Mortal Responsibilities: Bioethics and Medical-Assisted Dying

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A culture of dying characterized by end-of-life care provided by strangers in institutional settings and diminished personal control of the dying process has been a catalyst for the increasing prevalence of legalized physician-assisted dying in the United States and medically-assisted dying in Canada. The moral logic of the right to die that supports patient refusals of life-extending medical treatments has been expanded by some scholarly arguments to provide ethical legitimation for hastening patient deaths either through physician-prescribed medications or direct physician administration of a lethal medication. The concept of medical-assisted dying increases the role and power of physicians in ending life and allows patients who are not terminally ill, or who have lost decision-making capacity, or who are suffering from a irremediable medical condition to have access to medical procedures to hasten death. This extended moral logic can be countered by ethical objections regarding the integrity of the patient-physician relationship and last resorts in ending life, professional concerns about medicalization and a diminished identity of medicine as a healing profession, and social responsibilities to provide equal access to basic health care and to hospice care.

DYING WELL, DYING BADLY

The Danish philosopher Soren Kierkegaard observed that “dying well is the highest wisdom of life” [1]. However, as many scholars and physicians have observed, American culture is currently permeated with a “plague of bad dying” [2], which is characterized by dying in an institutionalized setting, under the depersonalized care of strangers, monitored by technologies, and substantially reduced personal and familial control over the dying process. One increasingly prevalent response to this culture of bad dying within biomedicine and in health care policy is the legalization of methods overseen by physicians to hasten the deaths of patients with incurable terminal illness. There are now ten US jurisdictions that permit physician-assisted death, that is, a process in which physicians may write a prescription that patients may choose to self-administer to end their life – Oregon (1994), Washington (2008), Montana (2008), Vermont (2013), California (2015), Colorado (2016), the District of Columbia (2017), Hawai’i (2018), New Jersey (2019), and Maine (2019). Physician-assisted death is now a legalized option for terminally ill patients in states that comprise nearly 25 percent of the US population. In this paper, I wish to situate the ongoing legalization of physician-assisted death within a conceptual narrative of the “right to die” since the 1970s, and then make an ethical argument against such legalization and its expanded scope into a right to “medical-assisted dying.”

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The Moral Logic of the Right to Die

Like many progressivist social movements that ex-tol exemplars, advocacy of legalized physician-assisted death has elevated the dying narrative of a relatable and identifiable individual, Brittany Maynard, for its public face and profile in courage. Ms. Maynard, a recently-married woman in her late 20s, was diagnosed in January 2014 with an advanced form of brain cancer that led her physicians to conclude she had a prognosis of approximately six months of remaining life. Ms. Maynard sought to retain control and personal dignity in her dying process and opted to receive a physician-prescribed medication to hasten her death. This process was complicated since Ms. Maynard and her spouse, Dan Diaz, lived in California, a state that at the time did not permit physician-assisted death. The couple re-located to Oregon, a state that had passed the nation’s first “death with dignity” statute in 1994. Prior to her death from the medication in November 2014, Ms. Maynard and her spouse became nationally-known advocates for legalization of physician-assisted death in all US states [3]. The compelling personal story had a direct impact on public policy: California passed an “End of Life Option Act” the following year that permitted terminally ill patients to receive a life-ending medication from their physician, and passage of similar laws modeled on the original Oregon statute subsequently followed in Colorado, Hawai’i, New Jersey, and Maine.

The increasing prevalence of legalized physician-assisted death reflects the moral logic of the concept of “the right to die,” which was introduced in public and professional discourse and in precedent-setting court cases about stopping ventilator support in the 1970s and cessation of nutrition and hydration through feeding tubes in the 1980s and 1990s [4]. The moral logic of the right to die affirms that patients have a fundamental interest in (1) bodily integrity, (2) freedom from invasive medical interventions that are likely to be futile in prolonging life or restoring a quality of life, and (3) self-determination about decisions to end life according to their values. These interests were recognized in federal and state laws authorizing patients to compose advance directives requesting treatment or its discontinuation. The scope of the right to die under advance directive legislation was primarily limited to rights to refuse or withdraw burdensome medical interventions.

