contributing to harming a patient when the evidence suggests that such harms are essential to a larger course of treatment that will prove beneficial to a patient. Many treatments have harmful side effects. But surely medical personnel are permitted to administer or recommend such treatments, despite their harmful side effects, precisely because of the reasonable expectation that the patient stands to benefit on the whole. It would remarkable if, for example, (2) disallowed medical personnel from administering chemotherapy to early stage cancer patients simply because chemotherapy is known to subject patients to identifiable harms.

Supposing that (2) could be amended to meet this worry, other worries become apparent when we consider whether medical personnel may contribute to harming their patients in non-suicidal cases. If a competent patient opts not to receive (or to forego) a life extending treatment, few medical personnel believe they are entitled to recuse themselves from the provision of care because of their belief that such care contributes to the patient being harmed. Their belief that the patient's choice is harmful to her may well be true (and true according to the comparativist account of death's badness). But medical personnel routinely involve themselves in courses of care or treatment that harm patients via the withholding or withdrawal of treatment. It would, I propose, be a dramatic reinterpretation of extant medical ethics if medical personnel could refuse to provide care or treatment that *they* believed to be on balance harmful to patients, even when their belief is true.

This illustrates that (2) intersects with (1) in thorny ways: To assume that medical personnel may not contribute to harming patients is to prioritize non-maleficence over other core bioethical principles, most notably, patient autonomy. It seems rather to be the case that either (a) medical personnel must honor patient autonomy and provide care that is objectively harmful to patients, or (b) patient autonomy rests on the thesis that a patient's competent judgment regarding whether a course of action is harmful to her is determinative, that is, a judgment to that effect is one to which medical personnel ought to defer, perhaps on the grounds that only the patient is epistemically positioned or entitled to make such a judgment on her own behalf. Either way, medical personnel who refuse to provide specified forms of care in order to avoid doing what they believe harms the patient thereby consign patient autonomy to a rather marginal role in their understanding of their clinical obligations.

I conclude, then, that this dilemma dissolves under further scrutiny. It rests either on contestable claims about the harmfulness of suicide or is difficult to make consistent with the value the medical community ascribes to patient autonomy. The apparent dilemma is therefore best resolved in favor of medical personnel being obligated to participate in medically enabled suicides.

10.5 Dilemma 2: Self-determination Versus Contributing to Suicide

A second dilemma caregivers may face with respect to medically enabled suicides arises from the conviction that suicide is morally wrong. That conviction is clearly controversial, and I will not attempt to decide that matter here (Cholbi 2011a, 39–69). But if, as some believe, it is reasonable to permit medical personnel who conscientiously object to abortion to forego participating in abortion procedures or to forego the provision of abortifacient drugs, then it is reasonable to permit those who conscientiously object to suicide to forego involvement in medically enabled suicides. Indeed, conscientious objection to involvement in medically enabled suicide may rest on similar grounds to conscientious objection to abortion (that it kills the innocent, etc.). If so, those with conscientious objections to suicide may believe that medically enabled suicides place them in a dilemma, demanding that they either ignore their own consciences or ignore patient autonomy.

This second dilemma can be resolved by addressing an importantly different case from R.'s:

S. is injured in a gruesome industrial accident. Though S. survives her injuries and could likely live for a significant period of time post-hospitalization, many of her injuries are permanent. S. had one leg and one arm amputated. In addition, S. suffered injuries to her chest, abdomen, and lungs, and as a result S. has lost the ability to speak and requires supplementary oxygen. S. will be unable to feed herself and will never be employed again. Although S. may be able to return home, the regular presence of a home health aide will be necessary.

A few months after returning home, S. suffers an episode of severe respiratory distress. Once stabilized, S. tells nurses present that she no longer wishes to live with such poor quality of life, at constant risk of complications or hospitalization. She asks that her respirator and feeding tube be removed later that day. S.'s family congregates at the hospital. S. permanently loses consciousness several hours after the respirator and feeding tube are removed. She is declared brain dead 16 h later.

The most morally salient difference between R.'s situation and S.'s is the causal role played by their respective desires to die. In R.'s case, her desire to die is a *cause* of the state of the affairs produced by her self-injury, a state of affairs she directs others to intervene in so that she will die. In S.'s case, her desire to die is an *effect* of the state of the affairs produced by her injury, a state of affairs she directs others to intervene in so that she will die.

Those who believe that medical personnel should be entitled to abstain from involving themselves in medically enabled suicides must put a great deal of argumentative weight on this contrast. For it seems uncontroversial that S.'s competent request to cease life sustaining measures must be honored. Thus, if R.'s advance directive is not to be honored but S.'s request is, this pair of judgments must rest on plausibly ascribing inherent moral significance to the different roles played by the desire to die in each case. It will not suffice to assert that the difference is that R.'s desire led her to suicide, whereas S.'s did not. For one, it is arguable that both are suicides, inasmuch as both R. and S. undertake courses of action intended to result in a death that has their rational endorsement in the circumstances. But even if we embrace the contrary view that R. engaged in suicide while S. merely allowed herself to die, we do not yet have a principled basis for a conscientious objection to not medically enabling R.'s death while acceding to S.'s request, aware that it will end her life. As LaFollette and LaFollette (2007) observe, a claim of conscientious objection is subject to a number of criteria, among them that the objection rests on a "core belief" of the objector, "consistent with other things he says or does" in the course of his professional practice. In my estimation, the objector bears the burden of proof here to show that his objection(s) to the treatment in question can be coherently squared with his other attitudes. No doubt *some* avenue is available to justify disparate treatment of R. and S., but I cannot ascertain an avenue that would succeed in showing that the differing causal roles played by their respective desires to die justify their disparate treatment by medical personnel.

I propose, then, the contrast between a desire to end one's life being a cause of an injury and its being an effect cannot bear the weight necessary to justify conscientious objection to medically enabled suicide. Furthermore, advocates of such an objection must address the apparent comparative unfairness faced by R. Both R. and S. are victims of bad moral luck. R.'s bad luck is a combination of circumstantial and constitutive luck, luck emanating both from her surroundings or environment and from her unchosen traits or dispositions. S.'s bad moral luck is circumstantial and resultant, emanating from her surroundings or environment and from variations in outcomes (i.e., S. or other workers had been in the same workplace situation many times in the past without being injured) (Nagel 1979). I cannot address the large scale questions about justice raised by how victims of bad moral luck should be treated. Luck egalitarian theories of justice, for example, requires that differences in individuals' well-being, opportunities, etc., should hinge wholly on their choices and not on the sort of bad luck that befell R. and S. But we need not embrace such theories wholeheartedly to conclude that, absent some compelling argument to the contrary, victims of bad moral luck who are otherwise alike should not be treated differently. As we saw above, there is one notable difference between R. and S. that does not depend on luck, namely, that R. put herself in a life-threatening medical condition through her own conscious acts (granting that those acts would not have been performed were it not for facts about R., such as her illness, that arguably are the product of luck). But this difference, not dependent on luck, does not warrant differential treatment of them. Yet no luck-based differences exist between R. and S. to warrant differential treatment of them either. Again, that R.'s desire to die causally prompted her injury, whereas S.'s desire to die was effected by her injury, is not a difference that warrants differential treatment of them. R. may rightfully complain that if, her advance directive is not honored and her medically enabled suicide attempt stymied, but S.'s request to end life sustaining interventions is honored, then she is treated differently without any moral basis. She would thus be twice victimized, first by her own moral luck, and second, by those medical personnel who unjustifiably refuse to honor her directive. It does not seem reasonable for our moral obligations to differ from patient to patient simply because the patient has a self-inflicted condition (Salter 2014, 44).

10.6 A Note About Competency and Mental Illness

To this point, I have shown that medically enabled suicide is attractive to those in particular medical and social circumstances. Moreover, the apparent dilemmas that medically enabled suicide raises for medical caregivers are just that: apparent. Upon further analysis, there are not plausible arguments, appealing either to the wrongfulness or harmfulness of suicide, that make sense of caregivers justifiably disregarding the wishes of those suicidal persons who enlist those caregivers in enabling their suicides. Hence, one horn of each dilemma turns out to be specious. Suicidal persons have a right to have medical personnel enable their suicides.

In reaching this conclusion, I do not claim that medically enabled suicide is in no way morally problematic. One might think that medically enabled suicide amounts to exploiting or taking advantage of ethical rules or protocols designed for a very different purpose, to wit, to ensure that individuals can choose the courses of treatment that they judge best for their health and well-being. But we do not have to admire R. or her choices to believe that she has the right to make them and that medical personnel are obligated to enable her to achieve her chosen ends.

One possible reaction to the arguments I offered in Sects. 10.3 and 10.4 is to claim that there are other bases for medical personnel disregarding R.'s advance directive besides the harmfulness or wrongfulness of suicidal conduct. R. collapses into unconsciousness soon after arrival, rendering her an incompetent decision maker. And of course those are precisely the circumstances in which an advance directive is applied: when an individual is unable to render competent decisions on her own behalf. A defender of medical personnel having the right to disregard the advance directive might argue that, in light of R.'s ongoing mental illness, the advance directive should be disregarded. But this assumes that the mere fact of R.'s being mentally ill (or having been ill when she fashioned her directive) is sufficient to overcome the strong burden of proof normally associated with challenges to advance directives (Appelbaum 2007). Note that it is rarely assumed that those who create advance directives while suffering from the travails of 'physical' disorders are creating invalid directives. Indeed, there remain pervasive prejudices about mental illness, prejudices that deny that these conditions are genuine or that the suffering they produce can measure up to other forms of suffering. We should therefore be very wary of those willing to dismiss R.'s advanced directive solely on the grounds that her condition, being mental, is 'all in her head' (Cholbi 2013). I am thus sympathetic with the conclusion reached by Brown et al. (2013, 10–11) that the cause of a patient's condition, including whether that cause is psychiatric in nature, should not affect clinicians' willingness to forego or withdraw life support, and that such acts are the "rough moral equivalent of withdrawal after comparable critical illness or injury." In any case, the determination of R.'s competency at the time when the advance directive was already performed by other professionals, and it would be imperious indeed for medical personnel to later decide that the directive was itself incompetently fashioned.

Those advocating that the advance directive may be disregarded may then appeal to the claim that R. engaged in irrational suicide behavior. Even if the advanced directive was competently fashioned, R. only needs medical attention because of an irrational act on her part. But this argument is even less appealing: As we saw in Sect. 10.3, the comparativist account implies that ending one's life prematurely is not necessarily irrational. Furthermore, to allocate medical care on the basis of whether a person's condition stems from an irrational choice on her part is anomalous, even cruel. Medical personnel do not deny care to motorcycle riders who irrationally choose not to wear their helmets, nor do they deny care to those whose injuries result from irrational alcohol abuse. It is simply no part of recognized medical ethics to determine which patients deserve care by appeal solely to clinicians' judgments about the wisdom of those patients' choices. Lastly, the central rationale for advance directives is to enable individuals to exercise a form of penumbral autonomy—to ensure that medical decisions made while one is incompetent reflect the values or preferences one can express while competent. Among R.'s purposes in creating the advance directive was to provide guidance to medical personnel on how she ought to be treated while in the incompetent condition that she herself created through her suicidal act. Yet an unsettling precedent would be set were medical personnel to set aside the advance directive purely because the patient's own act triggered the condition under which the directive became salient.

Admittedly, competency is a more difficult matter if, unlike R., the patient is conscious and expressing wishes regarding her care. Here familiar, but not simple, problems arise concerning the determination of competency. Medical personnel would be advised to consider not just the suicidal patient's expressed wishes in the moment, but also other evidence concerning her wishes (an advance directive should one exist, suicide notes, prior statements to family members, and so on). But determining competency is an ongoing feature of clinical practice, to be pursued on a case by case basis, and so cannot offer a principled, or even presumptive, basis for medical personnel refusing to involve themselves in medically enabled suicides.

10.7 Conclusion

In arguing that these two dilemmas are specious, I have sought to undermine whatever principled moral ground there might be for permitting medical personnel to refuse participation in medically enabled suicide. An implication of my arguments is that the fact the individual arrives at a life-and-death point via an act of suicide is not per se ethically relevant to the treatment obligations that medical personal bear toward such an individual (Lowenthal 2002). Again, concerns about patient competency are relevant, but no special issue of clinical ethics is raised by the facts of the patient having engaged in suicide or having done so in the hope of achieving a medically enabled suicide. For neither fact is more than contingently related to morally salient facts that do shape treatment obligations. Desperate times call for desperate measures, and so long as most suicidal individuals lack access to assisted dying, it appears likely that at least a handful will seek what they believe is a good death for themselves. Medically enabled suicide offers such individuals the advantages of a death with medical personnel acting as death's non-consensual guarantor. If I am correct, medical personnel must fulfill this role, however distressing that may seem.

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References

Appelbaum, Paul S. 2007. Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine* 357: 1834–1840.

Association of American Medical Colleges. 2013. State physician workforce data book. http://bit.ly/1zVifbV. Accessed 21 July 2014.

Brown, Samuel M., C. Gregory Elliott, and Robert Paine. 2013. Withdrawal of nonfutile life support after attempted suicide. *American Journal of Bioethics* 13: 3–12.

Cholbi, Michael J. 2011a. *Suicide: The philosophical dimensions*. Peterborough, Ontario: Broadview.

Cholbi, Michael J. 2011b. Depression, listlessness, and moral motivation. *Ratio* 24: 28–45.

Cholbi, Michael. 2013. The terminal, the futile, and the psychiatrically disordered. *International Journal of Law and Psychiatry* 36: 498–505.

Dresser, Rebecca. 2010. Suicide attempts and treatment refusals. *Hastings Center Report* 40: 10–11.

Feldman, Fred. 1991. Some puzzles about the evil of death. *Philosophical Review* 100: 205–227.

Groenewoud, Johanna, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen, Dick L. Willems, Paul J. van der Maas, and Gerrit van der Val. 2000. Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. *New England Journal of Medicine* 342: 551–556.

Joiner, Thomas. 2007. *Why people die by suicide*. Cambridge: Harvard University Press.

Joiner, Thomas. 2010. *Myths about suicide*. Cambridge: Harvard University Press.

Kapur, Navneet, Caroline Clements, Nick Bateman, Bernard Foex, Kevin Mackway-Jones, Richard Huxtable, David Gunnell, and Keith Hawton. 2010. Advance directives and suicidal behavior. *BMJ* 341: c4557.

LaFollette, Eva, and Hugh Lafollette. 2007. Private conscience, public acts. *Journal of Medical Ethics* 33: 249–254.

Lowenthal, David. 2002. Commentary on D'oronzio, "The suicide note". *Cambridge Quarterly of Healthcare Ethics* 11: 423–425.

Miller, Franklin G., Truog, Robert D., and Brock, Dan W. 2010. Moral fictions and medical ethics. *Bioethics* 24: 453–60.

Nagel, Thomas. 1979. Moral luck. In Thomas Nagel, ed. *Mortal Questions*, 24–38. New York: Cambridge University Press.

Oregon Health Authority. 2014. Death with dignity act annual reports. http://1.usa.gov/UjAE1k. Accessed 21 July 2014.

Pew Research Forum. 2013. Views on end-of-life medical treatments. Religion and Public Life Project. http://bit.ly/1nM4p1v. Accessed 17 July 2014.

Salter, Erica K. 2014. The desire to die: Making treatment decisions for suicidal patients who have an advance directive. *Journal of Clinical Ethics* 25: 43–49.

Szawarski, Piotr. 2013. Classic cases revisited: The suicide of Kerrie Wooltorton. *Journal of the Intensive Care Society* 14: 114–211.

US Centers for Disease Control. 2012. Suicide facts at a glance, 2012. http://1.usa.gov/WxaABz. Accessed 17 July 2014.

US Department of Health and Human Services. 2010. Health, United States 2010. http://1.usa.gov/1nsPbo0. Accessed 21 July 2014.

World Health Organization. 2006. Live your life. http://bit.ly/1n2ChvP. Accessed 20 July 2014.

Chapter 11
Saving Lives with Assisted Suicide and Euthanasia: Organ Donation After Assisted Dying

David M. Shaw

Abstract In this chapter I consider the narrow and wider benefits of permitting assisted dying in the specific context of organ donation and transplantation. In addition to the commonly used arguments, there are two other neglected reasons for permitting assisted suicide and/or euthanasia: assisted dying enables those who do not wish to remain alive to prolong the lives of those who do, and also allows many more people to fulfill their wish to donate organs after death. In the first part of this chapter I explore the possibility of allowing those who die with assistance to donate their organs and the potential benefits of doing so in countries where some form of assisted dying is legal; in the second part I consider the added force that organ donation considerations bring to the argument in favour of legalizing assisted dying in countries where such practices remain forbidden.

11.1 Introduction

The ongoing debate concerning the ethics of assisted suicide and euthanasia continues to focus on the interests of the person who wants to die and the perceived risk to vulnerable patients posed by legalizing the practice. On the one hand, proponents of assisted dying argue that it is inhuman to deny assistance in dying to terminally ill or severely handicapped people when they are experiencing immense suffering or indignity and wish to die; on the other, campaigners for the disabled warn that assisted dying legislation implies that their lives are not worth living, and other opponents warn that vulnerable groups might feel themselves a burden and that legislating for assisted dying is the beginning of a slippery slope. These are all old arguments. Although this war appears to be slowly being won by advocates of assisted dying, this is largely due not to any novel reasons but

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rather to modern society's acceptance of individual autonomy, particularly in the face of an ugly death. But there are other arguments in favour of assisted dying that also have substantial force. In this chapter I consider the narrow and wider benefits of permitting assisted dying in the specific context of organ donation and transplantation. There are two other additional and neglected reasons for permitting assisted suicide and/or euthanasia: assisted dying enables those who do not wish to remain alive to prolong the lives of those who do, and also allows many more people to fulfill their wish to donate organs after death. In the first part of this chapter I explore the possibility of allowing those who die with assistance to donate their organs and the potential benefits of doing so in countries where some form of assisted dying is legal; in the second part I consider the added force that organ donation considerations bring to the argument in favour of legalizing assisted dying in countries where such practices remain forbidden.

11.2 Part I

Despite the seeming turning of the tide in the debate about assisted dying, only a few jurisdictions currently permit assisted suicide or euthanasia. Switzerland, Germany, Columbia, Albania and Japan all permit assisted suicide under certain circumstances, as do five American states (Vermont, Washington, New Mexico, Montana and Oregon). Euthanasia is only permitted in Belgium, the Netherlands and Luxembourg. In the Netherlands, euthanasia accounts for almost 3 % of all deaths (Steck et al. 2013). While some countries have terminal illness as a requirement for accessing assisted dying services, many do not. Several thousand people use assisted dying services globally every year, but they are typically not able to donate their organs, for a variety of practical reasons.

It might be assumed that organs would not be suitable for transplantation following assisted suicide both because of the manner of death and because of the fact that most people who opt for assisted suicide have terminal illnesses that would tend to rule out donation. In fact, it is not medical contraindication that is the main barrier. Most assisted suicide and euthanasia techniques are not toxic to organs (Wood et al. 2003), and as many as 50 % of those using assisted dying do not have conditions that would rule out donation, such as cancer (and even cancer is not a total contraindication) (Fischer et al. 2008, 810). Advanced age is also no barrier to donation, and some of those using assisted suicide services are neither old nor terminally ill, meaning that their organs might be in prime condition (Intensive Care Society (UK) 2005). The real barriers to organ donation after assisted dying concern location and attitude. Patients often choose to die at home, meaning organs would no longer be viable by the time they reached a hospital. Furthermore, donation after assisted dying would involve donation after cardiac death or DCD (rather than donation after brain death or DBD), a procedure which is still relatively underdeveloped and unsupported in many countries. Furthermore, many doctors and hospitals are resistant to the idea of assisted dying and are therefore reluctant to use organs from this source.

However, facilitating organ donation after assisted dying in these countries would be relatively easy given sufficient investment of time and resources (Shaw 2014). Most countries are slowly improving and expanding their DCD capabilities in order to improve donation rates, which will make donation after assisted suicide more viable. If hospitals provided space for assisted suicide or euthanasia on their premises, organs could be transplanted speedily without compromising their function or risking harm to recipients. With regard to attitude, it is well-known that many doctors regard assisting suicide and euthanasia as contrary to their professional duties, but extending this view to the point that it prevents organs reaching recipients who could die without them appears to be taking things rather too far. In fact, transplant teams in Belgium have already cooperated with assisted dying organizations to transplant organs from patients who were euthanized, indicating that donation after assisted dying is possible given collaboration (Ysebaert et al. 2009).

It might be asked why we should bother investing time and resources simply to allow a few more people to donate their organs. The answer is that the wider benefits of facilitating organ donation after assisted suicide are potentially immense. If we take the example of Switzerland, around 100 people donate organs after death every year, with around 400 recipients benefiting. However, at least 1000 people remain in need on that waiting list in an average year. Some of these people will die soon if they do not receive an organ; many of them are not at immediate risk of death but will have to continue on dialysis until a suitable organ is found. Now consider that 500 people die via assisted suicide every year in Switzerland. If half of them (250) agreed to donate their organs after death and were medically suitable, 1000 more recipients could benefit; Switzerland could clear its waiting list within one year, and would soon have a surplus of organs. Although Switzerland also allows foreigners to access assisted suicide services, similar arithmetic would apply in other countries. Essentially, any jurisdiction where assisted dying is legal could solve its organ scarcity problem by investing in facilitation of organ donation after assisted suicide and/or euthanasia.

In addition to the having the potential to vastly improve the supply of organs, donation after assisted dying will also allow better testing and targeting of organs, reducing the chances of immune rejection. Most people cannot donate their organs unless they have a spontaneous catastrophic brain event or die violently, which means that donation rates are largely dependent on the rate of car crashes and other accidents in a given country. (Indeed, it has been suggested that improved road safety leads to greater scarcity of organs.) In contrast, assisted suicide and euthanasia are planned procedures. This means that potential recipients of organs could be preidentified and matched to the organs of the donor days or even weeks in advance of the planned death. In this sense, donation after assisted death is actually better than some more traditional forms of donation.

Another advantage of organ donation after assisted dying is that it does not cause any additional harm. While the dying patient might experience some inconvenience due to the necessity of dying near a hospital rather than at home, this does not amount to harm and any patient could die at home and not donate his or her organs if he wished. It is possible that some premortem organ preservation interventions (such as use of heparin) might make the patient uncomfortable, but again, this would only take place with the patient's consent.

We should also consider donation after assisted dying from the perspective of justice. In terms of resource allocation, it makes no sense whatsoever to have a system that permits assisted dying yet allows the immensely precious resource of solid organs to go to waste. Research is continuing into lab- and animal-based generation of organs for transplantation into humans, but it may be decades before any such biotechnology becomes clinically useful. Many terminally ill people want to die but still have perfectly functioning organs, and it is irresponsible of modern healthcare systems to neglect this most invaluable resource.

The benefits of permitting both assisted dying and donation after assisted dying are potentially substantial. But a case can be made for enabling donation after assisted suicide or euthanasia even without considering the wider benefits. Suicide and euthanasia are intended to provide an easier death for patients. Knowing that one's organs will be used to prolong other people's lives and to alleviate their suffering could also make one's own death easier to bear. [I have argued elsewhere than euthanasia and assisted suicide can aid eudaimonia, and organ donation after assisted dying adds further force to this argument (Shaw 2009).] Furthermore, in the normal context of organ donation after sudden death, bereaved families are often comforted by the idea that the death of their loved one has the silver lining of helping other patients. While assisted dying is planned rather than accidental, families may nonetheless derive similar consolation from the thought that others will benefit from their relative's death. Finally, most people who want to donate their organs after death never get a chance to, because they die in the 'wrong' manner. In contrast, people who use assisted dying services die in a controlled manner, making donation much more feasible than for most citizens. Given that many of those using assisted dying services around the world are registered organ donors, their wish to donate should be respected like any other registered donor.

11.3 Part II

Given the aforementioned considerations, it appears sensible for countries that currently permit assisted suicide or euthanasia to invest resources in facilitating organ donation after assisted dying. However, in countries where all forms of assisted dying are illegal, these factors also provide additional ammunition to those who support assisted dying. While the main reasons to permit assisted suicide and euthanasia will always remain to prevent dying patients' suffering and grant them death at a time of their choosing, the fact that legalizing assisted dying could save or improve thousands of lives every year is also a highly persuasive one. To take an example, if assisted suicide were legalized in all of the United States, tens of thousands of patients would no longer have to wait for an organ—an immense benefit. Given efficient organ donation and transplantation infrastructure, it is possible that any country that legalized assisted dying could solve its organ shortage at a stroke. (However, this is not to suggest that assisted dying should be legalized merely for this reason—see below.)

Legalising assisted dying and facilitating organ donation from those who use the service also makes sense in terms of justice. It is illogical and unethical to have a system where people who want to stop using their organs are forced to carry on doing so, while people who are in desperate need of organs are denied them. It has been estimated that 6000 people per year experience pain and suffering that cannot be managed by palliative care in the last few months of their life in the UK alone; many of these people would probably want to access assisted dying services. At the same time, there are several thousand people who are suffering and/or dying because they need a new organ. It is a sad irony that tens of thousands of healthy organs are prolonging the lives of those who want to die, while failing organs cause the deaths of those who want to carry on living. [Indeed, forcing people to persist in life amounts to their organs providing unwarranted life support (Shaw 2007).]

Of course, it is already controversial merely to suggest that organ donation from those using services in countries where assisted dying is legal should be permitted. Going further and suggesting that increasing organ supply is actually a good reason to legalize assisted dying is an even more provocative proposition. Opponents of assisted dying are likely to distort the arguments and insist that the idea is to kill people against their will in order to procure organs for other people. Indeed, I hesitated before writing this chapter given the relative progress in England and Wales represented by Lord Falconer's Assisted Dying Bill, which is currently progressing through the House of Lords. Even though it is true that legalizing assisted suicide could provide England with a surplus of organs, many people are likely to misunderstand (and misconstrue) the argument, meaning that a good additional reason to legalise assisted dying might be used as a reason against doing so. Controversy itself can be a powerful persuader, even if arguments based solely upon it tend to be very weak.

It seems appropriate to anticipate and discuss some of the objections that might be raised in opposition to organ donation after assisted dying. As mentioned above, a key criticism is likely to be that the suggestion is legalizing assisted suicide in order to procure organs for people. This is clearly not the idea at all. There are two separate arguments:

1. If someone is suffering and wants to die, she should be able to obtain assistance in doing so.
2. Anyone who wishes to be an organ donor should have those wishes respected if at all possible.

It is a happy coincidence that any country that legislates in support of these two assertions will also have an abundance of organs. Currently, most countries support 2 but not 1; somewhat ironically, those that support 1 also support 2 but tend to abandon 2 for those people who put 1 into practice.

Despite the weakness of this first objection, there are stronger potential arguments against donation after assisted dying, all of which also apply to countries where assisted dying is already legal. One of these is a variant of the familiar "burden" argument against assisted dying: people might feel obliged to die because they are a burden on their families and friends. This argument has been largely discredited, and opponents of assisted dying seemingly remain oblivious to the fact that people who ask for life-prolonging treatment to be withdrawn might themselves do so because they feel themselves a burden. (And as has been remarked by several commentators, feeling yourself to be a burden can be a perfectly reasonable reason to want to die.)

The modified version of the burden argument for this context is that people might feel obliged to end their lives in order to save the lives of others. A similar rebuttal also applies here: it seems very unlikely that the possibility of donating one's organs after death would be decisive in any choice regarding assisted dying. As I argue elsewhere, "The decision about suitability for assisted suicide must be kept separate from the decision to donate one's organs" (Shaw 2014): many people will already be registered organ donors before even considering assisted suicide, and careful use of protocols should ensure that those who are not yet decided should only be asked about donation after the decision to end one's life has been made. (Furthermore, assisted dying legislation in most countries is limited to the terminally ill and severely disabled.) Even if this factor were decisive in a decision to end one's life, some would argue that that would be fair enough; if anything, dying so that several other people might live would be an astonishingly altruistic way to end one's life. However, this is not to concede that people might regard themselves as burdens on others because they refuse to donate their organs. Only if we subscribed to Hardwig's concept of a "duty to die" would we be concerned about people feeling that they had an obligation to die in order to help others (Hardwig 1997). It is conceivable that an elderly family member might be tempted to consider assisted suicide if his daughter or granddaughter required a heart transplant, but the same is true of unassisted suicide. Although it is unlikely that anyone would choose to end his life simply because he could donate their organs, it is possible that some people who choose to use assisted suicide might end their lives a little earlier in order to improve viability of any donated organs. However, most people who use assisted suicide die at a time of their choosing and could have gone on living at least a little longer if they wished; if someone wants to die a little sooner in order to donate his organs, that would seem to be compatible with most current criteria for assisted dying.

A third objection is that some people who do want assisted dying might not want their organs to be taken after obtaining assistance. But this is a straw man: any such people could simply opt out (or not opt in) to organ donation. It is true that some people who do want to donate their organs might nonetheless prefer to die at home, making organ donation impractical, but that would be their choice. As donation after assisted dying involves DCD, organ viability could be improved by use of certain pre-mortem interventions such as cannulation, which some patients might not want; again, this would be their choice.

It might also be objected that people in need of an organ might not want to receive one that has been obtained from someone who received assistance in dying. The NHS does not normally provide detailed information about the circumstances of a donor's death, so this is unlikely to be a problem. If assisted dying were legalized in the UK it might be decided to make an exception to this rule, but this too seems unlikely. If the system gave recipients the chance to refuse organs on these grounds, it would lead to organ wastage and indeed to the potential death of the recipient, assuming that any potential recipient was so opposed to the idea of assisted suicide that he or she would effectively commit suicide by refusing an organ. Therefore, it seems probable that recipients would not be told about organs' origin. It might be argued that all potential recipients could at least be made aware of the possibility that they could receive an organ from someone who committed suicide. However, organ donation after violent non-assisted suicide is a quite routine practice in both Switzerland and the UK, provided that the local coroner gives permission. Patients are not usually informed of this possibility, so it is not obvious that the possibility of donation after assisted suicide should be brought to their attention either.

Ironically, some of the ethical issues raised by traditional DCD do not occur in the context of donation after assisted dying. Concerns are sometimes voiced about pre-transplantation procedures such as cannulation: in normal DCD cases, this raises issues as the family often cannot be contacted for consent, but the pre-planned nature of donation after assisted dying avoids this problem. Another concern with normal DCD is that treatment might be withdrawn before it is futile, but this is also not a problem in donation after assisted dying, because the patient wants to die. Normal DCD also involves a "cooling-off" period after the heart stops to ensure that the patient is dead before organ retrieval begins. However, given that the patient wants to die and is unconscious, it is not obvious that this precaution would be required in donation after assisted dying. (In any case, no heart has ever spontaneously restarted after 60 s and organ retrieval has been initiated after as little as 75 s in some cases.) It has already been suggested that a limited form of euthanasia should be legalized specifically for organ donors to avoid this practical problem with DCD (Wilkinson and Savulescu 2012). While "organ donation euthanasia" would certainly increase the number of viable organs for transplantation, it remains a limited proposal that is unlikely to be realized without more general assisted dying legislation.

11.4 Conclusion

I have argued that countries where assisted suicide or euthanasia are legal should endeavour to enable all patients to donate their organs after death. More importantly, countries where assisted dying is not (yet) legal should also consider the potential benefits to other patients in need of adopting a system that allows donation after assisted death. Legalising assisted dying and facilitating organ donation after it would ease the suffering of both the dying and the living. Doing so would grant death to those who want to die and save the lives of those who want to live, while also enabling those dying to fulfil their wish to donate. It is important for everyone involved in the assisted dying debate to remember that each assisted death could also save several lives.

References

Fischer, Susanne, et al. 2008. Suicide assisted by two Swiss right-to-die organizations. *Journal of Medical Ethics* 34: 810–814.

Hardwig, John. 1997. Is there a duty to die? *Hastings Center Report* 27: 34–42.

Intensive Care Society (UK). 2005. *Guidelines for adult organ and tissue donation*. http://www.ics.ac.uk/professional/standards_safety_quality/standards_and_guidelines/organ_and_tissue_donation_2005. Accessed 15 August 2013.

Shaw, David M. 2007. The body as unwarranted life support: A new perspective on euthanasia. *Journal of Medical Ethics* 33: 519–521.

Shaw, David M. 2009. Euthanasia and eudaimonia. *Journal of Medical Ethics* 35: 530–533.

Shaw, David M. 2014. Organ donation after assisted suicide. *Transplantation* 98: 247–251.

Steck, Nicole, Matthias Egger, Maud Maessen, Thomas Reisch, and Marcel Zwahlen. 2013. Euthanasia and assisted suicide in selected European countries and US states: Systematic literature review. *Medical Care* 51: 938–944.

Wilkinson, Dominic J.C., and Julian Savulescu. 2012. Should we allow organ donation euthanasia? Alternatives for maximizing the number and quality of organs for transplantation. *Bioethics* 26: 32–48.

Wood, David, Paul Dargan, and Alison Jones. 2003. Poisoned patients as potential organ donors: Postal survey of transplant centres and intensive care units. *Critical Care* 7:147–154.

Ysebaert, Dirk, G. Van Beeumen, Kathleen De Greef, Jean-Paul Squifflet, Olivier Detry, Arnaud de Roover, W. van Marie-Héléne Delbouille, Geert Roeyen Donink, Thiery Chapelle, D. van Jean Louis Bosmans, Marie-Elisabeth Faymonville Raemdonck, Steven Laureys, Maurice Lamy, and Patrick Cras. 2009. Organ procurement after euthanasia: Belgian experience. *Transplantation Proceedings* 41: 585–586.

Chapter 12
Implanted Medical Devices and End-of-Life Decisions

Michael B. Gill

Abstract If competent patients request that physicians participate in the deactivation of total artificial hearts and left ventricular assist devices, should physicians always comply? Patients and physicians currently have unsettled attitudes towards this question. I maintain that this issue is unsettling largely because the prospect of deactivation seems to give rise to a conflict between two deeply entrenched commitments of medical ethics: a commitment to the moral equivalency of withholding and withdrawing life-sustaining treatment, and a commitment to the prohibition on physicians' harming patients. I examine this apparent conflict and look at different ways of resolving it. I argue that the moral equivalency of withholding and withdrawing provides a decisive reason for physicians to participate in deactivation when a competent patient requests it, and that the prohibition on harming patients does not constitute a reason for physicians not to participate in deactivation. I also argue that an understanding of why it is acceptable for physicians to participate in deactivation reveals why physician-assisted death is morally acceptable in certain kinds of cases.

12.1 Introduction

It is becoming increasingly common to treat heart disease by surgically implanting devices, such as pacemakers, implantable cardioverter-defibrillators, left ventricular assist devices, and total artificial hearts. These durable circulatory support devices have had the obvious great benefit of prolonging lives. They have also raised a new question about end-of-life care: if competent patients request that physicians participate in the deactivation of these devices, should physicians always comply?

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Patients and physicians currently have unsettled attitudes towards this question (Goldstein et al. 2008; Kapa et al. 2010; Kramer et al. 2011). This unsettledness contrasts with attitudes toward the cessation of other life-prolonging treatments. There is, for instance, virtually no controversy nowadays about the legitimacy of physician participation in the discontinuation of a ventilator or artificial nutrition and hydration. What explains the comparatively unsettled attitudes toward physician participation in the disconnecting of implanted circulatory devices?

With regard to the deactivation of at least two of these devices—total artificial hearts (TAHs) and left ventricular assist devices (LVADs)—I believe some have found the issue unsettling largely because the prospect of deactivation seems to give rise to a conflict between two deeply entrenched commitments of medical ethics: a commitment to the moral equivalency of withholding and withdrawing life-sustaining treatment, and a commitment to the prohibition on physicians' harming patients. I will examine this seeming conflict and look at different ways of resolving it. I will argue that the moral equivalency of withholding and withdrawing gives us a decisive reason for physicians to participate in the deactivation of a TAH or LVAD when a competent patient requests it, and that the prohibition on harming patients does not constitute a reason for physicians not to participate in such deactivation. I will also argue that an understanding of why it is acceptable for physicians to participate in deactivation reveals why physician-assisted death is morally acceptable in some cases.[1]

12.2 Two Commitments of Medical Ethics

12.2.1 The Commitment to the Moral Equivalency of Withholding and Withdrawing Life-Sustaining Treatment

There was a time when many people believed that withdrawing life-sustaining treatment was morally more problematic than withholding it. But at least since the 1983 President's Commission on Bioethics, there has been widespread acceptance of the equivalency of withdrawing and withholding. As the President's Commission explains, there is no legal or intrinsic moral difference that would make "stopping a treatment … morally more serious than not starting it" (77).

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[1] If physician-assisted death for competent patients is morally acceptable—if it is acceptable for a physician to kill a competent patient when the patient requests it, or for a physician to assist a competent patient in killing herself—then it is hard to see how physician participation in the deactivation of a TAH or LVAD for competent patients could be unacceptable. In Sect. 12.6, I will be trying to make plausible the converse: that if it is morally acceptable for a physician to participate in the deactivation of a TAH or LVAD for a competent patient, then physician-assisted death should be morally acceptable as well.

"Whatever considerations justify not starting [a treatment] should justify stopping [it] as well" (Ibid). The President's Commission also contends that policies that demand greater justification for withdrawing than withholding can have significantly deleterious effects on patient care. Such policies can lead to the continuation of harmful treatment beyond the point at which it poses any compensating benefit to the patient. At least as worrisome, such policies can inhibit the initiation of a treatment that could possibly benefit a patient. In the words of the President's Commission, "An even more troubling wrong occurs when a treatment that might save life or improve health is not started because the health care personnel are afraid that they will find it very difficult to stop the treatment if … it proves to be of little benefit and greatly burdens the patient" (75). It is, consequently, now widely accepted that there is an ethical and legal symmetry between justifications for withholding treatment and justifications for withdrawing it.

The moral equivalency of withholding and withdrawing would seem to apply to decisions concerning TAHs and LVADs insofar as the implantation of one of these devices is an instance of the initiation of a treatment. It's perfectly clear that physicians have an ironclad obligation to respect every patient's right to refuse the implantation of a TAH or LVAD, regardless of whether or not the treatment is necessary to sustain life. The moral equivalency of withholding and withdrawing would seem to imply, therefore, that physicians have exactly the same obligation to respect a patient's right to discontinue the treatment constituted by a TAH or LVAD. And respecting such a patient's right to discontinue treatment may very well involve participating in the deactivation of the relevant device and then doing what is necessary to help the patient be as pain-free and comfortable as possible.

It might be thought that there is nothing problematic about prohibiting physicians from participating in the deactivation of devices so long as each patient is fully informed of this prohibition prior to the device's implantation. But the 1983 President's Commission's discussion of the equivalency of withholding and withdrawing explains why such a policy could have the undesirable consequence of some patients' not receiving devices even though they might have received great benefit from them. The President's Commission pointed out that when we make it more difficult (or impossible) to justify withdrawal of a treatment, we raise the specter of mandated continuation of a treatment past the point at which the patient believes herself to be benefited by it, which can inhibit the initiation of the treatment in the first place. If, on the other hand, withdrawing and withholding are taken to be morally equivalent, then a treatment can be initiated if there is any reasonable hope that it will benefit the patient, without such a decision's being unduly influenced by the concern that a time may come when the treatment is no longer wanted but cannot be discontinued. By the same reasoning, if we treat implantation and deactivation as morally equivalent, then a device can be implanted so long as there is a chance that it will benefit the patient. The possibility of a future wish to deactivate will not inhibit attempts to procure the possible benefits of implantation.[2]

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[2] But see footnote 18 for a consideration that may justify withholding very expensive or scarce treatments from patients who might choose later to discontinue those treatments.

12.2.2 The Commitment to the Prohibition on Physicians' Harming Patients

This second commitment is often expressed by the venerable maxim "Primum non nocere," or "Above all, do no harm." And while the moral equivalency of withholding and withdrawing goes back to the 1983 President's Commission, this second commitment is typically thought to go back considerably further—to ancient Greece and "the Hippocratic tradition of medicine of not harming or killing patients" (Rady and Verheijde, 10).[3] To elucidate why it might be thought that deactivating LVADs and TAHs violates this non-harming commitment, it will be helpful to compare such deactivation to two other cases: withdrawing a ventilator, and stopping the beating of a transplanted (organic) heart.

We do not think of withdrawing a ventilator as a violation of the non-harming commitment because once the ventilator is removed the patient merely returns to her natural or non-treated state. When the patient dies, her death is caused by a pre-existing condition. In contrast, most people believe that stopping the functioning of a transplanted (organic) heart is a violation of the non-harming commitment. A heart transplant is, of course, a treatment that any patient can refuse. But the right to refuse a transplant operation is not taken to imply a right to demand that physicians nullify the effects of that operation at a future date by supplying an injection or pill to stop the transplanted heart from beating. The "withdrawing" of the benefit of a transplanted heart is not taken to be morally equivalent to the "withholding" of an operation to transplant the heart.[4]

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[3] I think there are at least two features of the ethical prohibition on physicians' harming a patient that make it complicated to apply. First, this prohibition in its simplest form is outdated. In the past it might have made sense for physicians to take a prohibition on harm to forbid any course of action that could make a patient worse off than if she had never been treated by a doctor at all. But because of advances in medical technology, the possibility that a treatment will harm a patient is no longer a decisive reason not to undertake it. This is because doctors now have at their disposal options that both hold out the promise of spectacular improvement and carry with them undeniable risk. If someone has a serious back injury, it might be appropriate to operate even if there is some chance the patient will have less mobility as a result. If someone has cancer, it might be appropriate to treat her with certain therapy even if there is chance that the patient will die sooner as a result. Second, it is unclear how to define "harm." If a competent patient requests that something ought to be done to her, on what basis can we claim that it harms her? If the prohibition on harming is not to collapse into respect for autonomy (which is what would happen if harm is defined by whatever the competent patient wishes for herself), harm must be construed in a way that pulls apart from what a competent patient wishes to happen to her body, and it's far from obvious what the best such construal will be. Nonetheless, despite these difficulties, many people do believe that there is a prohibition on physicians' harming patients, and I think there are some cases in which it seems to make good sense of common and powerful intuitions. The prohibition on harming seems to explain, for instance, why a physician ought not to accede to a patient's request for performance-enhancing steroids or for health-destroying cosmetic surgery or to amputate a healthy leg. My goal is to show that the prohibition on harming, appropriately conceived of, does not constitute a reason to oppose physician participation in the deactivation of TAHs and LVADs and certain cases of physician-assisted death.

[4] Although in Sect. 12.6, I will oppose this view of heart transplantation. For a penetrating critique of this construal of the non-harming commitment, see Hopkins (1997).

One obvious explanation of this difference is that when a person is given a heart transplant her original heart is removed—and while it possible for humans to live without ventilators (the use of which does not involve the removing of the lungs), it is impossible for any human to live without a heart. The process of removing someone's original heart, transplanting a new heart, and then preventing the new heart from functioning will always lead to death.

Imagine John expresses an interest in crossing an abyss and in response Mary offers to build a span for him. John may have every right to turn down Mary's offer. John may also have the right to refuse to step on the span once Mary has built it. But that does not give John the right, once he is halfway across, to demand that Mary dismantle the span. Similarly, to stop a transplanted heart is not simply to discontinue a treatment and thus return the patient to her natural state. It is not like placing John back onto the side of the abyss from which he started. It is, with absolute certainty, to bring about the patient's death. It is to put the patient in a condition in which the human organism simply cannot survive—like dropping John into the abyss.

Opposition to physician participation in the deactivation of TAHs and LVADs can be fueled by the thought that such deactivation is morally similar to dismantling a span across an abyss when someone is in the middle of it. This moral similarity is easy to see in the case of TAHs. When an artificial heart is surgically implanted the original heart is removed. To deactivate the artificial heart may thus be viewed not simply as an act of withdrawing a medical treatment and returning the patient to her natural state but rather as the final step in a process that will necessarily bring about the death of any human being.