The passage of the Oregon Death with Dignity Act in 1994 permitting terminally ill patients to request a life-ending medication from their physician represented a new professional, ethical, and legal threshold. Philosophical and political advocacy of legalization relied on the core moral logic of the right to die while claiming that such logic warranted expanding the scope of the right to die from refusing or withdrawing burdensome life-pro-longing medical interventions to a terminally ill patient’s right to request assistance from a physician, effectuated through a prescribed medication, that would hasten their death in a “humane and dignified manner” [5]. Such philosophic and political arguments extending the scope of the right to die were not without controversy. Critics argued that the core patient interests protected by the right to refuse medical treatment constituted a “negative” right to non-intervention and non-interference in dying. Most of our civic, political, and human rights, after all, make a claim against others of non-intervention in personal liberty. A negative right to dying could not, however, legitimize a patient claim to physician-prescribed medication to end life, which reflects the moral logic of a “positive” right to assistance in carrying out one’s desired actions. Critics also claimed that physician assistance in a patient’s death compromised a professional’s commitment to healing and compassion. As argued by Justice Neil Gorsuch prior to his appointment to the US Supreme Court, constructing the right to die as a positive right contained an inexorable moral logic that would inevitably permit not only legalized physician-assisted death but also legalized physician-administered euthanasia [6]. Although every US jurisdiction that has legalized physician prescribed medications to hasten a patient’s death has also retained prohibitions of physician euthanasia, this seemed to critics defensible only as a prudential rather than principled consideration.

Legalization proponents, meanwhile, have long expressed concern that physician-assisted dying laws modeled after the Oregon statute risk exclusionary discrimination towards some terminally ill patients. Statutory provisions that require a patient to self-administer the life-ending medication and to retain decision-making capability throughout their dying process impose difficult, if not exclusionary, burdens for certain patients, such as persons with late-stage ALS who lack the physical mobility for self-administration or persons with late-stage dementia who may lose their decision-making capacity in the course of their illness. Legalization proponents have recently invoked a further policy precedent embedded in the moral logic of the right to die and claimed that patients seeking physician assistance in dying should not be held to a more demanding standard for expressing and effectuating their wishes than persons who utilize advance directives to exercise rights to refuse or withdraw life-sustaining interventions. The appropriation of requirements for decision-making capacity from advanced directive legislation into patient deliberation on requesting physician assistance in dying would mean proxies could make surrogate decisions for the patient based on the patient’s values in the event of loss of decision-making capacity [7].

These restrictions in current physician-assisted death
statistics have prompted ethical and professional arguments and patient advocacy to extend the scope of the right to die still further. These arguments, presented formally at a 2018 workshop sponsored by the National Academy of Medicine, maintain that the right to die should encompass (1) physician-administered medications for terminally ill persons, some of whom may no longer have (2) decision-making capacity. Moreover, advocates contend that certain medical conditions afflicting chronically ill persons can impose an experience of unbearable pain and suffering for which even the best of palliative care measures are inadequate for the patient. Consequently, access to either self-administered or (3) physician-administered medications to end life should also be available to (4) non-terminally ill persons with no terminal diagnosis but who are experiencing (5) a grievous and irremediable medical condition [8]. That is, the moral logic of the right to die has evolved from patient decisions to refuse or withdraw burdensome or futile treatment to patient decisions to request physician prescribed medications to hasten death to patient decisions to request direct physician administration of a lethal agent when the underlying indication is not terminal illness but non-relievable pain and suffering. This latter ethical terrain, which historically has been designated by the concept “euthanasia,” has been re-conceptualized as a patient right to medically-assisted dying to avoid the historical associations of involuntary medical killing attached to “euthanasia.”

The concept of medical aid in dying was introduced in public discourse on the Colorado End of Life Options Act passed in fall 2016 that permitted patients to self-administer a medication to end life but retained the conventional prohibitions on physician-administered life-ending medications [9]. However, legalization advocates and bioethics scholars have found the inexorable moral logic of the right to die exemplified in legislation approved by the Canadian Parliament in June 2016. The Canadian law permits both “clinician-administered medical assistance in dying” in which a physician or nurse practitioner “directly administers a substance that causes death” and “self-administered medical assistance in dying,” in which a physician or nurse practitioner “provides or prescribes a drug that the eligible person takes themselves, in order to bring about their own death.” The stipulation in US physician-assisted death statutes that a patient must be diagnosed with a terminal illness is not a requirement for access to medically-assisted dying in Canada; rather, the triggering condition is designated as a “grievous and irremediable medical condition,” a construct referring to a “serious illness, disease, or disability” that has advanced to a stage where the condition is (a) no longer reversible by medical intervention and (b) causes the patient to “experience unbearable physical or mental suffering … that cannot be relieved under conditions that [the patient] consider[s] acceptable” [10]. Within this construct, (c) a person’s death will have become “reasonably foreseeable,” but this does not presuppose any specified minimal temporal duration to their life expectancy. The Canadian legislation builds on the central principles of patient self-determination, personal bodily integrity, and freedom from unwanted medical interventions in the moral logic of the right to die, but extends these principles by supplementing personal autonomy with an appeal to the historical professional imperative to address “unbearable” pain and suffering. Scholars have advocated appropriating features of the Canadian legislation to address the perceived inadequacies of current physician-assisted death statutes in the US [11,12].