It might not be immediately obvious how this line of thinking leads to opposition to deactivating an LVAD, but the similarity becomes clear when we attend to the details of how such a device is implanted. The key point is that even though implantation of an LVAD does not involve the removal of the patient's heart, it does alter the patient's physiology in such a way that her heart cannot function properly once the LVAD is deactivated. As Rady and Verheijde (2014, 7) explain, "Surgical implantation of [an LVAD] permanently alters native structural and functional configuration of the heart, so that spontaneous effective systemic circulation can no longer be maintained if the device is interrupted. Prolonged LVAD support is also associated with irreversible disruption of normal heart valves." Kraemer (2013, 145) makes the same point when she writes, "Once an LVAD is implanted in a patient, he or she is not in a 'natural physiological state' any more. Already the *im*plantation of an LVAD has altered the heart's natural condition: in order to fix the LVAD, a physician has to drill a hole in the patient's heart." Similarly, Bramstedt and Wenger (2001, note 6) point out that "deactivating a LVAD is similar to turning off a ventilator, while leaving the endotracheal tube in place. This would make spontaneous respiration even more difficult for the patient due to the increased dead space of the tube… Similarly, leaving an implanted and yet unpowered LVAD in place actually impedes the natural heart function."

Implanting an LVAD and then deactivating it is like Mary's placing John on a boat in the middle of the ocean and then removing the boat. John might not die immediately. But Mary's removal of the boat puts him in imminent danger of drowning, which he was not in in his previous state. Similarly, the process of implanting an LVAD and then deactivating it alters a patient's situation in a way that leads some to hold that the patient's subsequent death is most accurately attributed to the process and not merely to natural causes. For this reason, Kraemer takes implanting and then deactivating an LVAD to violate the non-harming commitment, as such deactivation "can make the person worse" by "worsen[ing] the heart function." As Kraemer sees it, a physician who deactivates an LVAD "is not just stopping something and letting nature take its course. [He's] actually doing harm, potentially" (Kraemer 2013, 145). Rady and Verheijde (2014, 7) make the same point when they write, "Deactivating an LVAD … introduces a nontherapeutic lethal pathophysiology… We challenge the claim that a patient's death following LVAD … deactivation is a 'natural' death secondary to preexisting heart disease. The lethal pathophysiology in a patient who is dying naturally from heart disease and without an implanted device is different from a patient who dies after deactivating an LVAD."

So that's the apparent moral conflict in cases in which a patient requests physician participation in the deactivation of a TAH or LVAD: the patient's right to have any treatment withdrawn seems to conflict with a physician's obligation never to cause harm. How might we try to resolve this issue?

12.3 Bridges and Destinations

One approach to this issue is to distinguish between *bridge treatments* and *destinations therapies*. To conceive of something as a bridge treatment is to think of it not as a permanent solution but as a temporary measure to buy the patient time while a permanent solution is sought. The typical destination for a patient with severe heart disease is an organic heart transplant. But a patient may be in grave danger of dying before she is ready for transplantation or a suitable organ can be procured. A TAH may then be implanted as a *bridge*, a way to keep her going while the measures necessary for transplantation can be completed. An LVAD can also be implanted as a bridge, when it is thought that the patient will eventually be a suitable candidate for transplantation. Then again, an LVAD can also be implanted as a destination therapy, in cases in which the patient is not deemed suitable for transplantation.[5]

To see how this distinction between bridges and destinations might justify deactivation of a TAH or LVAD, consider the difference between discontinuing an ongoing treatment and reversing the effects of a completed treatment. After you have been successfully treated for a broken leg, it no longer makes sense to speak of withdrawing or discontinuing the treatment. The treatment is finished, over and

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[5] For discussion of the use of LVADs as destinations and bridges, see Dudzinski (2006), Mueller et al. (2010), and Patel et al. (2014).

done with. Your new status quo—your baseline—is a state in which you do not have the broken leg. To undo the effects of the treatment (to re-break your leg) would be to drop you below your baseline. To drop you below your baseline would be to harm you. And a physician is prohibited from harming you even if you request it. This is why your right to refuse treatment for a broken leg does not imply your right to demand physician participation in re-breaking your leg. Because the treatment is over and done with, re-breaking cannot be an instance of withdrawing treatment. A physician's refusal to re-break does not violate the moral equivalency of withholding and withdrawing, because, since the treatment has been completed, re-breaking is not a case of withdrawing treatment. Similarly, we might think of a heart transplant as a completed treatment, a procedure that is over and done with, a permanent solution, a new status quo.[6] Thus, once the transplantation has been completed, there can be no withdrawing of the treatment because the treatment is no longer ongoing. It might be a bit of a stretch to say that the natural state of the transplant recipient is now that of someone with a fully functioning heart. (Can we say that the result of transplanting one person's heart into another person's body is 'natural'?) But we can say that once the transplantation has been completed, the recipient's baseline—her status quo—now includes having a fully functioning heart. To stop the heart from beating is, therefore, to drop her below her baseline, and to drop a person below her baseline is to harm her, which violates the physician's non-harming commitment. This is in contrast to the withdrawing of a ventilator or the cessation of dialysis. When someone is on a ventilator or dialysis her treatment is ongoing. Her baseline is not recovered health but rather the state she would be in if the treatment in question had never been initiated or were stopped. The moral equivalency of withholding and withdrawing applies to ventilators and dialysis machines in a way it does not apply to fixed legs and transplanted hearts.

This distinction might seem to allow for deactivation of a TAH insofar as a TAH is thought of merely as a bridge to transplantation, and not as a destination. Because a TAH is a bridge, it constitutes an ongoing treatment. But since a TAH is an ongoing treatment, we should take the patient's baseline to be the state she would be in if that treatment had never been initiated or were stopped. To deactivate the TAH, then, is not to harm the patient because it is not to drop the patient below her baseline. To deactivate the TAH is to withdraw a treatment, which calls for a justification that is no different from the justification of the choice not to initiate a treatment in the first place. So while the moral equivalency of withholding and withdrawing does not apply to destinations like heart transplants, it does apply to bridges like TAHs. And while the prohibition against harming patients forbids the stopping of a transplanted organic heart (a destination therapy), it does not attach to the deactivation of a TAH (a bridge treatment).

This way of justifying deactivation does not stand up to scrutiny. TAHs are currently not approved as destination therapies. A TAH is officially a bridge treatment.

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[6] For the purposes of this section, when I am trying to explain the opposition to deactivation, I will proceed as though an organic heart transplant is a completed treatment. But in Sect. 12.6, I will deny exactly this, holding instead that organic heart transplants are continuous treatment.

But the day is soon coming when TAHs will be destinations. More importantly, the distinction between bridge and destination, when its application to TAHs is examined closely, is morally hollow. Consider a patient who is implanted with a TAH but is then later deemed an unsuitable candidate for transplantation. It is disingenuous to continue to classify the patient's TAH as a bridge treatment, as it is understood by all that the TAH is going to be the only heart the patient is going to have for the rest of her life. (If it's a bridge, it's a bridge to nowhere.) It seems morally unsupportable, however, to hold that the moment a patient is deemed unsuitable for transplantation her status changes from someone whom a physician should assist in TAH deactivation into someone whom the physician must not assist. The more coherent position is that if a suitable-for-transplant patient has the right to help with deactivation because she has the right to decide whether or not continuing with a treatment is worthwhile to her, then she will retain that right if she becomes unsuitable for transplantation. Indeed, the question of whether continued TAH-treatment is worthwhile would seem to be even more important for the patient to have the right to answer when there is no possibility of transplantation—when it becomes clear that the TAH is not merely a bridge that the patient must put up with for a circumscribed period of time but is as good as it's ever going to get for her. It seems morally perverse to hold that deactivating a TAH is permissible when it is a temporary bridge and impermissible when it is a permanent destination.

For the same reasons, the bridge-destination distinction cannot adequately resolve the issue of deactivating LVADs. Consider a patient who is deemed suitable for transplantation when she is implanted with an LVAD but is at a later point deemed unsuitable. It would be ethically very dubious to hold that the very moment at which it becomes clear that the LVAD is not merely a temporary measure the patient should lose the right to request physician assistance in deactivation. If anything, it seems that the patient's right to decide whether or not to deactivate the LVAD becomes more important the moment it becomes clear that the LVAD is not merely temporary—the moment when it becomes clear that the LVAD is not merely a bridge that the patient must put up with for a circumscribed period of time but is as good as it's ever going to get for her. But if we think it acceptable to deactivate the LVAD of a patient with no prospect of transplantation, then it seems that coherence demands that we also hold it acceptable to deactivate an LVAD when it is a destination therapy. It seems incoherent to hold that LVADs may not be deactivated when they are thought of as permanent but may be deactivated when they are thought of as temporary.[7]

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[7] Others have also argued that we ought not to take into moral account the distinction between bridge treatments and destination therapies. Teuteberg et al. (2013, 374) write, "Our data highlight the artificial dichotomy of the currently accepted implant strategies of [bridge treatment] and [destination therapies], which are increasingly less representative of the clinical circumstances in which [a TAH or LVAD] is used… Additionally, we have shown that the initial implant intent is dynamic, with some patients becoming more likely to be transplanted and others becoming less likely to be transplanted or changed to a strategy of [destination]." Fang and Stehlik (2013, 380) write, "[i]s it even relevant to have a strategic intent at the time of LVAD implant other than to extend survival and improve quality of life?… The distinction between transplant and nontransplant candidates is arbitrary and poorly defined by hard evidence. The condition, advanced heart failure, is the same; the affected populations are not distinct."

12.4 Four Distinctions

A number of commentators have identified certain features of TAHs and LVADs that distinguish them from ventilators, feeding tubes, and other life-prolonging technologies, and some seem to think that the presence of these features makes deactivation of TAHs and LVADs impermissible even while it is permissible to discontinue ventilators and feeding tubes. Commentators have identified the following four features that distinguish TAHs and LVADs from other life-sustaining technologies.

1. The devices are *inside* the body, while the other technologies are outside the body.
2. The devices are *fixtures* in the body (“biofixtures”) while the other technologies are not.
3. Patients come to identify the devices as *parts of their selves*, while they do not think the same thing about the other technologies.
4. The devices *replace* a body’s organic way of performing a function while those other technologies merely regulate the body’s way of performing a function.

Each of these proposals has been developed in ways that raise intriguing questions about how new technologies are challenging traditional views of medicine, health, and self. But none of these distinctions supports the view that physicians ought not to participate in the deactivation of TAHs and LVADs.[8]

It is hard to see why 1 or 2—the devices being *inside* or *fixtures* of the body—should morally distinguish TAHs and LVADs from ventilators, feeding tubes, and the like.[9] The physical placement of a machine that is delivering a medical treatment has no intrinsic moral importance. The moral principles that are crucial to the question before us are the principle that a patient should have the right to decide what treatments are performed on her own body and the principle that a physician ought not participate in the harming of a patient. Physical placement on its own doesn’t tell us how to apply these values or balance them when they seem to come into conflict. My hunch is that the distinctions described by 1 and 2 will eventually be viewed in much the same light as we now view the distinction between withdrawing ventilators and withdrawing feeding tubes. There was a time when many people thought that it was morally permissible to withdraw life-sustaining ventilators but morally impermissible to withdraw life-sustaining feeding tubes. Since the 1980s, however, it has become widely accepted that the differences between ventilators and feeding tubes are irrelevant to the moral question of whether a patient has the right to request physician participation in the withdraw of treatment. There are certainly physical differences between ventilators and

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[8] For a searching discussion of the difficulties of trying to apply these distinctions in medical contexts, see Jansen (2006).

[9] For discussion of the ways in which our judgments can be affected by a medical technology’s “aesthetic” appearance, see Hopkins (1997, 36).

feeding tubes, but we no longer take those physical differences on their own to cut any moral ice. Similarly, I believe, once we become more accustomed to the technologies that are currently new to us, we will come to think of the mere physical differences between internal or fixed devices and external or removable devices as on their own morally insignificant.[10]

It is plausible that 3—conceiving of devices as *part of one*'*s self*—can influence a patient's decision about whether or not to request deactivation. But once again I don't see how it bears on the moral question of the permissibility of physician participation in deactivation (see England et al. 2007; Kraemer 2013; Simon 2008). If a patient conceives of a device as part of her self, she may be less likely to request deactivation. It seems very unlikely, however, that every patient will view a device as being as part of her self in exactly the same way as every other patient. More plausible is that there will be variation, with some patients conceiving of devices as more integral and other patients conceiving of them as less. And I cannot see how it could be that any policy concerning physicians' obligations should track those thoughts of the patients. If it's unacceptable for a physician to participate in deactivation, then a patient's contention that the device is not part of her self seems morally irrelevant. Some people may come to think of one of their limbs as being a foreign body, not part of themselves, but that does not imply that it is acceptable for physicians to accede to their requests for amputation. Conversely, if it is acceptable for a physician to accede to a request for deactivation, then the fact that other patients identify a device as part of their selves is simply beside the point. We can imagine a patient with a cancerous leg who identifies so completely with her limbs that she refuses amputation, but that has absolutely no implication for whether or not a physician ought to accede to the request of another patient to have her cancerous leg amputated. The question of the extent to which individuals might end up identifying with machines implanted in their bodies is a fascinating one. I just don't see how it bears on the question of what policy physicians ought to follow with regard to deactivation.

Those who find distinction 4 compelling claim that it is permissible to discontinue a technology that *regulates* the body's performance of a function but impermissible to discontinue a technology that *replaces* an essential feature of the body (see Kay and Bittner 2009; Simon 2008; Sulmasy 2008; Lampert et al. 2010; Zellner et al. 2009). On this way of thinking, it is permissible to discontinue the merely regulative technologies of a ventilator or dialysis machine, but impermissible to discontinue the replacement technologies of a transplanted organic heart. It is problematic, however, to use this distinction to oppose deactivation of a TAH or LVAD. A plausible case can be made that organic heart transplants are *more* of a regulative technology than TAHs and LVADs. Rady and Verheijde (2014, 6) write, "[a] transplanted heart is immunologically incompatible and the recipient is dependent on regular intake of immunosuppressive medication and expert supervision to prevent biological rejection, making it less likely that the criteria of a

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[10] For insightful discussion of this kind of view, see Paola and Walker (2000).

replacement treatment have been met… In contrast, an implanted LVAD/TAH is immunologically compatible, physically integrated in the body, capable of intrinsically responding to the changing body demands." But the advocates of the distinction between regulation and replacement do not intend to show that it is *more* permissible to discontinue the functioning of a transplanted organic heart then to deactivate a TAH or LVAD. Indeed, Sulmasy, who has done the most to develop the regulation-replacement distinction, is coauthor of an article that argues that LVADs should not be thought of as replacement therapies because they do not respond "to the host's physiologic changes" and are not "independent of external energy sources and the control of an expert" (Mueller et al. 2010).

It is unclear, moreover, how strong the distinction between regulation and replacement even is. Dialysis is taken to be an uncontroversial case of regulation, not replacement. But if a person's kidneys are truly non-functional, and if a dialysis machine is performing the function of removing waste from the blood, then it is difficult to see what principled reason there can be for classifying dialysis as merely regulative. It's true that the dialysis machine is outside the body, unlike an organic heart transplant. But the inside-outside distinction is different from the regulative-replacement distinction. When pressed, the latter distinction is not supposed to collapse into the former.

I suspect that some judgments of the impermissibility of deactivation are responsive to a technology's being *both* a replacement *and* inside the body. If a technology is a replacement but outside the body—such as dialysis—then deactivation seems permissible. If a technology is inside the body but regulative—such as a pacemaker—then deactivation seems permissible. But if a technology is both a replacement and inside the body—such as a TAH—then deactivation seems impermissible. But if something's being inside the body does not on its own impart negative moral weight to its deactivation, and if something's being a replacement does not on its own impart negative moral weight to its deactivation, why should the combination of being a replacement and inside the body impart negative moral weight to a technology's deactivation? That is not a rhetorical question. It can be the case that two features, each of which in isolation imparts no moral weight, can in combination carry a lot of moral weight. But I do not see why we should believe that the combination of being a replacement and being inside the body is such a case. Until such a case is made, I do not think we have good reason to base opposition to deactivation on that combination.

12.5 Why Physician Deactivation Does Not Harm Patients

As we saw in Sect. 12.2, some believe that physician deactivation of a TAH or LVAD is morally impermissible because it constitutes harming a patient. In this section, I will argue that most cases of physician activation do not harm the patient and thus are morally permissible.

Here is Rady and Verheijde's (2014, 7) way of putting this opposition to deactivation: "Deactivating an LVAD or TAH introduces a nontherapeutic lethal pathophysiology related to device type and implantation surgical procedure. Surgical implantation of durable MCS [mechanical circulatory support] devices permanently alters native structural and functional configuration of the heart, so that spontaneous effective systemic circulation can no longer be maintained if the device is interrupted. Prolonged LVAD support is also associated with irreversible disruption of normal hearth valves (e.g., aortic valve) and introduces new lethal pathophysiology upon device deactivation in some patients" (see also Wu 2007). It is, however, problematic to characterize the deactivation of an LVAD or TAH as the introduction of a new nontherapeutic, lethal pathophysiology. If a patient's TAH or LVAD is deactivated, she will die very quickly. But the quickness of her death cannot be the reason for the impermissibility of deactivation. Some patients will die very quickly if they are taken off a ventilator but that is not taken to imply the impermissibility of ventilator discontinuation. The claim we are examining is that what makes deactivation impermissible is that it, unlike the withdrawal of a ventilator, harms a patient because it "introduces new nontherapeutic lethal pathophysiology." The problem comes in thinking of deactivation of a device that is already implanted in a patient as the "introduction" of something "new."

Typically, we say Person A *introduces* something *new* to Person B only if A brings B into contact with something B previously did not have contact with. A TAH or LVAD that would be deactivated is already inside the patient. So in what sense would the physician's deactivation be the introduction to the patient of something new?[11]

Neither implantation nor deactivation considered on its own can sensibly be described as the "introduction of a new nontherapeutic lethal pathophysiology." Implantation on its own is neither lethal nor nontherapeutic. Deactivation is not the introduction of something new. But the combination of implantation and deactivation is lethal: a person cannot long survive if she is implanted with a TAH or LVAD *and* that device is deactivated. And the combination of implantation and deactivation is the introduction of something new: a person with a TAH or LVAD is not in her natural state but has been significantly altered by medical procedures. So the conduct that constitutes a harmful introduction of something new and lethal must be the combination of the act of implantation and the act of deactivation. The

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[11] One could argue that because deactivation leads to patient's death, and the patient's death is a new state, deactivation does introduce something new—the state of death of the patient. The problem with this argument is that it turns "the introduction of something new" into too wide a notion to do the work of morally distinguishing between deactivation of a TAH or LVAD, on the one hand, and the withdraw of a ventilator, on the other. If we take the state that follows from any action to be something new that that action has introduced, then the withdrawal of a ventilator from a ventilator-dependent patient will introduce the state of the patient's death. But it is a fixed point in this discussion that it is not wrong for a physician to participate in the withdrawal of a ventilator. So those who want to hold that there is something wrong with deactivation but not with withdrawal of a ventilator cannot construe "the introduction of something new" as widely as the causing of a state.

scope of the action under evaluation (i.e., the act that is the introduction of something new and lethal) must include both implantation and deactivation.

On this way of thinking, when a patient whose TAH or LVAD has been deactivated dies, the cause of her death is not the cessation of the patient's natural heart function. The cause of her death is, rather, the combination of acts that include both the alteration of the patient's natural heart function and the stoppage of the functioning of that alteration. The scope of the action that causes her death includes implantation and deactivation. On this way of thinking, as we put it in Sect. 12.2, a physician who implants and then deactivates a TAH or LVAD is morally similar to someone who builds a bridge over an abyss and then dismantles it while someone is standing in the middle.

This way of arguing for the impermissibility of deactivation—*implantation + deactivation = introduction of new nontherapeutic lethal pathophysiology*—is cogent when applied to a certain kind of case. But it is not cogent when applied to the majority of cases of deactivation that actually occur.

Here is the kind of case in which it is cogent to base moral opposition to deactivation on the impermissibility of introducing new nontherapeutic lethal pathophysiology. On January 1, a patient with heart disease who without treatment will die in six months is implanted with a TAH or LVAD. On January 14, the patient requests deactivation. Her physicians comply. On January 15, the patient dies. Had the physicians not performed the action whose scope encompasses both implantation and deactivation, the patient would have been alive on January 16. As a result of the physicians' actions, the patient has died earlier than if they and the patient had never interacted.

Here is the kind of case in which it is not cogent to base moral opposition to deactivation on the impermissibility of introducing new nontherapeutic lethal pathophysiology. On January 1, 2014, a patient with heart disease who without treatment will die in six months is implanted with a TAH or LVAD. On January 1, 2015, the patient requests deactivation. Her physicians comply. On January 2, 2015, the patient dies. Had the physicians not performed the action whose scope encompasses both implantation and deactivation, the patient would have died before January 2, 2015. As a result of the physicians' actions, the patient has lived longer than if she and the physicians had never interacted.

The difference is obvious. In the first case, the conduct of the physicians that is the object of evaluation (*implantation + deactivation*) has shortened life. In the second case, the conduct of the physicians that is the object of evaluation has not shortened life. And it must be the combination of implantation and deactivation that is the object of evaluation, for as we have seen, neither implantation nor deactivation on its own can coherently be characterized as the harmful introduction of a new nontherapeutic lethal pathophysiology. If person A harms the health of person B, then (ceteris paribus) the health of person B will be worse as a result of A's conduct than if A and B had never interacted. In the first case, if the physicians had not interacted with the patient, the patient would have lived longer. Because of the physicians' conduct, the patient has died earlier than she otherwise would have. It is, therefore, cogent to claim that the physicians have harmed the health of the patient in the first case. But in the second case, if the physicians had not interacted with the patient, the patient would have died sooner. How can the physicians' conduct be construed as harming the patient's health when the patient would have died sooner had they and the patient never interacted?

One might object that the argument I've just presented has an absurd implication. Consider the case of a patient whose leg has been so badly damaged on 1 January 2014 that he can no longer walk. On 2 January 2014, a physician performs an operation that fixes the leg. On 1 June 2014, the patient's leg is completely recovered and he can walk normally. On 1 January 2015, the patient requests that the physician damage the leg, and the physician complies. On 2 January 2015, as a result of the physician's action, the leg is damaged badly enough so that the patient has a pronounced limp and needs a cane to walk. It certainly seems that what the physician did on 2 January 2015 harmed the patient's health. But (so this objection goes) my argument implies that there has been no harm, for the combination of the acts of fixing the leg in January 2014 and of damaging the leg in January 2015 leaves the patient's health better than it would have been if he had never interacted with the physician at all. There must be something wrong with my argument, therefore, as it bases judgments about whether a physician physically harms a patient by comparing a patient's health after his interaction with the physician to what the patient's health would have been had he never interacted with the physician.

This objection fails because of a crucial difference between damaging the leg and deactivating a TAH or LVAD.[12] The physician who damages the patient's leg negates a completed medical treatment while the physician who deactivates a TAH

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[12] One could argue that damaging the leg is an act of commission while deactivating a TAH or LVAD is an act of omission. I myself do not want to place moral weight on the commission-omission distinction (a point to which I'll return in Sect. 12.6). Anyone who does want to rely on that distinction, however, will hold that damaging a healed, perfectly-functioning leg is an act of commission. Anyone who relies on that distinction as it is typically deployed in the context of medical ethics will also hold that discontinuing a ventilator or withdrawing artificial nutrition and hydration is an act of omission. And the act of deactivating a TAH or LVAD is like discontinuing a ventilator and withdrawing artificial nutrition and hydration, and not like damaging a healed, perfectly-functioning leg. In the case of the ventilator, artificial nutrition and hydration, and the TAH or LVAD, the act in question is the turning-off of an introduced life-sustaining technology. There are differences, of course, between a TAH or LVAD and those other life-sustaining technologies, as we saw in Sect. 12.4. But those differences do not bear on the question of whether the act of deactivation taken on its own is the stoppage of the functioning of an invasive medical treatment. Now I should point out that Rady and Verheijdge (2014, 4) say, "Deactivating a cardiac device is viewed medically and legally as an act of commission rather than an act of omission." But their only support for this claim is a reference to three articles, and none of those articles endorses characterizing the deactivation of MCS as an act of commission. Indeed, as the authors write in one of those articles, "In the context of ethical principles, regardless of the fact that [an MCS] is a constitutive therapy without the continued operation of which the patient may not survive, it still represents an artificial life-sustaining treatment that the patient has the right to refuse at any time. Furthermore, established case law holds that patients have the right to refuse or request the withdrawal of any treatment and have repeatedly held that no single treatment holds unique moral status" (Kapa et al. 2010).

or LVAD discontinues an on-going medical treatment. In the leg-case (as we constructed it), the physician acts on the patient after the patient has been healed. By the time the physician damages the leg, the patient is no longer a patient. When a patient receives a TAH or LVAD, in contrast, she continues to be a patient. It is not the case that someone who is implanted with a TAH or LVAD needs only to be given moderate post-op care and can then be sent on her way. A person with a TAH or LVAD requires continual medical attention. Her way of life is permanently, constantly, profoundly affected. Her treatment is not a discrete event but a persistent condition.

Physicians must respect every fully competent person's decision to refuse any medical treatment. That's because every fully competent person has the inviolable right to determine for herself whether the benefits of a proposed medical treatment are worth the costs. Nor do patients lose the right to determine for themselves whether the benefits of a proposed medical treatment are worth the costs the moment after the treatment has begun. They retain that right—the right to decide whether to submit to any procedure on their own bodies—while the treatment is on-going. Indeed, it may only be after the treatment has begun that they are in the best position to decide whether they wish to submit to it.

Because the treatment constituted by a TAH or LVAD is on-going—because a person with a TAH or LVAD requires continual medical attention, because the treatment constituted by a TAH or LVAD is a persistent condition rather than a discrete event—a patient's decision to deactivate a TAH or LVAD should have the same moral status as a patient's decision not to be implanted with a TAH or LVAD. Physicians should treat a patient who opts for deactivation just as they would a patient who opts not to receive a TAH or LVAD in the first place. The moral equivalency of withholding and withdrawing should apply to the implantation and deactivation of TAHs and LVADs. Moreover, the on-going character of TAH- and LVAD-treatment is the fundamental reason deactivation does not violate the prohibition on physicians' physically harming patients.

A treatment harms a patient when it lowers the patient below her baseline. How do we determine a patient's baseline? If a treatment has not yet begun, the patient's baseline is the state she would be in if she never began the treatment at all. If the treatment has been completed, the patient's baseline is the state she is in after the treatment's completion. What if the treatment is on-going, if the patient is in the midst of it? The moral equivalency of withholding and withdrawing—the fundamental ethical mandate to allow every patient to decide for herself whether the benefits of a treatment are worth the costs—requires that we conceive of the baseline in a case of on-going treatment not as the state the patient would be in if she continued with the treatment but rather the state the patient would have been in if the treatment had not been initiated in the first place.

Why hold that the baseline in a case of on-going treatment should be thought of not as the state the patient would be in if she continued with the treatment but rather the state the patient would have been in if the treatment had not been initiated in the first place? Consider the alternative, which is to take the baseline to be the state the patient would be in if she continued treatment. This alternative is unacceptable because it implies that when physicians withdraw a ventilator from a ventilator-dependent patient, they harm the patient (by lowering her below her baseline) and thus are doing something morally impermissible. But it is a fixed point that it is not wrong for physicians to accede a competent patient's request for the withdrawal of a ventilator, even if the patient is ventilator-dependent. The reason it is permissible for physicians to accede to such a request, even though it will lead to the patient's death, is that the treatment constituted by the ventilator is on-going, and every competent patient has the inviolable right not only to refuse but also to discontinue any treatment on her own body.[13]

The treatment constituted by a TAH or LVAD is persistent, on-going. The baseline in the case of a patient with a TAH or LVAD should therefore be conceived of as the state the patient would have been in had she never been implanted with the device in the first place. So deactivating a TAH or LVAD harms a patient only if lowers her below the state she would have been in if she had never been implanted with the TAH or LVAD in the first place. If as a result of the treatment constituted by a TAH or LVAD a patient has already lived longer than she would have lived without it, then deactivating the TAH or LVAD, even though she will die shortly thereafter, does not lower the patient below her baseline. When physicians participate in deactivating a TAH or LVAD in such cases, they do not harm the patient.

The same point can be put in terms of the scope of the medical action that is the object of evaluation. The moral equivalency of withholding and withdrawing requires that if a treatment is on-going, the scope of the medical action to be evaluated is the set of acts that began with the initiation of the treatment and continue

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[13] Lynn Jansen raised an interesting objection about the account of a baseline and harming that I use here. On this account, if a treatment is ongoing, then the patient's baseline is the state she would have been in before the treatment began, and thus, physicians harm a patient only if they lower her below the state she was in before treatment began. But imagine that there is a treatment that is necessary to keep a patient alive; if the treatment had not been initiated, the patient would have died. Now imagine that the patient wishes to continue the treatment but that the physician discontinues it, against the patient's wishes, and the patient subsequently dies. It might seem that my account commits us to saying that the physician has not harmed the patient, because the patient is no worse off than she would have been if the treatment had not been started in the first place. But, so this objection goes, it seems perfectly clear that the physician has harmed the patient. I think the best response to this objection is to hold that the wrong the physician has committed is violating the patient's right to determine for herself what happens to her body, not harming the patient's health by lowering her below her baseline. If there is a harm involved, it is not that of lowering the patient's health below her baseline but of failing to respect the patient's wishes about how she wants to be treated. Lynn Jansen also pointed out that there is often a continuum between a treatment that is on-going and a treatment that is finished, not a clear line. What if the person who has had his leg fixed still needs to rub an ointment in every night for a year, and needs to see the doctor once every six months to get a prescription for the ointment? If the leg is otherwise healthy, it seems incorrect to say that the patient is not physically harmed if the physician re-breaks the leg because the patient is still receiving some care from the physician. But it also seems ad hoc to say that the treatment is *completely* finished. I will proceed as though we are discussing only cases in which we can draw a clean line between on-going and completed treatments. It might be, however, that there is a continuum of harming that tracks the extent to which a medical treatment is on-going: the more significant and life-affecting a treatment is at a particular moment, the less of a harm it is for a physician to return the patient to the state she would have been in if she had never interacted with the physician.

to the present moment. So if the treatment constituted by a TAH or LVAD is persistent and if a patient has lived longer with a TAH or LVAD than she would have done with it, then the medical action that includes deactivation does not lower the patient below her baseline. The medical action that is the object of evaluation is the one whose scope encompasses both implantation and deactivation, and that action has prolonged the patient's life.

A patient should have the right to decide not merely between the following two options: (1) no treatment and imminent death, and (2) treatment that will prolong life and must continue indefinitely. A patient should also have a third option: (3) treatment that will prolong life but that may be discontinued when the patient wishes. Once you board an airplane, you lose the right to choose for yourself when to end the ride. My point is that the decision to be implanted with a TAH or LVAD should not be like the decision to board an airplane.[14]

12.6 Deactivation of TAHs and LVADs and Physician-Assisted Death

Our focus up to now has been the question of whether it is permissible for physicians to participate in the deactivation of TAHs and LVADs. In this final section, I will discuss how the previous points may be extended to the question of the permissibility of physician-assisted death.

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[14] An important issue that I cannot discuss here is the scarcity of resources. The implantation of a TAH or LVAD is an expensive, resource-intensive treatment. In the world of medicine today, there clearly is an obligation to husband our medical resources as efficiently as possible. Might this imply that we develop selection criteria for TAHs and LVADs such that we only implant them in people whom we have compelling reason to believe will continue to live with them for as long as possible? We already have in place such criteria for organ transplantation. Whatever we might think about a person's right to hasten her own death, donated organs are in such short supply that it is widely accepted that we ought to transplant them only in people who will get the most possible life out of them. A patient who is likely to live significantly less time than otherwise equivalent patients, either because her medical prospects are bleaker or because we believe she very well may decide in the near future that she prefers not to live any longer, is less likely to receive a transplanted organ than those others. Should we screen potential TAH and LVAD patients in the same way, so that we do not implant these very expensive devices in people if we suspect that they may later decide that they want the devices deactivated, reserving the devices and the resources needed to develop them for those patients who will use them to live as long as possible? Can we legitimately enforce an informed consent-type contract that the patient signs and that forbids future deactivation? How would this square with the President's Commission's admonition against withholding possibly beneficial treatment because of the specter of future decisions to withdraw? I think these questions are important and that answering them warrants a thorough investigation of its own. I am arguing here that there is nothing intrinsically wrong with physician participation in the deactivation of TAHs and LVADs. But that leaves open the possibility that there are consequentialist considerations and contingent features of resource allocation that imply weighty reasons not to implant these devices in patients whom we have reason to believe will request deactivation.

Let's start with the case of a person who has received an organic heart transplant. Up to now, we have used the case of a physician who stops the beating of a transplanted organic heart as an example of a violation of the prohibition on physician harming. But in light of our discussion of deactivating TAHs and LVADs, we need to reassess the moral status of a physician's stopping of the beating of a transplanted heart.

Receiving a transplanted heart and being implanted with a TAH or LVAD are similar in this important respect: both treatments are persistent conditions, not discrete events. A transplant recipient does not stop being a patient after the operation any more than someone with TAH or LVAD does. As Rady and Verheijde (2014, 6) put it, "[a] transplanted heart is immunologically incompatible and the recipient is dependent on regular intake of immunosuppressive medication and expert supervision to prevent biological rejection." Living with a transplanted heart is not like living with a leg that was broken and is now healed. As with a TAH or LVAD, one's life is permanently profoundly affected. Physician participation in the stopping of a transplanted heart need not, consequently, be conceived of as the harming of a patient. If the patient has already lived longer than she would have had she not had the transplant, and if the patient judges that the costs of the transplant are no longer worth the benefits, then physicians who participate in the stopping of the transplanted heart can be conceived of as respecting the patient's wish to discontinue treatment and not as harming the patient by dropping her below her baseline. The physicians' actions in such a case include in their scope both transplantation of the heart and participation in the stoppage of the heart. And when the physicians' actions are taken to have this scope, they do not harm the patient because they do not lower her below her baseline. Were it not for the physicians' actions, the patient would have died sooner rather than later.

Of course TAHs and LVADs are mechanical while transplanted hearts are organic. But that distinction in material constitution does not imply any moral difference. What matters morally is that the thing is performing a certain function, not how it was made. As Hopkins explains, "What is significant about lungs is not what they are made of, but rather simply their functional role in the development and behavior of the human body. Whether made of synthetic polymers, metal, genetically engineered tissue, or genetically inherited tissue, lungs are significant for what they do—gas exchange—not for some essentialized composition. The same is true for hearts, livers, or any other organ. After all, why does a lung or a heart ever figure as valuable in the first place? … Is it because they are made of biological tissue? … In fact, the reason hearts and lungs and livers and kidneys are valued and their malfunction met with great concern is not because of what they are made of, but because of what they do… Irrespective of its genesis, developmental history, or molecular structure, any object that performs the same function as a heart, lung, or liver actually is a heart, lung, or liver" (Hopkins 1997, 34–35). If a person wishes to continue living, whether one of the organs keeping her alive is composed of organic or inorganic material is morally irrelevant to our obligation to respect her wishes. And if a person wishes to discontinue treatment that is maintaining one of her life-sustaining organs, that organ's material composition is equally morally irrelevant.

One might object that there is another morally crucial respect in which physician participation in deactivating a TAH or LVAD differs from physician participation in the stopping of a transplanted heart: deactivating a TAH or LVAD is an act of omission, while the stopping of a transplanted heart is an act of commission. Now the issue of the viability and relevance of the omission/commission distinction is a massive one, and I cannot provide anything close to an adequate discussion of it here. But let me briefly sketch why I believe the distinction does not establish a moral difference between physician participation in deactivating a TAH or LVAD and physician participation in the stopping of an organic heart transplant.

Let us say that a TAH or LVAD is implanted in such a way that its operation can be discontinued by pressing a small button on the device itself. The button has become inaccessible from the outside of the patient. But it can be pressed by inserting a needle under the patient's skin, and by the needle's being guided to the button. Let us also say that there is another TAH or LVAD that can be stopped if a certain "chemical button" on it is pushed—i.e., it can be stopped if the patient takes a pill that releases an ingredient that causes the device to cease its operation. Consider as well a third TAH or LVAD that can be stopped only by waving a powerful magnet across the patient's mid-section. These three types of TAH or LVAD differ from the typical TAH or LVAD in that the typical TAH or LVAD can be stopped by manipulating a bit of machinery outside the patient's skin. But that difference does not have moral significance. If you believe it is morally permissible to discontinue the operation of a TAH or LVAD by pressing a button outside of the patient's body, then you should also accept that it is morally permissible to discontinue its operation by pressing a button underneath the patient's skin, or by activating a chemical button, or by waving a magnet. The mere physical differences between these methods of stopping a TAH or LVAD bear no moral weight. There may be some sense in which using a needle or a pill or a magnet is an act of commission, but whatever sense there may be in that, it does not reverse the moral status of deactivation from permissible to impermissible. But if the change from flipping an external switch to inserting a needle or administering a pill or waving a magnet does not invert the moral status of deactivating a TAH or LVAD, why should the physical characteristics of inserting a needle or administering a pill or waving a magnet make it impermissible to stop the operation of an organic rather than an artificial heart? There may be a sense in which stopping the functioning of a transplanted heart by discontinuing immunosuppressive medication is an act of omission and stopping the functioning of a transplanted heart by inserting a needle or administering a pill or waving a magnet is an act of commission. But if the physical differences between these types of acts have no moral significance in the case of a TAH or LVAD, then this difference should have no moral significance in the case of a transplanted heart either.

If the idea of conceiving of physician participation in the stopping of a transplanted heart as the cessation of treatment and not as the lowering of the patient below her baseline continues to seem counterintuitive, it might be because our thinking is influenced by an antiquated view of medical treatment. On this antiquated view, when a person becomes gravely ill, she is given a treatment that either succeeds or fails. If the treatment succeeds, the patient recovers health and is no longer a patient. If the treatment fails, the patient dies. But in fact heart transplantation, the implantation of TAHs and LVADs, and many other current treatments do not fall into either of these categories. Advances in medical technology have created a new category, that of patients whose continued existence requires persistent medical treatment, patients for whom medical care enables them to live with disease as opposed to either overcoming or succumbing to it. The treatments involved in such persons' care can keep disease at bay but not entirely defeat it. Persistent medical care sustains the patients, but does not cure them. The diseases are parried, not defeated. We can keep the diseases from killing people, but we cannot restore the afflicted to health. The afflicted live with the treatment and the disease. They become persistent patients. Both disease and treatment are ongoing.

We have already discussed how heart transplant recipients and those with TAHs and LVAD fall into this category of persistent patients. There are other examples as well. Consider kidney disease. In the past, those with severely compromised kidney function died in a matter of weeks or months. But now, with dialysis, someone with minimal kidney function can live for many years. But receiving dialysis several times a week and controlling for the other symptoms of kidney disease significantly alters one's life. These are not merely trivial inconveniences. The way someone with kidney disease lives today is very different from—much more bound up with illness and treatment than—the way anyone lived a hundred years ago. The same is true of the long-term discomfort of someone who has a cancer that cannot be eliminated but can be kept at bay through continual rounds of radiation or chemotherapy. Or of someone with ALS who has been kept alive much longer than she would have been without medical treatment but who as a result lives with severe respiratory discomfort that ALS patients in the past would never have experienced.

None of this is meant to denigrate the great benefits of the medical advances that have extended life for people with heart disease, ALS, kidney disease, cancer, and the like. They are clearly glorious achievements we should all be grateful for. As a result of these advances, people spend more of their lives being sick, but that is because people now have more years of life. At the same time, these treatments do result in patients' having deleterious experiences that they would not have had if they had never interacted with physicians at all. Those deleterious experiences are side effects of the treatments, not merely natural aspects of living and dying. When a patient whose life has already been extended asks a physician to help her hasten death in order to eliminate those side effects, she is asking for assistance in acting on her judgment about the balance of costs and benefits of a treatment. She is not asking the physician to lower her below her baseline.

The crucial distinction is between two types of people who ask physicians for assistance in a course of action that will lead to their death. The first type is not undergoing medical treatment. The second type is undergoing medical treatment, and that treatment has already extended her life beyond the point she would have lived without it. If physicians accede to the request of the first patient it may be correct to characterize what they do as participating in a course of action that physically harms a patient by lowering her below her baseline. But if physicians accede to the request of the second patient, what they are doing is enabling the patient to act on her own judgment of the balance of costs and benefits of continuing a treatment. What they are doing is respecting a right that encompasses the freedom both to refuse to begin any medical treatment and to discontinue any medical treatment that has already begun.

Some current medical treatments for heart disease, cancer, ALS, and the like continue indefinitely. They are not discrete events. The side effects of those treatments continue indefinitely as well. Indeed, even after the physical interventions have been stopped, patients can continue to experience deleterious side effects. Even after the physical interventions have stopped, patients can continue to have painful experiences that they would not have had if they had not begun the treatments in the first place. A person facing a situation with this potential outcome should be able to choose between three options: (1) no treatment at all, (2) treatment that continues as long as it is physically possible, and (3) treatment that continues right up to the point at which the patient deems the harms of the side effects no longer worth the benefits of the treatment. To respect a patient's decision to choose (3), a physician might have to undertake a course of action that involves treating a patient for a time and then participating in a procedure that leads to the patient's hastened death. For in some cases, it is only by physicians' participating in hastening death that deleterious side effects of medically prolonging life can be avoided.

The view I've just sketched has two consequences that are worth underscoring. First, physician-assisted death is morally acceptable for some competent patients but may not be morally acceptable for all competent patients. It is acceptable for a competent patient whose life has been prolonged by treatment that is persistent and has deleterious side-effects, but it may not be acceptable for a competent patient who is not sick. Second, physician-assisted suicide may not always have been morally acceptable but has become so as a result of developments in medical technology. The crucial aspect of these developments is the creation of situations in which we can prolong life but only by having patients submit to persistent medical treatment with deleterious side-effects. Both of these consequences are welcome. What's right for physicians to do for one patient may be wrong for physicians to do for another patient. And changes in technology can create new situations that do not fit neatly into previous moral categories. We cannot decide what to do in situations saturated by new technology simply by applying the moral wisdom of times before that technology existed. The ethics of nuclear weaponry cannot simply be read off the rules of medieval warfare. The ethics of internet privacy and copyright cannot simply be read off rules of book and magazine publication. And the ethics of physician-assisted death for patients whose lives have been prolonged by persistent, invasive, technologically-intensive treatment cannot simply be read off the medical rules from times before those treatments existed.

12.7 Conclusion

In Sect. 12.1, I maintained that there is uncertainty about the moral status of physician participation in the deactivation of TAHs and LVADs. In Sect. 12.2, I tried to make plausible the idea that this uncertainty is due to the apparent conflict between two fundamental principles of medical ethics: the moral equivalency of withholding and withdrawing treatment, and the prohibition on physicians' physically harming patients. In Sects. 12.3–12.5, I argued that in most actual cases this conflict is only apparent, not real; when physicians participate in the deactivation of a TAH or LVAD in a patient who has already lived longer as a result of being implanted with the device, they are acting in accord with the moral equivalency of withholding and withdrawing and are not violating the prohibition on harming patients. In Sect. 12.6, I pointed to the similarity between TAHs and LVADs and other treatments that prolong life without curing the underlying disease at which they are directed. I argued that when a treatment is a persistent condition (not a discrete event), when that treatment has already prolonged life, and when continued prolongation of life involves more hardship than benefit, physician participation in the hastening of death is morally equivalent to physician participation in the deactivation of a TAH or LVAD. In such cases, physicians respect the moral equivalency of withholding and withdrawing and do not violate the prohibition on harming. This is because the physicians' actions in such cases have already prolonged the patient's life, and because the hardships the patient is facing are side-effects of medical treatment and not merely natural consequences of the progression of a disease.

References

Bramstedt, Katrina A., and Neil S. Wenger. 2001. When withdrawal of life-sustaining care does more than allow death to take its course: The dilemma of left ventricular assist devices. *Journal of Heart and Lung Transplantation* 20: 544–548.

Dudzinski, Denise M. 2006. Ethics guidelines for destination therapy. *Ethics in Cardiothoracic Surgery* 81: 1185–1188.

England, Ruth, Tim England, and John Coggon. 2007. The ethical and legal implications of deactivating an implantable cardioverter-defibrillator in a patient with terminal cancer. *Journal of Medical Ethics* 33: 538–540.

Fang, James C., and Joseph Stehlik. 2013. Moving beyond 'bridges'. *JACC Heart Failure* 1: 379–381.

Goldstein, Nathan E., Davendra Mehta, Saima Siddiqui, Ezra Teitelbaum, Jessica Zeidman, Magdelena Singson, Elena Pe, Elizabeth H. Bradley, and R. Sean Morrison. 2008. 'That's like an act of suicide': Patients' attitudes toward deactivation of implantable defibrillators. *Journal of General Internal Medicine* 23(supp. 1): 7–12.

Hopkins, Patrick D. 1997. Why does removing machines count as 'passive' euthanasia? *Hastings Center Report* 3: 29–37.

Jansen, Lynn A. 2006. Hastening death and the boundaries of the self. *Bioethics* 20: 105–111.

Kapa, Suraj, Paul S. Mueller, David L. Hayes, and Samuel J. Asirvatham. 2010. Perspectives on withdrawing pacemaker and implantable cardioverter-defibrillator therapies at end of life:

results of a survey of medical and legal professionals and patients. *Mayo Clinic Proceedings* 85: 981–990.

Kay, G Neal, and Gregory T. Bittner. 2009. Should implantable cardioverter-defibrillators and permanent pacemakers in patients with terminal illness be deactivated? *Circulation: Arrhythmia and Electrophysiology* 2: 336–339.

Kraemer, Felicia. 2013. Ontology or phenomenology? How the LVAD challenges the euthanasia debate. *Bioethics* 27: 140–150.

Kramer, Daniel B., Aaron S. Kesselheim, Dan W. Brock, and William H. Maisel. 2011. The ethical and legal views of physicians regarding deactivation of cardiac implantable electrical devices: A quantitative assessment. *Heart Rhythm* 7: 1537–1542.

Lampert, Rachel, David L. Hayes, George J. Annas, Margaret A. Farley, Nathan E. Goldstein, Robert M. Hamilton, G. Neal Kay, Daniel B. Kramer, Paul S. Mueller, Luigi Padeletti, Leo Pozuelo, Mark H. Schoenfeld, Panos E. Vardas, Debra L. Wiegand, and Richard Zellner. 2010. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 7: 1008–1026.

Mueller, Paul S., Keith M. Swetz, Monica R. Freeman, Kari A. Carter, Mary Eliot Crowley, Cathy J. Anderson Severson, Soon J. Park, and Daniel P. Sulmasy. 2010. Ethical analysis of withdrawing ventricular assist device support. *Mayo Clinic Proceedings* 85: 791–797.

Paola, Frederick A., and Robert M. Walker. 2000. Deactivating the implantable cardioverter-defribrillator: A biofixture analysis. *Southern Medical Journal* 93: 20–23.

Patel, Chetan B., Jennifer A. Cowger, and Andreas Zuckermann. 2014. A contemporary review of mechanical circulatory support. *Journal of Heart and Lung Transplantation* 33: 667–674.

Rady, Mohamed Y., and Joseph L. Verheijde. 2014. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: Left ventricular assist devices and total artificial hearts. *Journal of Intensive Care Medicine* 29: 3–12.

Simon, Jeremy R. 2008. Doctor, will you turn off my LVAD? *Hastings Center Report* 38: 14–15.

Sulmasy, Daniel P. 2008. Within you/without you: Biotechnology, ontology, and ethics. *Journal of General Internal Medicine* 23(supp. 1): 69–72.

Teuteberg, Jeffrey J., Garrick C. Stewart, Mariell Jessup, Robert L. Kormos, Benjamin Sun, O.H. Frazier, David C. Naftel, and Lynne W. Stevenson. 2013. Implant strategies change over time and impact outcomes: Insights from the INTERMACS (interagency registry for mechanically assisted circulatory support). *JACC Heart Failure* 1: 369–378.

Wu, Eugene B. 2007. The ethics of implantable devices. *Journal of Medical Ethics* 33: 532–533.

Zellner, Richard A., Mark P. Aulisio, and William R. Lewis. 2009. Should implantable cardioverter-defibrillators and permanent pacemakes in patients with terminal illness be deactivated? *Controversies in Arrhythmia and Electrophysiology* 2: 340–344.

Chapter 13
Everyday Attitudes About Euthanasia and the Slippery Slope Argument

Adam Feltz

Abstract This chapter provides empirical evidence about everyday attitudes concerning euthanasia. These attitudes have important implications for some ethical arguments about euthanasia. Two experiments suggested that some different descriptions of euthanasia have modest effects on people's moral permissibility judgments regarding euthanasia. Experiment 1 (N = 422) used two different types of materials (scenarios and scales) and found that describing euthanasia differently ('euthanasia', 'aid in dying', and 'physician assisted suicide') had modest effects (≈3 % of the total variance) on permissibility judgments. These effects were largely replicated in Experiment 2 (N = 409). However, in Experiment 2, judgments about euthanasia's moral permissibility were best predicted by the voluntariness of the treatment. Voluntariness was a stronger predictor than some demographic factors and some domain general elements of moral judgments. These results help inform some debates about the moral permissibility of euthanasia (e.g., the slippery slope argument) suggesting that some of the key premises of those arguments are unwarranted.

13.1 Introduction

In the United States, voluntary passive euthanasia is often thought to be both legally and morally permissible. One reason for the permissibility of voluntary passive euthanasia is that it promotes the two main goals of contemporary medical decision making in the United States—protecting patient autonomy and promoting patient well-being. Allowing the patient to die can respect the patient's wishes and could result in promoting patient well-being by preventing unavoidable future suffering. However, other types of euthanasia are often thought to be immoral and are

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illegal in many parts of the world. For instance, the American Medical Association does not condone actively taking steps to end a patient's life (i.e., active euthanasia) ("Decisions near the end of life. Council on Ethical and Judicial Affairs, American Medical Association," 1992). The conflict concerning the ethical, legal, and procedural permissibility of some types of euthanasia is also reflected in the philosophical literature. Some argue that some kinds of euthanasia are sometimes morally permissible, others argue that those same kinds of euthanasia are not morally permissible (Battin 2005; Beauchamp 2006; Brock 1992; Jackson and Keown 2012; McLachlan 2010; Raz 2013; Velleman 1992).

While the correct ethical, legal, and procedural views about euthanasia are important, weighing in on those debates is not the primary goal of this paper. Rather, there is a more modest goal. Parties to the debate often give detailed and nuanced arguments about the permissibility of different kinds of euthanasia (see, for example, some of the chapters in this volume). While these arguments are philosophically rich, they often reference everyday thought, attitudes, or other empirically discoverable facts about whether some kinds of euthanasia are permissible. For example, some have argued that allowing voluntary active euthanasia would result in a slippery slope toward other, less morally permissible forms of euthanasia (e.g., involuntary active euthanasia). In its empirical form, the slippery slope is most efficiently and perhaps best addressed by using empirical methods. Does allowing some kinds of euthanasia *actually* lead to an acceptance of other less ethically desirable kinds of euthanasia?

The overarching aim of this chapter is to provide evidence about everyday attitudes concerning euthanasia by addressing two main issues. The first issue involved measuring the extent to which different ways of characterizing euthanasia (e.g., 'assisted suicide' versus 'aid in dying') influence everyday attitudes about the morality of those practices. Results from the two experiments suggested that the effect of description is real but small. The second issue involved predicting everyday attitudes about euthanasia. One of the major factors predicting judgments about the moral permissibility of euthanasia was the voluntariness of the decision. Voluntariness predicted attitudes independently of other demographic variables and some domain general components of moral cognition. These results not only provide additional evidence about everyday attitudes about euthanasia's moral permissibility, they also help inform some philosophical arguments about the ethics of euthanasia's (e.g., the slippery slope argument). These results suggest that a key empirical premise in the slippery slope argument against euthanasia is false. People who accept some forms of euthanasia simply are not led to accept other, more morally objectionable forms of euthanasia.

13.2 Euthanasia: Philosophical and Empirical Work

Generally, it is agreed that there are at least six conceptually distinct kinds of euthanasia. Euthanasia can be passive (allowing a patient do die) or active (actively taking steps to end a patient's life). Euthanasia can also be voluntary (the procedure is requested), non-voluntary (the patient is unable to request the procedure), or involuntary (the patient does not want the procedure). Crossing these two categories of euthanasia produces six distinct kinds of euthanasia (e.g., voluntary active euthanasia) (Brock 1992).

There is a growing body of empirical research about attitudes toward euthanasia (Achille and Ogloff 1997; DeCesare 2000; Domino 2002; Emanuel 2002; Gamliel 2013; Genuis et al. 1994; Ho and Penney 1992; Jorgenson and Neubecker 1981; MacDonald 1998; Ostheimer 1980; Parkinson et al. 2005; Rogers 1996; Singh 1979; Verbakel et al. 2009; Wolfe et al. 1999). Unfortunately there are some common conceptual problems and ambiguities that make interpreting the ethical significance of these empirical data difficult (Rogers 1996; Wasserman et al. 2005).

First, there are definitional confusions about euthanasia. For example, the AMA defines 'euthanasia' as "the administering of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering" ("Decisions near the end of life. Council on Ethical and Judicial Affairs, American Medical Association," 1992). This definition clearly involves active euthanasia only. On this definition, all passive ways to end life are not part of the definition of 'euthanasia'. More than that, the AMA's definition does not reference the voluntariness of the euthanasia. These ambiguities also occur in many experimental explorations of attitudes toward euthanasia. For example, in one study, participants were instructed to rate whether practices indicated by a word on a card were justified. One of the words was 'euthanasia' (Verbakel et al. 2009). It is unclear which, if any, of the six general notions of euthanasia participants thought 'euthanasia' referred to.

Second, terms may be appropriately disambiguated yet impermissible inferences are made to euthanasia in general. For example, The National Opinion Research Center has one prominent question that has been analyzed a number of times (DeCesare 2000; Jorgenson and Neubecker 1981; Ostheimer 1980; Singh 1979): "When a person has a disease that cannot be cured, do you think doctors should be allowed to end the patient's life by some painless means if the patient and his family request it?". This question clearly focuses on voluntary euthanasia and is naturally (although not necessarily) interpreted as actively ending a patient's life as opposed to allowing the patient's life to end. The other five types of euthanasia are left unexplored by this question. Since this procedure constitutes just one kind of euthanasia, it is impermissible (or at least risky) to infer that answers to this question reflect attitudes about euthanasia *in general* or to make inferences about the moral permissibility of some other types of euthanasia.

Finally, kinds of euthanasia can be nested, yet the nested nature is not noticed or is glossed. For example, questions of euthanasia are also discussed under the rubric of "physician assisted death." Though this is not always acknowledged or made clear, physician assisted death divides into two "species." In physician assisted suicide, the patient is the one who actually administers the deadly treatment whereas in voluntary active euthanasia the agent who initiates the lethal treatment is typically a doctor (Brock 1992, 10). If there is this conceptual and practical distinction, one might think that physician assisted suicide is an acceptable form of physician assisted death but voluntary active euthanasia is not. Or one might think that killing one's self is not permissible but having a professional do it might be. So, one could think that one type of physician assisted death is permissible, but not both types of physician assisted death.

Theorists can avoid many of these problems by stipulating definitions of euthanasia. But, not paying attention to these conceptual distinctions is risky. These conceptual confusions raise the possibility that attitudes toward euthanasia are confounded by terminology rather than assessing core issues about euthanasia—a phenomenon that is similar to the psychological effect known as *framing*. Typically, framing occurs when apparently logically identical, but different, descriptions of a choice elicit different decisions (for a review, see Levin et al. 1998). The classic example of framing is Tversky and Kahneman's (1981) Asian Flu case. In this case, participants were asked to decide between two programs to combat a new Asian Flu that will affect up to 600 people. Participants could choose program A that would *save* 200 lives for sure, or program B that has a 1/3 chance of *saving* everybody and a 2/3 chance of *saving* nobody. A different group of participants received a similar description but their choices were between program C where 400 people will *die* for sure and program D where there is a 1/3 chance nobody *dies* and a 2/3 chance everybody *dies*. On the surface, these two descriptions are logically identical. However, in the "save" condition, 72 % took that less risky program A whereas in the "die" condition 78 % took the more risky program D. One explanation for this phenomenon is that people become risk averse in the "gain frame" to lock in the desirable outcome, whereas people become risk seeking in the "loss frame" to have a chance of avoiding the negative outcome.

Similar framing may happen when using different terminology to refer to euthanasia. To illustrate, "physician assisted suicide" may focus people's attention on a specific type of goal—suicide. One may be inclined under this description to avoid that undesirable goal thereby increasing the odds that one judges it morally impermissible. Another description that may be logically identical to physician assisted suicide is "aid in dying." 'Aid' may focus attention on a very different goal that is evaluated as more favorable. Given that favorable evaluation, one may be more inclined to obtain that positive goal and thus judge the action morally permissible. If physician assisted suicide and aid in dying refer to the very same thing, then perhaps describing the type of euthanasia one way may generate a very different reaction compared to describing euthanasia in a logically identical, alternative way.[1]

Some data suggest that different descriptions of euthanasia can influence judgments about the legality of euthanasia (Barry 2007). A 1997 public opinion poll conducted by Princeton University found that 45 % of people responded 'yes' to

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[1] It is unclear whether these two descriptions really are logically identical. Even if they are not logically identical, it is an open question whether attitudes about them vary sufficiently for there to be an empirical distinction between the two. See discussion.

the following question "Do you think that it should be legal for a doctor to help a terminally ill patient commit suicide, or not?". However, a poll conducted by Louis Harris and Associates found that 69 % of people responded 'yes' to the following question "Do you think that the law should allow doctors to comply with the wishes of a dying patient in severe distress who ask to have his or her life ended, or not?" (Barry 2007). On the face of it, the only substantive difference between the two questions is whether it should be legal for doctors to help patients commit 'suicide' or respect patients' wishes to end their life. This small difference saw the majority of people disagree that the former should be legal while the majority thought the latter should be legal. Others have found a similar difference comparing different measures of euthanasia and physician assisted suicide (Hains and Hulbert-Williams 2013).

There are subtle but possibly important differences in the wording of the questions in the two polls, making interpretation of direct comparisons difficult. Huber et al. (1992) provide more systematic and direct evidence. Their studies suggest that there are important differences between end of life decisions described as 'euthanasia', 'mercy killing', 'physician assisted suicide', and 'some form of control over death'. They asked participants "If adequate safeguards could be developed, would you like to see (one of the four terms) legalized?" (Huber et al. 1992, 7). Averaging across all four descriptions, 64 % of people thought that these treatments should be legalized. However, there was variability associated with different descriptions. More people thought that euthanasia should be legalized (about 78 %) compared to physician assisted suicide (about 40 %). These results suggest that the description can have an impact on judgments about whether euthanasia should be legalized.

These studies highlight some difficulties in assessing everyday attitudes about the moral permissibility of euthanasia. First, there are conceptual problems. Terms used in existing studies are often not sufficiently clear to measure the relevant attitudes. Second, studies often measure the legality and not morality of euthanasia. It is sometimes difficult to infer moral permissibility from legality. For example, one could think that euthanasia should be legal while at the same time think it is morally impermissible. Even if there is likely to be some correlation between many legal and moral judgments, the strength of that relation remains unknown. Third, most of the research about wording does not directly compare responses in the same studies or samples. The one study that does relies on one question that may have questionable reliability and that requires replication. Finally, given that there are ambiguous and varied descriptions of end of life decisions involving death, framing effects may influence some judgments about the moral permissibility of those decisions.

These conceptual and empirical issues are important for assessing and interpreting some arguments about euthanasia. The slippery slope argument will serve as an illustrative example. The slippery slope argument is often presented in a logical or an empirical form (see Lewis 2007 for an overview). On both versions, accepting some, perhaps morally permissible, version of euthanasia would lead one either conceptually or empirically to accept less morally permissible versions.

For example, on the conceptual version, people may not be able to fully appreciate the conceptual difference between non-voluntary and involuntary euthanasia once they have already accepted non-voluntary euthanasia. Or, on the empirical version, accepting some forms of euthanasia would *cause* one to accept other definitions of euthanasia—or at least endorse practices that are consistent with those morally objectionable types of euthanasia. So the slippery slope arguments have key premises that, in fact, people (a) do not appreciate conceptual distinctions among types of euthanasia once they accept some types of euthanasia, or (b) accepting some types of euthanasia causes people to accept other types of euthanasia.

Unfortunately, the current state of the science does not help much to address either (a) or (b). Conceptual problems make it difficult to interpret whether those who endorse some acceptable forms of euthanasia see no conceptual distinction between less acceptable forms of euthanasia. Relatedly, given the conceptual problems in the currently existing empirical data, it is difficult to understand any of the causal relations among those definitions. Finally, different ways to frame euthanasia could give divergent evidence for (a) and (b). Theoretically, if one focuses on positive aspects (e.g., "aid in dying") one may find fuller endorsement of all types of euthanasia compared to negative frames for euthanasia (e.g., "physician assisted suicide"). The former may support slippery slope arguments while the latter may not. Without knowing the extent of the influence of framing, it will be difficult to interpret people's core attitudes about euthanasia. To fully address (a) and (b), new data are required. Experiments 1 and 2 were designed to help provide some of these data.

13.3 Experiment 1

Experiment 1 had three different goals. The first was to measure the effect of different descriptions of end of life decisions on the moral permissibility of those decisions. This was done using two different kinds of materials. The first set of materials was scenarios that systematically altered the description of the end of life decision. The second set of materials involved scales that systematically altered the description of the end of life decision. Based on previous research, it was predicted that the most morally permissible action would be described as "aid in dying." The least morally permissible treatment would be described as "physician assisted suicide." Treatments described as 'euthanasia' were predicted to be morally permissible, but not as acceptable as aid in dying since "aid in dying" is a proper subset of euthanasia in general (euthanasia could be interpreted in one of its less acceptable forms, i.e., involuntary active euthanasia).

13.3.1 Participants

Four hundred and twenty-two participants were recruited from Amazon's Mechanical Turk.[2] Twenty-five participants were excluded for not completing the survey. One participant was excluded for reporting an age less than 18. The mean age was 35.59, $SD = 12.9$ ranging from 18–79. Fifty-six percent ($N = 223$) were women.

13.3.2 Materials

The scenarios were inspired by those developed by Frileux et al. (2003). Their scenarios focused on physician assisted suicide and euthanasia. Their data suggested that generally, physician assisted suicide is less preferred than euthanasia. In addition, their data suggested that requests for euthanasia were one of the primary factors in whether the treatment was acceptable (along with age of patient, mental health, and prognosis). Their scenarios were modified in this experiment to include a description of "aid in dying" in addition to descriptions of physician assisted suicide and euthanasia. Finally, the scenarios were modified to make the non-voluntary versus voluntary nature of the decision clear (see Appendix for the actual text of all six scenarios).[3] Participants responded to the moral permissibility of the procedure on a 6-point scale (1 = strongly disagree, 6 = strongly agree).

The second set of materials involved scales composed of 11 items concerning euthanasia, physician assisted suicide, and aid in dying (see Appendix for full scales). Participants responded to each prompt on a 6-point scale (1 = strongly disagree, 6 = strongly agree). These scales were based on Roger's (1996) scale that measured attitudes about euthanasia. The basic methodology was adopted from Kemmelmeier et al. (1999) who systematically changed 'euthanasia' to 'physician assisted suicide' in each of Roger's scale items that had 'euthanasia' in it.[4] In addition to systematically altering 'euthanasia' to 'physician assisted suicide', one scale also used the phrase 'aid in dying'. Scales were used in addition to scenarios because one-item measures can be of limited validity. Many extraneous factors, question wordings, or other features idiosyncratic to the scenario or question

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[2] For an overview of the quality of Amazon Mechanical Turk's participants, see Buhrmester et al. (2011), Paollacci et al. (2010).

[3] It may seem somewhat forced to include the category "non-voluntary physician assisted suicide" since physician assisted suicide is typically taken to be a kind of voluntary, active euthanasia. In the non-voluntary scenario, the wishes of the patient are left unspecified so one cannot be sure if the patient volunteers for the treatment. Alternatively, the patient may be understood to be functioning, yet incompetent (hence, not able to give adequate consent).

[4] Kemmelmeier et al. (1999) did not gather data on the 'euthanasia' scale, so direct comparisons between the two scales was not possible.

may influence participants' responses. Instruments with more than one question allow assessing the degree of internal reliability of responses. If items measure roughly the same underlying construct, then the internal reliability of the scale should be relatively high. In this way, the scales provide an additional source of evidence that can converge with evidence from the scenarios.

Participants first answered each of the three scales for euthanasia, physician assisted suicide, and aid in dying (counter balanced for order). Participants then were randomly assigned to only one of the six scenarios. Next, participants completed the Ten Item Personality Inventory (TIPI) (Gosling et al. 2003). The TIPI is a brief, 10-item measure of the Big Five personality traits extraversion, openness to experience, emotional stability, agreeableness, and conscientiousness. Next, participants completed the Berlin Numeracy Test (BNT) (Cokely et al. 2012). The BNT is a brief measure of the ability to understand and use statistical information and has been related to increased focus, attention, and some normatively correct choices. Finally, basic demographic information was collected including a brief measure of political orientation: "Here is a seven point scale on which political views people might hold are arranged from extremely liberal to extremely conservative. Where would you place yourself on this scale" (1 = extremely liberal, 4 = moderate, 7 = extremely conservative). This measure of political orientation is an efficient and reliable way to measure general political orientations (Kroh 2007).

13.3.3 Results

13.3.3.1 Scenarios

Scenarios were analyzed first. Means and standard deviations for the 6 scenarios are reported in Table 13.1.

An Analysis of Variance (ANOVA) with the different scenarios as the independent variable and responses to the permissibility question as the dependent variable showed an overall difference between scenarios $F\ (5, 390) = 20.43$, $p < 0.001$, $\eta^2_{\mathrm{p}} = 0.21$. There was no main effect of sex $F < 1$, and sex did not reliably interact with judgments $F\ (5, 384) = 1.67$, $p = 0.14$, $\eta^2_{\mathrm{p}} = 0.02$. Because sex was not reliably related to judgments and for ease of analyses, sex was excluded as an independent variable for all subsequent analyses.

Planned comparisons with voluntariness as the independent variable and responses to the permissibility question as the dependent variable revealed

Table 13.1 Means and standard deviations from scenarios in Experiment 1

	Non-voluntary	Voluntary
Euthanasia	$N = 57$, $M = 3$, $SD = 1.91$	$N = 61$, $M = 4.67$, $SD = 1.42$
PAS	$N = 62$, $M = 2.95$, $SD = 1.83$	$N = 74$, $M = 4.5$, $SD = 1.8$
Aid in dying	$N = 73$, $M = 3.14$, $SD = 1.86$	$N = 69$, $M = 5.04$, $SD = 1.33$

an overall difference between non-voluntary ($M = 3.04$, $SD = 1.86$) and voluntary ($M = 4.74$, $SD = 1.55$) conditions, $F\ (1, 394) = 96.93$, $p < 0.001$, $\eta_p^2 = 0.2$. Pairwise comparisons were next performed for each type of end of life decision (euthanasia, PAS, and aid in dying) to determine the effect of voluntariness on judgments of permissibility. These analyses revealed large overall differences in judgments as a function of voluntariness: Euthanasia, $F\ (1, 116) = 29.37$, $p < 0.001$, $\eta_p^2 = 0.2$, physician assisted suicide $F\ (1, 134) = 24.56$, $p < 0.001$, $\eta_p^2 = 0.16$, aid in dying $F\ (1, 140) = 48.85$, $p < 0.001$, $\eta_p^2 = 0.26$.

Finally, analyses were conducted to determine differences in judgments of permissibility as a function of the description. There were no detectable differences in permissibility judgments for non-voluntary descriptions of euthanasia, $Fs < 1$. There was a significant difference between voluntary physician assisted suicide and voluntary aid in dying $F\ (1, 141) = 4.16$, $p = 0.04$, $\eta_p^2 = 0.03$. There was no reliable difference between voluntary euthanasia and voluntary physician assisted suicide, $F < 1$. There was no reliable difference between voluntary euthanasia and voluntary aid in dying $F\ (1, 128) = 2.36$, $p = 0.13$, $\eta_p^2 = 0.02$.

Correlations among the dependent variables for the scenarios are reported in Table 13.2. There were no systematic relations between the permissibility question and these demographic factors.

13.3.3.2 Scales

The mean responses and internal reliabilities were similar for the euthanasia scale ($M = 4.11$, $SD = 1.23$, $\alpha = 0.92$), physician assisted suicide scale ($M = 4.11$, $SD = 1.28$, $\alpha = 0.92$) and aid in dying scale ($M = 4.22$, $SD = 1.18$, $\alpha = 0.91$). A mixed-model ANOVA with responses to the three scales as within subjects factors and order of presentation as between subjects factors revealed an overall small

Table 13.2 Correlations for scenarios Experiment 1

	Euthanasia					
	Non-voluntary	Euthanasia voluntary	PAS non-voluntary	PAS voluntary	Aid non-voluntary	Aid voluntary
BNT	0.08	−0.03	−0.17	0.02	−0.02	−0.01
Extraversion	0.19	0.08	−0.06	−0.04	0.2	−0.26*
Agreeableness	0.05	0.14	−0.12	−0.03	−0.08	−0.12
Conscientiousness	−0.04	0.12	−0.05	−0.06	−0.04	0.2
Emotional	0.06	−0.02	0.03	−0.08	0.02	0.13
Openness	−0.15	0.12	0	0.12	−0.03	0.12
Age	−0.05	0.13	−0.17	0.06	−0.17	0.15
Gender	0.08	0.18	0.03	−0.21	−0.22	−0.04
Politics	0.1	−0.16	0.07	−0.37**	−0.14	−0.21
Area	0.23	0.06	−0.24*	0.03	0.09	−0.13

*$p < .05$
**$p < .01$

effect of description F (2, 392) = 7.33, $p = 0.001$, $\eta_p^2 = 0.02$. However, this effect was qualified by an interaction of order of presentation F (2, 393) = 6.04, $p < 0.001$, $\eta_p^2 = 0.03$. To control for the order effect, only first responses were analyzed. An ANOVA revealed no overall difference among first responses $F < 1$.

Correlations among the dependent variables are reported in Table 13.3. Political orientation predicted permissibility to all three scales. No other reliable relations to the three scales were found.

13.4 Experiment 2

Experiment 1 suggested that there were some modest effects of description on people's judgments of euthanasia's moral permissibility. However, there seemed to be remarkable consistency among judgments. For example, there were strong correlations between responses to the scaled items (*rs* > 0.83). Experiment 1 also suggested that voluntariness was an important factor in attitudes toward euthanasia suggesting that attitudes toward euthanasia may form coherent clusters that center on the voluntariness of the treatment. But what could predict these attitudes across different descriptions? Experiment 2 was designed to help answer this question.

In order to predict attitudes toward euthanasia, the Berlin Euthanasia Scale-6 (BE-6) was used. The BE-6 is a 6-item instrument that measures people's general attitudes about the moral permissibility of euthanasia (Feltz and Cokely, submitted). Evidence from this scale suggests that people do not measurably distinguish active and passive euthanasia, but people do distinguish among three different kinds of voluntariness: Voluntary (i.e., the treatment is requested), non-voluntary (i.e., the person is unable to request treatment due to, for example, a coma), and involuntary (i.e., the person requests the treatment not be performed). The BE-6 uses two items to measure these three different types of euthanasia. In addition, the Moral Foundations Questionnaire (MFQ) was used (Graham et al. 2011). The MFQ measures five different foundations for people's moral judgments: Harm/care, fairness/reciprocity, in-group/loyalty, authority/respect, and purity/sanctity. The elements of the MFQ have been argued to be major components in people's general moral views. It was predicted that the BE-6 would be the major predictor of judgments about euthanasia even when considering other demographic variables and the MFQ.

13.4.1 *Participants*

Four hundred and nine participants were recruited from Amazon's Mechanical Turk. Twenty-two participants were excluded for not completing the survey. Two people were excluded for reporting an age less than 18. The mean age was 37.23, *SD* = 13.48, *Range* 18–74. Sixty-seven percent ($N = 260$) were female.

Table 13.3 Correlations for scales Experiment 1

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Euthansia	1												
2. PAS	.86**	1											
3. Aid	.83**	0.88*	1										
4. BNT	0.05	0.12*	0.08	1									
5. Extraversion	−0.05	−0.05	−0.07	−0.03	1								
6. Agreeableness	0.06	−0.08	−0.04	−0.04	0.07	1							
7. Conscientiousness	−0.03	−0.04	−0.01	0.01	0.08	0.29**	1						
8. Emotional	−0.04	−0.04	-0.05	0.04	0.21**	0.43**	0.43**	1					
9. Openness	0.06	0.07	0.09	−0.04	0.23**	0.23**	0.15**	0.18**	1				
10. Age	−0.03	0.01	0.06	0.03	0.01	0.19**	0.2**	0.24**	−0.03	1			
11. Gender	−0.01	−0.02	0.02	−0.09	0.04	0.08	0.05	−0.22**	0.04	0.03	1		
12. Politics	−0.28**	−0.3**	−0.33**	−0.09	0.09	−0.05	0.1	0.12*	−0.11*	0.1*	−0.03	1	
13. Area	−0.04	−0.02	−0.02	−0.05	0	−0.02	0.01	0.01	−0.03	0.05	0.11*	0.1*	1

13.4.2 Materials

Participants received the same three scales from Experiment 1, counterbalanced for order. Participants then randomly received only one of the six scenarios from Experiment 1. Next, participants completed the BE-6, MFQ, the TIPI, and the BNT. Finally, basic demographic information was gathered.

13.4.3 Results

13.4.3.1 Scenarios

Analyses proceeded in the same fashion as Experiment 1. Responses to the scenarios were analyzed first. Means and standard deviations are reported in Table 13.4. An ANOVA with the different scenarios as the independent variable and responses to the permissibility question as the dependent variable showed an overall difference between scenarios F (5, 380) = 29.85, $p < 0.001$, $\eta_p^2 = 0.28$. An ANOVA with voluntariness as the independent variable and responses to the permissibility question as the dependent variable revealed an overall difference between non-voluntary ($M = 2.45$, $SD = 1.7$) and voluntary ($M = 4.51$, $SD = 1.69$) conditions, F (1, 384) = 142.34, $p < 0.001$, $\eta_p^2 = 0.27$.

Pairwise comparisons were next performed to determine differences in permissibility judgments as a function of voluntariness. ANOVAs revealed large differences for each description as a function of voluntariness: Euthanasia, F (1, 136) = 49.57, $p < 0.001$, $\eta_p^2 = 0.27$, physician assisted suicide F (1, 111) = 66.23, $p < 0.001$, $\eta_p^2 = 0.37$, aid in dying F (1, 133) = 35.01, $p < 0.001$ $\eta_p^2 = 0.21$.

ANOVAs tested differences in judgments of permissibility as a function of the description. A statistically significant difference was found between non-voluntary euthanasia and non-voluntary physician assisted suicide F (1, 110) = 4.46, $p = 0.04$, $\eta_p^2 = 0.04$, and non-voluntary physician assisted suicide and non-voluntary aid in dying F (1, 109) = 4.71, $p = 0.03$, $\eta_p^2 = 0.04$, but not between non-voluntary euthanasia and non-voluntary aid in dying ($F < 1$). Next, voluntary end of life decisions were analyzed using each description as the independent variable and response to the permissibility question as the dependent variable. There were no reliable differences between the different types of voluntary end of life decisions ($Fs < 1$).

Table 13.4 Means and Standard Deviations for Scenarios in Experiment 2

	Non-voluntary	Voluntary
Euthanasia	$N = 65$, $M = 2.62$, $SD = 1.77$	$N = 73$, $M = 4.64$, $SD = 1.62$
PAS	$N = 47$, $M = 2.0$, $SD = 1.43$	$N = 66$, $M = 4.47$, $SD = 1.75$
Aid in dying	$N = 64$, $M = 2.64$, $SD = 1.79$	$N = 71$, $M = 4.42$, $SD = 1.71$

13.4.3.2 Scales

The scales had excellent internal reliabilities and the mean responses were similar for each scale: Euthanasia Scale ($M = 3.62$, $SD = 0.75$, $\alpha = 0.92$), physician assisted suicide scale ($M = 3.65$, $SD = 0.79$, $\alpha = 0.92$), and aid in dying scale ($M = 3.74$, $SD = 0.74$, $\alpha = 0.92$). A mixed-model ANOVA with responses to the three scales as within subjects factors and order of presentation as the between subjects factor revealed an overall significant difference $F\ (2, 382) = 8.16$, $p = 0.001$, $\eta_p^2 = 0.04$. However, this effect was qualified by a trend for an interaction of order $F\ (2, 383) = 2.51$, $p = 0.08$, $\eta_p^2 = 0.01$. To control for the order effect, first responses were analyzed. An ANOVA found an overall difference between the three scales, $F\ (1, 383) = 4.59$, $p = 0.01$, $\eta_p^2 = 0.02$. Pairwise comparisons found a small but reliable difference between euthanasia ($M = 3.28$, $SD = 0.63$) and physician assisted suicide ($M = 3.46$, $SD = 0.63$), $F\ (1, 257) = 4.89$, $p = 0.03$, $\eta_p^2 = 0.02$, and aid in dying ($M = 3.5$, $SD = 0.58$) $F\ (1, 257) = 8.46$, $p = 0.004$, $\eta_p^2 = 0.03$, but not between aid in dying and physician assisted suicide ($F < 1$).

13.4.3.3 Predicting Responses

A separate goal of Experiment 2 was to determine what predicted judgments about the 6 scenarios and 3 scales. Stepwise linear regressions were employed. Stepwise regressions proceed by finding the single best predictor. Then, the next step is to find the two best predictors. Then the next step is to find the $3\ldots n$ predictors until some pre-specified level of significant is not met by subsequent predictors. In these series of stepwise regressions, predictors that were significant at the $p = 0.05$ level were retained in the models. The predictor variables for all analyses involving responses to the 3 scales and 6 scenarios were the BE-6 (Voluntary $M = 4.25$, $SD = 1.67$, Non-voluntary $M = 3.43$, $SD = 1.68$, Involuntary $M = 1.95$, $SD = 1.27$), BNT, MFQ, political orientation, sex, age, and personality. See Table 13.5 for the stepwise regressions for the scenarios and Table 13.6 for the stepwise regressions for the scales. As predicted, the items for the BE-6 were the strongest predictors for the responses to both scenarios and scales. There were no other variables that consistently predicted in these models.

13.5 Discussion

Overall, the results from these two experiments suggested that there is some influence of descriptions on the judgments of permissibility for euthanasia. In Experiment 1, there was an overall modest effect of description in the scenarios for some voluntary, but not non-voluntary, end of life decisions. As predicted, physician assisted suicide was the least preferable option and aid in dying was the most preferable option. This modest effect was reproduced with the scales in

Table 13.5 Stepwise regressions for scenarios in Experiment 2

	Model	Variable	Adjusted R^2	*df*	*F*	*p*	R^2_{change}	F_{change}	$p\ F_{\text{change}}$
Euthanasia	1	BE voluntary	0.41	1385	267.6	<0.001	0.41	267.6	<0.001
	2	BE non-voluntary	0.42	2384	141.33	<0.001	0.01	9.29	0.002
	3	Loyalty	0.43	3383	98.56	<0.001	0.01	7.93	0.005
PAS	1	BE voluntary	0.48	1385	356.69	<0.001	0.48	356.69	<0.001
	2	Gender	0.49	2384	184.52	<0.001	0.01	6.9	0.009
	3	BE Non-voluntary	0.49	3383	125.89	<0.001	0.01	4.89	0.03
	4	Fairness	0.5	4382	96.43	<0.001	0.01	4.55	0.03
Aid	1	BE Voluntary	0.45	1385	310.52	<0.001	0.45	310.52	<0.001
	2	BE Non-voluntary	0.46	2384	167.82	<0.001	0.02	14.35	<0.001
	3	Gender	0.47	3383	115.2	<0.001	0.01	5.78	0.02

Table 13.6 Stepwise Regressions for Scales in Experiment 2

	Model	Variable	Adjusted R^2	*df*	*F*	*P*	R^2_{change}	F_{change}	$p\ F_{\text{change}}$
Euthanasia	1	BE non-voluntary	0.07	163	6.05	0.02	0.09	6.05	0.02
Non-voluntary	2	Emotional stability	0.16	162	7.06	0.002	0.1	7.45	0.01
	3	Gender	0.2	161	6.37	0.001	0.05	4.25	0.04
Euthansia voluntary	1	BE voluntary	0.65	171	131.99	<0.001	0.65	131.99	<0.001
PAS non-voluntary	1	BE involuntary	0.24	146	15.7	<0.001	0.25	15.7	<0.001
PAS voluntary	1	BE voluntary	0.8	164	260.39	<0.001	0.8	260.39	<0.001
Aid non-voluntary	1	BE voluntary	0.14	162	11.59	0.001	0.16	11.59	0.001
Aid voluntary	1	BE voluntary	0.46	169	61.08	<0.001	0.47	61.08	<0.001
	2	BE non-voluntary	0.54	268	41.83	<0.001	0.08	12.55	0.001
	3	Emotional stability	0.56	367	30.73	<0.001	0.03	4.28	0.04
	4	Age	0.58	466	25.26	<0.001	0.03	4.31	0.04

Experiment 1. Again aid in dying was more permissible than physician assisted suicide. Experiment 2 found a modest effect for voluntary end of life decisions in the scenarios. Aid in dying was preferred to physician assisted suicide. For the scales, aid in dying was preferred to euthanasia. However, no measurable differences were found between aid in dying and physician assisted suicide. In sum, the different descriptions of euthanasia used in the current series of experiments had modest and intermittent effects on judgments of moral permissibility.

These results suggest that if there is a stable, reliable effect of different descriptions of euthanasia, this effect is small. To illustrate, one of the largest differences occurred in Experiment 2 between scenarios involving non-voluntary physician assisted suicide and non-voluntary aid in dying. Differences in descriptions accounted for about 4 % of the total variance in judgments ($d \approx 0.4$). This is typically thought to be a small to medium effect size. To put the effect into perspective, only about 66 % of responses to aid in dying were more favorable than the mean response to the physician assisted suicide scenario. In other words, 86 % of the distributions of responses between the groups overlap. To illustrate in one final way, a person would have a 61 % chance of being able to identify correctly which scenario the participant was responding to given the participant's answer. Most of the other effects in the current series of studies were smaller. Hence, while the description of the end of life treatment may be a factor in some people's judgments of the moral permissibility of euthanasia, these descriptions are not very important factors for most people.

Even if the effect of description was modest, the current series of studies provide some relevant empirical evidence for some contemporary debates surrounding euthanasia. For one, they add to the evidence that some demographic variables are associated with some judgments about euthanasia. A number of demographic factors have been found to predict judgments about euthanasia including age (DeCesare 2000; Domino 2002; Ho and Penney 1992; Huber et al. 1992; Jorgenson and Neubecker 1981; Ostheimer 1980; Sawyer and Sobal 1987; Singh 1979), sex (Domino 2002; Emanuel 2002; Jorgenson and Neubecker 1981; Sawyer and Sobal 1987; Singh 1979), political orientation (Domino 2002; Emanuel 2002; Hains and Hulbert-Williams 2013; Jorgenson and Neubecker 1981; Sawyer and Sobal 1987; Singh 1979), and religious affiliation (Domino 2002; Emanuel 2002; Genuis et al. 1994b; Hains and Hulbert-Williams 2013; Jorgenson and Neubecker 1981; Kemmelmeier et al. 1999; Meier et al. 1998; Ostheimer 1980; Singh 1979; Wasserman et al. 2005). However, these associations are not always consistently found and sometimes some of the associations go in the opposite direction (e.g., Chong and Fok (2013) found a *positive* relation with age and acceptance of euthanasia contrary to other evidence suggesting a *negative* relation). Results from Experiment 1 supported some of these relations. While there were very few systematic associations with demographic variables for the six scenarios, there was a strong and consistent relation between political orientation and judgments concerning the scaled items.

Judgments about the moral permissibility of euthanasia appear to be largely stable, yet varied. There were strong and persistent differences between voluntary and non-voluntary euthanasia independent of the descriptions of euthanasia (Ho 1998). Moreover, the BE-6 was the best predictor of the permissibility judgments for these end of life decisions (Feltz and Cokely, submitted). The BE-6 predicted better than any demographic variables and predicted better than domain general components of moral judgments measured by the MFQ. The lack of a substantive effect of descriptions along with the strong predictive ability of the BE-6 suggests that judgments about euthanasia are relatively stable and center on the voluntariness of the procedure—even if those descriptions refer to conceptually distinct types of euthanasia. In many instances, the BE scale was the only predictor of judgments about the moral permissibility of the end of life treatment. When there were multiple predictors, the BE-6 scale was the major predictor of those judgments accounting for the most variance. For example, the relation of BE-6's voluntary subscale accounted for 41 % of the overall variance in judgments about the permissibility of the voluntary euthanasia scenario in Experiment 2. Additional factors only accounted for about 1 % of the variance. The influence of different descriptions of the end of life decision was small at around 3 % of the total variance. These findings suggest that judgments about the permissibility of many end of life decisions form a coherent cluster that is relatively uninfluenced by framing. Judgments are much more influenced by the voluntariness of the procedure (about 12 times stronger). This coherent clustering could explain the relatively small influence of framing on permissibility judgments. As long as the procedure is voluntary (or non-voluntary or involuntary), it is relatively less important what kind of treatment it is.

Not only do these data suggest that description is not likely to be an important factor in some people's permissibility judgments, they also undercut some central premises in some arguments against the permissibility of voluntary active euthanasia. As mentioned, one prominent argument against allowing voluntary active euthanasia is the *slippery slope* argument. Take the logical slippery slope argument first. It appears that, on average, most people accept many forms of voluntary euthanasia. However, people are much less likely to judge as permissible non-voluntary (much less involuntary) types of euthanasia. This suggests that for many people, they have no problem making important moral and conceptual distinctions between different kinds of euthanasia. As such, it appears that they feel no conceptual or logical pressure to accept other kinds of euthanasia given that they accept voluntary euthanasia. Of course, it could be that people are inattentive or simply making a mistake. But to substantiate either of those two possibilities requires an argument that can account for the current body of evidence.

The empirical version of the slippery slope argument could still be sound. Is it true that, *as a matter of fact*, if we allow voluntary active euthanasia, then that would *cause* a reduction in the judgments of impermissibility of less desirable forms of euthanasia (e.g., active involuntary euthanasia)? Some empirical data has already been used to help address the strength of the empirical slippery slope argument. Acceptance of active voluntary euthanasia does not necessarily lead to acceptance of any less desirable forms of euthanasia (primarily involuntary active euthanasia) (Lewis 2007). The data reported in this chapter support this claim. Overall, the mean responses to the BE-6 scale indicated that people agree that voluntary and non-voluntary types of euthanasia are permissible whereas involuntary types of euthanasia are not. The correlation between Voluntary and Involuntary subscales of the BE-6 was very modest (r (386) = 0.15, $p = 0.002$, or about 2 % of the total variance). However, the difference was very large (repeated measures ANOVA F (1, 385) = 542.92, $p < 0.001$, $\eta_p^2 = 0.59$, or about 35 % of the total variance). As such, there is little reason to think that one who accepts voluntary active euthanasia will be led to accept involuntary active euthanasia. In fact, overall there are robust differences between Voluntary and Involuntary subscales. Hence, there is some good reason to think that there are already people who accept voluntary euthanasia but do not accept involuntary euthanasia, contrary to what would be predicted by the empirical slippery slope argument.

In summary, different descriptions of euthanasia appear to have minimal impact on people's judgments of the moral permissibility of euthanasia. Other factors like the voluntariness of the decision are more important. In addition, the BE-6 was the best predictor of a host of attitudes about end of life decisions. These data suggest that the BE-6 quickly assesses a cluster of related attitudes about euthanasia. This instrument thereby has the potential to be used to help ensure that patients' autonomy is respected by following their treatment preferences. Rather than assessing any number of possible framings (e.g., aid in dying, euthanasia, physician assisted suicide), the BE-6 likely does a very good job of predicting these (and other) decisions about ending life.

Appendix

Scenarios

Instructions: The following scenario is meant to explore some of your feelings toward end of life decision making. It is not meant to test what you know.

Euthanasia/Physician Assisted Suicide/Aid in Dying Not Voluntary

Mr. Smith has a serious illness that is totally incurable given current knowledge. He is currently receiving the best possible treatment. He suffers atrociously and pain medication cannot relieve his suffering. He has never expressed a wish for (euthanasia/physician assisted suicide/aid in dying).
(Euthanasia/Physician assisted suicide/Aid in dying) is morally permissible in this case.

Euthanasia/Physician Assisted Suicide/Aid in Dying Voluntary

Mr. Smith has a serious illness that is totally incurable given current knowledge. He is currently receiving the best possible treatment. He suffers atrociously and pain medication cannot relieve his suffering. He has clearly and repeatedly requested (euthanasia/physician assisted suicide/aid in dying).
(Euthanasia/Physician assisted suicide/Aid in dying) is morally permissible in this case requested aid in dying.
(Euthanasia/Physician assisted suicide/Aid in dying) is morally permissible in this case.

Scales

Instructions: The following scale is meant to explore some of your feelings toward end of life decision making. It is not meant to test what you know. (* *indicates item to be reverse scored.*)

1. (Euthanasia/Physician assisted suicide/Aid in dying) is acceptable if the person is old.
2. (Euthanasia/Physician assisted suicide/Aid in dying) should be accepted in today's society.
3. There are never cases when (euthanasia/physician assisted suicide/aid in dying) is appropriate.*
4. (Euthanasia/Physician assisted suicide/Aid in dying) is helpful at the right time and place (under the right circumstances).
5. (Euthanasia/Physician assisted suicide/Aid in dying) is a humane act.
6. (Euthanasia/Physician assisted suicide/Aid in dying) should be against the law.*
7. There are very few cases when (euthanasia/physician assisted suicide/aid in dying) is acceptable.*
8. (Euthanasia/Physician assisted suicide/Aid in dying) should only be used when the person has a terminal illness.
9. (Euthanasia/Physician assisted suicide/Aid in dying) is acceptable in cases when all hope of recovery is gone.
10. (Euthanasia/Physician assisted suicide/Aid in dying) gives a person a chance to die with dignity.
11. (Euthanasia/Physician assisted suicide/Aid in dying) should be practiced only to eliminate physical pain and not emotional pain

References

Achille, Marie A., and James R.P. Ogloff. 1997. When is a request for assisted suicide legitimate? Factors influencing public attitudes toward euthanasia. *Canadian Journal of Behavioral Science* 29: 19–27.

American Medical Association (AMA), Council on Ethical and Judicial Affairs. 1992. Decisions near the end of life. *JAMA* 267: 2229–2233.

Barry, Vincent E. 2007. *Philosophical thinking about death and dying*. Belmont, CA: Thomson/Wadsworth.

Battin, Margaret Pabst. 2005. *Ending life: Ethics and the way we die*. Oxford: Oxford University Press.

Beauchamp, Tom L. 2006. The right to die as the triumph of autonomy. *Journal of Medicine and Philosophy* 3: 643–654.

Brock, Dan W. 1992. Voluntary active euthanasia. *Hastings Center Report* 22: 10–22.

Buhrmester, Michael, Tracy Kwang, and Samuel D. Gosling. 2011. Amazon's Mechanical Turk: A new source of inexpensive, yet high-quality, data? *Perspectives on Psychological Science* 6: 3–5.

Chong, Alice Ming Lin, and Shiu-Yeu Fok. 2013. Validation of the Chinese expanded euthanasia attitude scale. *Death Studies* 37: 89–98.

Cokely, Edward T., Mirta Galesic, Eric Schulz, Saima Ghazal, and Rocio Garcia-Retamero. 2012. Measuring risk literacy: The Berlin Numeracy Test. *Judgment and Decision Making* 7: 25–47.

DeCesare, Michael A. 2000. Public attitudes toward euthanasia and suicide for terminally ill persons: 1977 and 1996. *Social Biology* 47: 264–276.

Domino, George. 2002. Community attitudes toward physician assisted suicide. *Omega (Westport)* 46: 199–214.

Emanuel, Ezekiel J. 2002. Euthanasia and physician-assisted suicide: A review of the empirical data from the United States. *Archives of Internal Medicine* 162: 142–152.

Feltz, Adam and Edward T. Cokely. submitted. The Berlin euthanasia scale.

Frileux, S., C. Lelievre, M.T.M. Sastre, E. Mullet, C. Paul, and Sorum. 2003. When is physician assisted suicide or euthanasia acceptable? *Journal of Medical Ethics* 29: 330–336.

Gamliel, Eyal. 2013. To end life or not to prolong life: The effect of message framing on attitudes toward euthanasia. *Journal of Health Psychology* 18: 693–703.

Genuis, Stephen J., Shelagh K. Genuis, and Wei-Ching Chang. 1994. Public attitudes toward the right-to-die. *Canadian Medical Association Journal* 150: 701–708.

Gosling, Samuel D., Peter J. Rentfrow, and William B. Swann. 2003. A very brief measure of the big-five personality domains. *Journal of Research in Personality* 37: 504–528.

Graham, Jesse, Brian A. Nosek, Jonathan Haidt, Ravi Iyer, Spassena Koleva, and Peter H. Ditto. 2011. Mapping the moral domain. *Journal of Personality and Social Psychology* 101: 366–385.

Hains, Carrie A.M., and Nicholas J. Hulbert-Williams. 2013. Attitudes toward euthanasia and physician-assisted suicide: A study of the multivariate effects of healthcare training, patient characteristics, religion and locus of control. *Journal of Medical Ethics* 39: 713–716.

Ho, Robert. 1998. Assessing attitudes toward euthanasia: An analysis of the subcategorical approach to right to die issues. *Personality and Individual Differences* 25: 719–734.

Ho, Robert, and Ronald K. Penney. 1992. Euthanasia and abortion: Personality correlates for the decision to terminate life. *Journal of Social Psychology* 132: 77–86.

Huber, Ruth, V.M. Cox, and W.B. Edelen. 1992. Right-to-die responses from a random sample of 200. *The Hospice Journal* 8: 1–19.

Jackson, Emily, and John Keown. 2012. *Debating euthanasia*. Portland: Hart.

Jorgenson, David E., and Ron C. Neubecker. 1981. Euthanasia—A national survey of attitudes toward voluntary termination of life. *Omega-Journal of Death and Dying* 11: 281–291.

Kemmelmeier, Markus, Eugene Burnstein, and Kaiping Peng. 1999. Individualism and authoritarianism shape attitudes toward physician-assisted suicide. *Journal of Applied Social Psychology* 29: 2613–2631.

Kroh, Martin. 2007. Measuring left-right political orientation: The choice of response format. *Public Opinion Quarterly* 71: 204–220.

Levin, Irwin P., Sandra L. Schneider, and Gary J. Gaeth. 1998. All frames are not created equal: A typology and critical analysis of framing effects. *Organizational Behavior and Human Decision Processes* 76: 149–188.

Lewis, Penney. 2007. The empirical slippery slope from voluntary to non-voluntary euthanasia. *Journal of Law Medicine and Ethics* 35: 197–210.

MacDonald, William L. 1998. Situational factors and attitudes toward voluntary euthanasia. *Social Science and Medicine* 46: 73–81.

McLachlan, Hugh V. 2010. Assisted suicide and the killing of people? Maybe. Physician-assisted suicide and the killing of patients? No: The rejection of Shaw's new perspective on euthanasia. *Journal of Medical Ethics* 36: 306–309.

Meier, Diane E., Carol-Ann Emmons, Sylvan Wallenstein, R. Timothy Quill, Sean Morrison, and Christine K. Cassel. 1998. A national survey of physician-assisted suicide and euthanasia in the United States. *New England Journal of Medicine* 338: 1193–1201.

Ostheimer, John M. 1980. The polls: Changing attitudes toward euthanasia. *Public Opinion Quarterly* 44: 123–128.

Paollacci, Gabriele, Jesse Chandler, and Panagiotis G. Ipeirotis. 2010. Running experiements using Amazon Mechanical Turk. *Judgment and Decision Making* 5: 411–419.

Parkinson, Lynne, Katherine Rainbird, Ian Kerridge, Gregory Carter, John Cavenagh, John McPhee, and Peter Ravenscroft. 2005. Cancer patients' attitudes toward euthanasia and physician-assisted suicide: The influence of question wording and patients' own definitions on responses. *Journal of Bioethical Inquiry* 2: 82–89.

Raz, Joseph. 2013. Death in our life. *Journal of Applied Philosophy* 30: 1–11.

Rogers, James R. 1996. Assessing right to die attitudes: A conceptually guided measurement model. *Journal of Social Issues* 52: 63–84.

Sawyer, Darwin, and Jeffery Sobal. 1987. Public attitudes toward suicide—Demographic and ideological correlates. *Public Opinion Quarterly* 51: 92–101.

Singh, B.Krishna. 1979. Correlates of attitudes toward euthanasia. *Social Biology* 26: 247–254.

Tversky, Amos, and Daniel Kahneman. 1981. The framing of decisions and the psychology of choice. *Science* 211: 453–458.

Velleman, David J. 1992. Against the right to die. *Journal of Medicine and Philosophy* 17: 665–681.

Verbakel, Wilko F.A.R., Johan P. Cuijpers, Daan Hoffmans, Michael Bieker, Ben J. Slotman, and Suresh Senan. 2009. Volumetric intensity-modulated arc therapy vs. conventional IMRT in head-and-neck cancer: A comparative planning and dosimetric study. *International Journal of Radiation Oncology*Biology*Physics* 74: 252–259.

Wasserman, Jason, Jeffrey M. Clair, and Ferris J. Ritchey. 2005. A scale to assess attitudes toward euthanasia. *Omega (Westport)* 51: 229–237.

Wolfe, Joanne, Diane L. Fairclough, Brian R. Clarridge, Elisabeth R. Daniels, and Ezekiel J. Emanuel. 1999. Stability of attitudes regarding physician-assisted suicide and euthanasia among oncology patients, physicians, and the general public. *Journal of Clinical Oncology* 17: 1274.

Chapter 14
"You Got Me Into This…": Procreative Responsibility and Its Implications for Suicide and Euthanasia

Rivka Weinberg

Abstract This paper investigates connections between procreative ethics and the ethics of suicide and euthanasia. Regarding euthanasia/assisted suicide, we might think it too demanding to ask parents to help euthanize their terminally ill, suffering child, but had the parents not procreated, their child wouldn't need euthanizing. If you need help killing yourself, shouldn't your parents, who got you into life in the first place—without your consent—help you out of it? Yet knowing that your parents would help you kill yourself may increase your desire to die: a conundrum. Regarding suicide, the fact that we are forced into life should bolster the right to suicide, even for reasons that others might find wanting. The ways in which we are brought into life have moral implications for the ways in which we are entitled to get out of it.

14.1 The Ethics of Starting and Ending Life: Are They Linked?

Usually, when we think about the connections between the ethics of starting life and the ethics of stopping life, we are more focused on the morality of the end than we are on the morality of the beginning. We may be concerned about when we may permissibly end life, at its earliest and latest stages, i.e., the ethics of abortion and euthanasia. Questions regarding the permissibility of these two kinds of killing often center on issues related to personal identity and when people begin to have interests, particularly an interest in continuing to live. Regarding abortion and euthanasia, if we get clearer on how and when identity and interests form and disintegrate, we might be able to set parameters to personal identity and interests.

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And if we successfully set personal identity and interests parameters, we may think that we can permissibly kill outside those parameters (see McMahan 2003). But, setting our murderous impulses aside, what other connections may there be between the ethics of beginning and ending life?

We might question whether these connections exist at all and, even if they do, whether they are of sufficient strength and interest to warrant our attention. We have reason to be skeptical because it seems clear that there is a difference between our evaluations regarding whether a life is worth starting and our evaluations regarding whether a life is worth continuing. For example, although we might regret the fact that we began to exist, that does not rationally compel us to kill ourselves (see Smilansky 2007; Benatar 2006) because we may value the continuation of something that we would not necessarily have chosen to begin. I would not have chosen to walk into that seedy bar but I do not want to break up the party so I go in with my friends. Once inside the seedy bar, I meet a really interesting person—a seedy person, admittedly, but one I find interesting anyway and I then choose to stay even after my group has left. I value the continuation of something even though I did not value starting it. If I had to do it over again, I would still prefer not to go to a seedy bar even though it worked out well for me this time. The difference between our ways of evaluating whether a life is worth starting and whether a life is worth continuing can seem to argue for a disconnect between the ethics of the beginning and the ethics of the end of life.

However, if we analyze the reasons for distinguishing between what might make a life worth starting and what might make a life worth continuing, we will see that these reasons, while persuasive as far as they go, don't provide us with reasons to sever the ethics of the beginning and end of life more generally. There are two main reasons for distinguishing between a life worth starting and a life worth continuing:

(a) *Risk*: The nature of the risk we take by starting life and by continuing life is radically different. When procreating, we impose tremendous risk on the future person since we don't know whether they will suffer a terrible birth defect or early life trauma. There is a lot we don't know and can't control about a future person's birth circumstances, and birth circumstances can be very important to determining the course of a person's life. Once a person is born, although life still poses great risks, some of those risks have passed. The person is alive, and we now know whether their birth circumstances have saddled them with terrible burdens or not. The risks of their being born with terrible problems may have been high but those risks may not have ripened into harms and, now, the risk of their continued life may be relatively low for burdens and high for benefits. It may have been a bad idea to create that person but it may still be a good idea for that person to continue living the life that no one should have started for them. The valuation is different.

(b) *Investment*: Another major difference between the value of starting and continuing life is the investment people make in their lives. Before we exist, we have no interests, projects, or commitments and we therefore have no

> investment in the life we might lead should we start leading it. Once we start living, however, we usually take an interest in our own life; we invest in projects and pursuits and we may want to see those through. We may have an interest in getting a return on our investments or simply in continuing to pursue them because we enjoy or value them. Personal relationships are another example of investments we make, once alive, that may provide us with reason to want to continue our lives. But these relationships don’t necessarily provide us with a reason to start our lives. Indeed, sometimes we don’t enjoy those relationship very much at all but we have committed to them and invested in them and that gives us reason to want to continue them, but it does not necessarily give us reason to have started them in the first place.

We can accept all this and still wonder what implications our procreative ethics might have for euthanasia, assisted suicide, and suicide, assuming that these ways of ending life are at least sometimes permissible.[1] That is what I would like to explore. I will begin with euthanasia, proceed onto assisted suicide, and end with some thoughts on suicide.

14.2 Procreative Responsibility and (Voluntary) Euthanasia

In the Ibsen (1881, Act III) play, *Ghosts*, Oswald, a man suffering from inherited syphilis, begs his mother, Mrs. Alving, to euthanize him:

Oswald: Well, now you have got to give me that helping hand, mother.
Mrs. Alving (with a loud scream): I!
Oswald: Who has a better right than you?
Mrs. Alving: I! Your mother!
Oswald: Just for that reason.
Mrs. Alving: I, who gave you your life!
Oswald: I never asked you for life. And what kind of a life was it that you gave me?
I don’t want it! You shall take it back!

Is Mrs. Alving obligated to take it back? Is she, as Oswald’s mother, particularly responsible to help him die? If someone is terminally ill, in unrelenting pain, and

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[1] I am not going to consider the arguments for and against suicide, assisted suicide, and euthanasia. Instead, I will explore the questions regarding the connections between procreative responsibility and suicide, assisted suicide, and euthanasia. For purposes of this discussion, I assume that these ways of ending life are sometimes justified and permissible. I am also not going to consider the possibility that children owe their parents help with ending life, out of gratitude toward their parents for having created or raised them (or for any other reason). In my view, the obligation children may have to their parents is more complex and controversial than the obligations parents have toward their children. I leave filial obligations for others to investigate.

is begging to be euthanized—if someone deserves and wants to be euthanized, whatever you take that to entail—who ought to do the euthanizing?

A popular candidate for the job is The Doctor. This candidate is so popular that some people have all but renamed euthanasia "physician-assisted suicide." But why doctors? Is it the angelic/scientific costumes—the white coats, the stethoscopes, the blood pressure cuffs, the note pads—that lend doctors the air of purity and gravitas that seem appropriate to the euthanizing task? That may explain why some think doctors should do our euthanizing but it does not justify it. A justification might be that doctors (perhaps especially palliative care or hospice doctors) have the knowledge and skills required to end life reliably and with minimal suffering. But that knowledge is not that hard to acquire, even for a layperson. Why should doctors shoulder the burden of killing? Killing people, even when done at their request and in order to avoid a more painful and prolonged death, is difficult and stressful. It's not clear to me that doctors are obligated to undertake this burden.

Remember executioners? We still have them, actually, though we don't identify them the way we used to. We could hire the euthanizing job out. Surely, there'd be takers. But somehow this is off-putting. We don't want eager volunteers killing our loved ones. We don't want people who are not eager but are desperate for a job and therefore decide to become euthanizers either.

So who should a person in need of euthanasia turn to for help? Why not their own parents?[2] We can think of many good answers to that question. For starters, the job is likely to be more painful, stressful, awful, and difficult for the parents than for almost anyone else. We might think it nearly impossible for a parent to be able to kill their own child, even in order to relieve unremitting suffering and avoid a more painful and prolonged death for the child. That's why god, clever dude that he is, tests Abraham's loyalty by commanding him to kill his own son, Isaac. Killing your own child seems like the ultimate sacrifice, and one we should not ask of people. Besides, given the difficulty that euthanizing one's own children would likely pose, parents are not the most reliable candidates for the job.

But they might still be the ones most responsible to do it. Parents are more obligated, in most cases, to help their children than anyone else is, unless others have put that child in the position of needing the help or have made an explicit commitment to help. So if Harry throws Sally under the bus, he is more responsible to help her recover from her injuries (or to pay for her burial) than are Sally's parents. But, if Sally is dying slowly and painfully from an incurable terminal illness and is in need of euthanasia, Sally's parents seem more connected to and responsible for Sally's predicament than anyone else. They are the ones who put Sally at risk of this outcome when they decided to toss their condoms out the window and have a child. It can seem particularly fitting, I suggest, to ask the people who put you into life to help you out of it.

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[2] Assuming, of course, that their parents are still alive. Given that terminal illnesses usually occur later in life, often this will not be the case. I am interested here in situations where it is the case that a parent of the person in need of euthanasia is still alive.

Just as drivers who hit pedestrians who are crossing the street in accordance with the traffic lights are responsible to alleviate harm or mitigate damages when the risk they pose to the pedestrian ripens into a harm, we may consider parents whose children are suffering from a painful and prolonged terminal illness responsible to alleviate the harm that results when the risk they pose to their child by creating her ripens into this sort of harm. Procreation imposes foreseeable risks on future people. Parents procreate knowing, or in the position to know, these risks, sometimes quite specifically (as is the case of many autosomal recessive diseases, for example, which run in carrier couples at a 25 % risk to their children). But we don't need specific knowledge of particular risk conditions in order to bear some responsibility for alleviating the resulting harm. Knowing, as we all do, that procreation imposes all of life's risks on our children is enough to implicate parents in the harm their procreativity foreseeably imposes on their children.

To clarify, the central source of the responsibility I am talking about is the responsibility we incur when we impose risks on others or expose others to risk of harm. We all impose risks on each other all the time—it's the cost of doing business, of living life. Merely breathing near others exposes them to risk (of airborne contagions). As a society, we decide how to handle risk. In my view, this is contractual: we choose the rules that we think are fair to all to live by. Very roughly speaking, we generally:

- Permit the risks that we deem worthwhile or necessary;
- Set a standard of care that we require to be met in the imposition of those risks;
- Deem those who fail to meet the standard to be negligent and liable for their negligence whether the risk ripens into a harm or not.
- When the standard of care has been met but the risk ripens into a harm anyway, we usually require the risk imposer or exposer to mitigate damages and/or compensate the victim.

To continue our driving example, we allow people to drive. We set a standard of care that includes being a certain age, being sober, passing a test about the rules of the road, etc. But, if the risk we pose to others by driving ripens into a harm anyway, e.g. we slide in the rain into a parked car, then we have to mitigate damages, compensate the victim, pay to fix the car. This risk model is what I have in mind when thinking about procreative responsibility for euthanasia. When people procreate, they expose their children to many life risks, including the risk of getting a painful and terminal illness. If the risk ripens into a harm, the parents may be obliged to mitigate/compensate (Might others be obligated as well, for whatever reason? Quite possibly. But that is not my concern here). I am concerned here about the implications of procreative responsibility and, by exposing children to the need for euthanasia, it is possible that parents incur the responsibility to euthanize their children who need it. What grounds the responsibility is not the fact that parents caused their child to be sick enough to need euthanasia and it is not the fact that parents caused unjustified harm to their child. Rather, it's that creating persons exposes them to significant risks. One of those risks is the risk of a painful terminal illness. Even if one has not negligently procreated—you didn't drive drunk—if the risk ripens into a harm, the imposer may be obligated to mitigate the risk or compensate the victim.[3]

I am not suggesting that parents are required to compensate their children for any and all life burdens. That is similar to a strict liability standard[4] that we hold people to when they engage in very high risk behavior for no good reason. An example would be something like owning a pet lion. That's an unnecessary pastime that puts your neighbors at high risk of injury. If injury does occur, you are responsible even if your pet lion was guarded by an electrical fence that it shockingly managed to breach. Having children, however, is something that people have a strong and legitimate interest in doing. Moreover, some harms that befall people are their own fault or someone other than their parents' fault. These factors explain why procreativity is not an act held to a strict liability standard of care. So strict liability is not the reason why I think that parents may be obligated to euthanize their children, when euthanasia is called for. The reason is simply that if someone ought to help Sally by euthanizing her, her parents seem more connected to the risk that ripened into her need for euthanasia than anyone else (unless she is dying because she chose to take up smoking, for fun, in her thirties, say). And, for those who find talk of risk imposition speculative or beside the point, we can simply point to the fact that parents are generally more obligated to help their children than other people are. Just as we expect parents to help their children emotionally, physically, and financially, we may expect them to help their children euthanasially, should the need arise.

There are various views held about the source of parental obligations and how they are incurred (see Weinberg 2008). Whatever one's view of the basis of procreative parental responsibility—be it risk imposition, gestation, causation, intent to raise, genetic relation—all theories of what parental responsibility includes, whatever their basis, seem to cover whatever significant needs children have that they are unable to provide for themselves and that parents are able to provide for them (at not undue cost). Thus, regardless of one's view regarding how parental obligations are *incurred*, most people think that parental obligations usually *include* the obligation to care for and raise one's children and to care for them, even once they are adults, in a variety of special ways (barring special circumstances or justified estrangement). If your child is in serious and legitimate need of something that they can't provide for themselves and that you can provide for them, your special caring role as a parent, or your special obligations as a parent, or whatever view you take to be correct regarding parental-child relations, will likely direct you to provide it. I am suggesting that euthanasia might be that serious and legitimate something that your child needs, that she cannot quite provide for herself, and that you can provide for her.

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[3] David Boonin has suggested that this reasoning may apply to those who breed a dog and raise it as their pet.

[4] Shiffrin (1999) argues in favor of holding all parents to this sort of standard. I argue against Shiffrin's view in Weinberg (2015).

14.3 Exceptions and Objections

14.3.1 Someone Else's Fault

As I noted earlier, an exception to holding parents particularly responsible to help euthanize their children, when euthanasia is appropriate, is the category of cases where the need for euthanasia is someone else's fault (not the parents'). If Harry beat Sally within an inch of her life, causing her to need euthanasia to relieve her suffering so that she dies quickly and less painfully rather than slowly and more painfully, it is the person who beat Sally who is most obligated to help her. But, in that sort of case, Sally, her parents, and almost everyone else probably don't want Harry anywhere near Sally and it would probably increase Sally's suffering to have Harry involved in helping her die. Still, there may be other cases where the fact that Sally is in need of euthanasia is someone else's non-criminal, non-sadistic fault and in those cases that person might be more obligated than Sally's parents to help Sally die. Imagine that Harry introduced Sally to smoking when he was 22 and she was 19. She should have had the good sense to resist engaging in this sick-making act but Harry was really charming and charismatic. Sally succumbed. Now she's dying, very slowly and agonizingly, of lung cancer. Between the two of them, Harry and Sally are more responsible for Sally's dying than Sally's parents are. Sally's parents are off the risk imposing hook, though they are still, in some sense, responsible to help Sally for any reason and in any way—that's what parents do and that's what we think they ought to do (usually, anyway).

If Sally's dying is mostly her own fault, say due to her own risk taking, that too may distance her parents from Sally's need for euthanasia that might result. If Sally has a sky diving or motorcycle accident that puts her in the position of needing euthanasia, we might think it is her own damn fault and that her parents have suffered enough as it is, by watching this whole process. We would not then find it fair to add to the parents' suffering by requiring them to be the ones who euthanize their reckless daughter. Sally's own risk taking distances her parents, in terms of the risk that ripened into a harm, from the harm that befalls her as a result of her self-imposed risk. The connection between Sally's harm and her parents' procreativity may be too weak at this point to obligate her parents to help euthanize her. But if Sally inherited her risk-taking proclivities from her parents, who are thrill-seekers themselves and know that thrill-seeking is a heritable trait (see Gower 2000; Friedman 2005), then maybe Sally's parents are implicated in a close enough way as to reinstate the obligation. In any case, as I suggested earlier, even if we set the risk imposition claims aside, the obligation parents have to help their children, period, regardless of why help is needed, argues in favor of holding parents responsible to help their children with euthanasia, should that need arise.

We might also wonder about the possibility of cases where people fight very hard to stay alive, and consciously choose to live.[5] Years later, if they need

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[5] I owe this case to Justin Weinberg.

euthanasia, are they now solely responsible for risks posed by their own lives, including the risk of needing euthanasia? Are they “born again,” of their own choice, so to speak? I am not sure about this sort of case because it is hard to imagine a realistic instance that is not strongly influenced by the very strong biological survival instinct, which casts doubt on the possibility of true “born again of one’s own volition” type cases.

14.3.2 Too Demanding

It may be too hard for parents to actively participate in the death of their own child. This may be the case (though maybe people should think about these potential obligations before they have children). On the other hand, when a person is suffering terribly and euthanasia would be the most merciful act to do for her, parents may want to do it, even though it is hard. Watching your child die a slower and more painful death might be even harder. Some of the most famous and influential lawsuits pressing for the right to die and demanding to be disconnected from life support were filed by parents on behalf of their children (as happened in the Karen Ann Quinlan case).[6] Although parents, in those cases, were asking for hospital removal of life support, their lawsuits serve as reason to think that, if necessary, the parents would gladly have removed the life support themselves (though it does not give us reason to believe that the parents would prefer it was them rather than the hospital that euthanized their child). On the other hand, we also have cases where parents are suing hospitals to maintain life support even though the hospitals insist that the patient is brain dead and there is no life to continue to support (see Shoicet 2013). Even though these parents’ reactions to their child’s terminal illness seem to contradict each other, what they have in common is parents trying or thinking that they are trying to do what is best for their children. That’s what most parents try to do and they succeed often enough for me to conclude that, in many cases, when euthanasia is in their child’s best interests, parents will find that they are able to do the extremely difficult act of euthanizing their own child.

As a parent, though, I find myself shuddering as I write this and wondering if there might not be something a little (or a lot) wrong, both morally and emotionally, with a parent who is up to the euthanizing task. You can kill your own kid? What’s wrong with you? The depth of feeling and attachment you should have for your own child, and the unique quality of parental love, should make it impossible for you to kill your child. On the other hand, if your kid needs killing and you don’t do it, what kind of mother (or father) are you? Who is your love and caring helping? Is this love for your child or your own selfish self-protection? Maybe both. With regard to euthanasia, parents may be in a dilemma: damned if they do and damned if they don’t.

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[6] In re Quinlan (1976).

Still more damned if they don’t, I think, given that euthanasia, if and when needed, is something one might do for the sake of another, despite the cost to oneself. That is consistent with the way that parents are often (though certainly not always) expected to treat their children.

14.4 Procreative Responsibility and Assisted Suicide

The case for the parental obligation to help their child die is stronger if the child is not in need of euthanasia but, instead, requests assistance with their own suicide, as an adult, because they find life not worth living. The case against parental help with this sort of assisted suicide is stronger as well. It is a more vexing dilemma because the situation is more closely connected to parental decisions to procreate. Let me explain.

Shiffrin (1999) famously argued that all procreativity is morally problematic because it violates children’s consent rights, since children are created without their consent even though it’s no harm or deprivation not to exist. I have argued elsewhere against Shiffrin’s view on the basis of children’s lack of consent and autonomy rights (Weinberg 2015). I won’t go through the entire argument here but the gist of it is that parents are entitled to procreate without their child’s consent because children, being not yet fully competent, do not have autonomy or consent rights. Just as parents are entitled to make many other decisions that affect their child without their child’s consent, parents can procreate without their child’s consent (so long as it is reasonable for the parents to think that being procreated will not be contrary to their child’s interests).[7] But what if, despite the parents’ reasonable and justifiable procreativity, it turns out that the child, once grown, doesn’t enjoy life and doesn’t want to continue living it? Just as it may be reasonable and within one’s paternalistic authority to give your child violin lessons without asking them first (if they are very young, as they must be if they are to have any shot at getting good at it), it’s also reasonable for the child to stop playing the violin as she grows into an adult who doesn’t enjoy playing the violin. Not playing the violin is pretty easy to do on one’s own so no one needs to help their grown children abandon the violin in favor of pursuits that the grown children do enjoy. But if your children grow into adults who don’t enjoy living, it is not as easy for them to abandon life even if they really hate it. And since you got them into it, maybe you should help them out of it.

Before the child becomes a grown up, paternalistic authority may be exercised to prevent her suicide—the child is not old enough to be sure that she really wants

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[7] I say “not contrary” to the child’s interests rather than “in the child’s interests” because I don’t think that anyone has an interest in being created. That’s why paternalism alone will not justify procreativity, in my view. My view is that parents procreate to further their own interests in becoming parents but they are permitted to do so despite not being able to obtain their child's consent because the child does not have consent rights, among other reasons.

to end her life. She is not yet competent to make that sort of decision. But, if a child, once grown, realizes that not only does she no longer want to play the violin, because it is not worth the effort, she also no longer wants to live because it is not worth the effort, she may find walking away from the violin much easier to do on her own than walking away from life by killing herself. It can be hard to commit suicide even if one genuinely wants to die and wishes one were dead. We are biologically programmed for survival and that is an instinct that, like all strong instincts, is involuntary and hard to ignore even if, rationally, we want to ignore it. Moreover, suicide is a leap into the unknown, which is scary to contemplate and no less scary just because one may really not want to live anymore. At least life is the devil you know. Suicide also hurts those who love us, which is a very unfortunate side effect and one that many people who really really want to die are still loath to put their loved ones through. And a suicide attempt—that is, a failed suicide—can leave a person worse off than they were before. If you jump out of a fifth story window and live, the life you then live is likely to make you both more interested in dying and less able to kill yourself than you were before you tried to kill yourself by jumping out a fifth story window. As we see, there are serious obstacles to getting out of a life you don't want and never agreed to lead.

But with a little help from your friends, or, even better, your mama, these obstacles can be alleviated. It's easier to do something scary with help and support from a friend or a family member. It can make the leap into the unknown feel less lonely and overwhelming. If your loved ones help you commit suicide, you might be justified in thinking that your suicide, while still difficult for them, will be less of a trauma than it would be if you slit your wrists alone at home in the tub, leaving them to find you only after they don't hear from you for three weeks and get the police to open your door. And, finally, if you have help with your suicide, you are less likely to screw it up and therefore less likely to be worse off than you were before. All this adds up to a good case for wanting help with your suicide. It can make it a more bearable process.

Who should help you? A natural answer is, "no one." If you want to kill yourself just because you don't like living, it is not so easy to see why anyone has to help you, given that it is not the kind of help that is given at little cost—well, not the kind of help given at little cost by anyone you might want help from, i.e., no Dr. Kevorkian or ax murderer types need apply. What you want is help from your loving and supportive family and friends (yes, even people who have loving and supportive family and friends may tire of living and wish to stop). If you are going to kill yourself regardless, and it would make your end so much easier for you if you could have some help with it, why shouldn't your family, who are first in line to help you with all of your needs, help you with this one?

If a person wants help killing themselves, shouldn't their parents, who got them into life in the first place—and without their permission or consent—help them get out of life, if it turns out they don't enjoy living? It might be too hard, even harder than the case of euthanasia (for the terminally ill). Whereas euthanasia presents parents with the tragic task of helping their child avoid a prolonged death, helping a child kill herself because she does not enjoy living is not only tragic but also possibly a huge and lethal mistake. Not everyone who wants to die at some point later regrets that they did not then die at that point. In fact, one of the few to survive jumping off the Golden Gate Bridge described an experience common to attempted suicide. He said: “I still see my hands coming off the railing…. I instantly realized that everything in my life that I’d thought was unfixable was totally fixable—except for having just jumped.”[8] And even if a suicidal person is correct in thinking that her death wish will not pass and that she genuinely will be better off dead, her loved ones might want to work to help her enjoy her life rather than help her end it. It’s hard to give up on your own child.

I should hope! Isn’t believing in your child and always holding out hope for her one of a parent’s jobs? But, as a parent, you might still think that if your child is going to kill herself anyway, in order to exit a place you entered her into without her agreement, you should help make that exit easier. The problem is that knowing that your parents will help you kill yourself may, perversely, give you more reason to want to die: your own parents will help you kill yourself! You might as well die. It is reasonable to assume that, normally, if your parents love you as deeply and unconditionally as they are supposed to, they will not be able to participate in your suicide, even as a favor to you. It’s too much like giving up on you. This, I suggest, presents a dilemma for procreative ethics: As parents, you should help your child not want to die yet also help your child if it turns out that they would prefer to die, but the very knowledge that you would help your child die may contribute to your child’s desire to die.

Enough dilemmas. Let’s get to the good news. The good news is that thinking about procreative responsibility will help justify your suicide, should you wish to kill yourself.

14.5 Procreative Responsibility and Suicide

It is often thought that it is somehow morally or rationally remiss to kill yourself for no especially compelling reason. Over the course of human history, committing suicide has been considered, at one time or another, a sin, a crime, a sign of madness or some combination of all three. I am at a loss as to why suicide has gotten such a bad rap. If I am not enjoying a party, why am I an evil, criminal, maniac if I decide to leave?

We may note that the fact that we are born without our consent may bolster our right to kill ourselves, even for reasons that others might deem insufficiently weighty. Simply being tired of living should suffice. Our parents may have been within their rights to create us if the odds of our enjoying life were good. But that doesn’t not mean that if we defy the odds and don’t enjoy life, that we need anything more than that as a reason for suicide. Just as we can stop playing the violin

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[8] Ken Baldwin, as quoted by Friend (2003).

because we just don't feel like it, we can kill ourselves because we just don't feel like living.

I concede that last bit of reasoning may have been too quick. Kantians may tell me to respect my rational agency and not use myself as a mere means to my own happiness by killing myself. Consequentialists might point out that my suicide will decrease the happiness in the world because it will make people feel sad and guilty (though if I am miserable enough or make others miserable enough, I may be able to offset that decrease in happiness with the increase in happiness gained by ending my life). Aristotle might tell me that I am not being a good citizen and that I am certainly not faring well by contemplating suicide (though I may have already noticed this myself). All of these reasons against suicide may be good reasons though it is not clear that they are decisive, but it is not my aim here to show that.

What I am suggesting here is that the nature of the reasons we may have to want to die may not need to be as strong as some may have thought in order to justify suicide. Life was thrust upon us and some of us might not appreciate it. We didn't ask for it. We might not like it. In the words of Bernhard's (2003) character in *Amras*, "Why do we still have to live?"[9]

As with euthanasia and assisted suicide, so too with suicide: the ways in which we are brought into life affect the ways in which we are entitled to get out of it.

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References

Ackerman, Terrence F., Glenn C. Graber, Charles H. Reynolds, and David C. Thomasma (eds.). 1987. *Clinical medical ethics: Exploration and assessment*. Lanham: University Press of America.

American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition. Washington DC: American Psychiatric Publishing.

American Society for Bioethics and Humanities (ASBH). (2014). *Code of ethics and Professional responsibilities for healthcare ethics consultants*. http://www.asbh.org/uploads/files/pubs/pdfs/asbh_code_of_ethics.pdf. Accessed 24 July 2014.

Anderson, Gary R., and Valerie A. Glesnes-Anderson eds. 1987. *Health care ethics: A Guide for decision makers*. Gaithersburg: Aspen Publications.

Battin, Margaret Pabst. 1994. *The least worst death*. New York: Oxford University Press.

Battin, Margaret Pabst, Rosamond Rhodes, and Anita Silvers. eds. 1998. *Physician assisted suicide: Expanding the debate*. New York: Routledge.

Benatar, David. 2006. *Better never to have been: The harm of coming into existence*. Oxford: Oxford University Press.

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[9] The fact that we did not ask to live does not, by itself, tell us that we have no duties of any sort to continue to live. It's possible that some duties are involuntary. My point here, however, is that the fact that we did not ask to live counts in favor of our being able to stop living, should we so desire.

Bernhard, Thomas. 2003. *Three novellas*. Trans Peter Jansen and Kenneth J. Northcott. Chicago: University of Chicago Press.

Boller, Francois, Marc Verny, Laurence Hugonot-Diener, and Judith Saxton. 2009. Clinical features and assessment of severe dementia: a review. *European Journal of Neurology* 9: 125–136.

Bullock, Emma C. 2010. Informed consent as waiver: The doctrine rethought? *Ethical Perspectives* 17: 531–558.

CBC News. 2014. Gillian Bennett, suffering with dementia, dies leaving right-to-die plea. CBC News (21 August 2014). http://www.cbc.ca/m/touch/news/story/1.2742440. Accessed 30 April 2015.

Crisp, Johnny. 2013. Euthanasia bill runs out of time in Colombia’s senate. *Colombia Reports.* http://colombiareports.co/colombia-euthanasia-bill-runs-out-of-time-in-senate/. Accessed 28 April 2015.

Dees, Marianne, Myrra Vernooij-Dassen, Wim Dekkers, and Chris van Wee. 2010. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-Oncology* 19: 339–352.

D’oronzio, Joseph C. 2002. The suicide note. *Cambridge Quarterly of Healthcare Ethics* 11: 422.

Dworkin, Gerald, Raymond G. Frey, and Sissela Bok (eds.). 1998. *Euthanasia and physician assisted suicide: For and against*. Cambridge: Cambridge University Press.

Frankena, William K. 1973. *Ethics*, 2nd ed. New Jersey: Prentice-Hall.

Friedman, Richard A. 2005. Thrills: What’s the lure of the edge? The answer is all in their heads. *NewYork Times*, 20 June 2005.

Friend, Tad. 2003. Jumpers: The fatal grandeur of the Golden Gate Bridge. *New Yorker* 13 October.

Gill, Michael B. 2005. A moral defense of Oregon’s physician-assisted suicide law. *Mortality* 10: 53–67.

Gower, Timothy. 2000. Are some guys just born reckless? *Los Angeles Times*, 10 January 2000.

Hendin, Herbert, and Kathleen Foley. 2004. *The case against assisted suicide*. Baltimore: The Johns Hopkins University Press.

Hohfeld, Wesley N. 1923. *Fundamental legal conceptions as applied in judicial reasoning*. New Haven: Yale University Press.

Huxtable, Richard, and Alex Mullock. forthcoming. Voices of discontent? Conscience, compromise and assisted dying.

Ibsen, Henrik. 1881. Ghosts. http://www.gutenberg.org/files/8121/8121-h/8121-h.htm. Accessed 29 April 2015.

Legemaate, Johan, Marian Verkerk, Eric van Wijlick, and Alexander de Graeff. 2007. Palliative sedation in the Netherlands: starting-points and contents of a national guideline. *European Journal of Health Law* 14: 61–73.

Marcel, G.M., Olde Rikkert, Klodiana Daphne Tona, Lieneke Janssen, Alistair Burns, Anatonio Lobo, Philippe Robert, Norman Sartorius, Gabriela Stoppe, and Gunhild Waldemar. 2011. Validity, reliability, and feasibility of clinical staging scales in dementia: A systematic review. *American Journal of Alzheimer’s Disease & Other Dementias* 26: 357–365.

McMahan, Jeff. 2003. *The ethics of killing: Problems at the margins of life*. Oxford: Oxford University Press.

Quill, Timothy E., and Margaret Pabst Battin (eds.). 2004. *Physician-assisted dying: The case for palliative care and patient choice*. Baltimore: The Johns Hopkins University Press.

Regional Euthanasia Review Committees. 2010. *Annual report 2009*. http://www.rtde.eu/node/19. Accessed 29 April 2015.

Regional Euthanasia Review Committees (EU), Annual Reports. http://www.euthanasiecommissie.nl/archiefjaarverslagen.asp. Accessed 29 April 2015.

Shiffrin, Seana V. 1999. Wrongful life, procreative responsibility, and the significance of harm. *Legal Theory* 5: 117–148.

Shoichet, Catherine E. 2013. Jahi McMath’s mother: ‘I won’t stop fighting, for daughter on life support’ *CNN,* 23 December 2013.

Smilansky, Saul. 2007. Preferring not to have been born. In *Ten moral paradoxes,* Saul Smilansky. Malden, MA: Blackwell.

UK Police Firearms Officers Association (PFOA), n.d. Post-shooting procedures. http://www.pfoa.co.uk/211/post-shooting-procedures. Accessed 29 April 2015.

Van Parijs, Philippe. 1995. *Real freedom for all: What (if anything) can justify capitalism.* Oxford: Clarendon Press.

Veatch, Robert M. 1989. Clinical ethics, applied ethics, and theory. In *Clinical ethics: Theory and practice*, eds. Barry Hoffmaster, Benjamin Freedman, and Gwen Fraser, 7–25. Clifton, N.J.: Humana Press.

Veteran Health Administration (VHA), National Center for Ethics in Health Care. *Integrated ethics: Improving ethics quality in health care.* http://www.ethics.va.gov/ECprimer.pdf. Accessed 24 July 2014.

Weinberg, Rivka. 2008. The moral complexity of sperm donation. *Bioethics* 22: 166–178.

Weinberg, Rivka. 2015. *The risk of a lifetime: How, when, and why procreation may be permissible*. New York: Oxford University Press.

Court Cases and Rulings

Hoge Raad (1994) HR 21-06-1994, NJ 1994, 656, Chabot.

In re Quinlan (70 N.J. 10, 355 A.2d 647 (NJ 1976)).

Laws and Legislation

Oregon Death with Dignity Act. 127 Or Rev Stat §800-995 (1997). http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/statute.pdf. Accessed 16 December 2013.