This overview of the ethical, professional, and legal expansion of the right to die provides context for my subsequent normative argument. Philosophical and professional advocacy of this expanded right to die engages in two assumptions of ethical equivalence: (1) Physician-assisted death is the moral equivalent of withdrawing or refusing futile medical treatments, and (2) Medical-assisted dying is the moral equivalent of physician-assisted death. It follows from these claims that there is no moral difference between patient requests for medical-assisted dying administered by a clinician, that is, physician-administered euthanasia, and patient requests to withdraw or refuse futile life-prolonging medical treatments. I reject these claims of ethical equivalence. I contend there is a moral line between rights to refuse treatment and rights to physician-assisted death and that legalizing physician-assisted death does not resolve the ethical questions. I also contend that medically-assisted dying in the United States is premature and ethically objectionable, and risks compromising professional integrity and sound public policy regarding end-of-life care.

An Argument Against Legalization: A Premature Policy

While the frequency of legalizing physician-prescribed medications to hasten the death of a terminally ill patient has increased in the past five years, the majority of US states have found that advance directives, meaningful professional and familial conversations, and affirming the negative right to refuse medical treatment genuinely advances patient interests in end-of-life care. This more limited scope of the right to die allows choices about end-of-life treatment refusals to be the province of the patient (and family) and physician relationship without state micro-management. End-of-life care can of course be improved: numerous recent professional articles and public-oriented books by physician authors in end-of-life care suggests the “plague of bad dying” has very much captured both professional and medical attention and the focus of the public [13-15]. However, issues of deper-
sonalized care, mismanaged medical technologies, institutionalized dying, and diminished patient and familial control of the dying process can be addressed through advocacy of ongoing reforms in the patient-physician relationship (conversations about patient preferences), institutional settings (encouraging advance directives), and the social structures of care (providing sufficient palliative care and pain control). It is ethically premature to conclude that the primary way to remedy the medicalized culture of bad dying is allowing physicians to be directly involved in ending the life of their patient.

Advocacy of legalized medical assistance in dying is also premature because end of life care in the US has not utilized sufficiently the options that allow patients to experience control and quality of life as death draws near. The philosophy and practice of hospice care historically sought to provide a middle path in end-of-life care between vitalistic prolongation of life by medical technologies and physician intervention to hasten a patient’s death, to the ends of respecting the dignity of the patient as a person, minimizing pain, providing patient control over dying, and viewing dying as an opportunity for cultivating meaningful relationship closure and personal meaning [16]. The legal option of physician-assisted death is a relatively rare occurrence in part because of the continued commitments to holistic care delivered by hospice programs. However, hospice care remains an under-utilized option in the culture of dying, with the number of persons covered by Medicare and receiving hospice care at the time of death ranging by state from 23 to 58 percent. Referrals or access to hospice care still tend to occur late in the dying process. Patients who receive hospice care services for a week or less comprise 27.9 percent of the hospice population [17]. Hospice has been portrayed by prominent physicians and writers in end-of-life care as the artes moriandi or “art of dying” for our era of high-technology, depersonalized, and protracted dying [18]. Bioethical and professional cultures have an ethical responsibility to work towards universal access to hospice care when hospice can be most effective in meeting both patient needs and its historical moral mission before determining that medically-assisted dying is the remedy for the plague of bad dying.

Ethical Objections

There are compelling philosophical considerations supporting legalization of physician-assisted death and medical-assisted dying: At a broad conceptual level, who would really be opposed to a dignified death? However, legalization arguments appealing entirely to patient self-determination mistakenly presume that such actions involve a “private” patient choice and are thereby immune from moral assessment. A patient who requests medical aid in dying requires the assistance of a professional, a qualified physician or nurse practitioner, that is, a person who is part of a moral profession in whom society has reposed trust that the profession’s members will exercise their knowledge, skills, and proficiencies in the healing arts for the benefit of both patient and society. Physician-assisted dying and medical-assisted dying are necessarily “public” actions that require forums for professional and public accountability. The focus of legalization advocates on patient rights and interests has generated moral myopia regarding the presence of other stakeholders including various intermediate communities such as families, the healing professions, hospice care, and spiritual care advisors, as contributors to end-of-life caregiving.

The moral logic of ending human life in any context requires that any such actions be undertaken as a last resort. There are alternative options in end-of-life care that can bestow on dying persons a measure of control over the dying process, confer value to dying and open paths to meaning short of a perceived necessity to hasten death by medical means. Even physician advocates of legalized physician-assisted dying have identified several “last resort” options for assuring an experience of dying well for terminally ill persons, including exercising the substantial legal rights persons and their proxies already have in all states to refuse life extending medical treatments through advance directives; the gold standard of hospice care and palliative medicine; the double effect practice of providing sufficient sedation to alleviate pain even if an unintended outcome is a hastened death; and, voluntarily stopping eating and drinking [19]. It is ethically incumbent to retain these methods as resorts for dying of last resort rather than offer physician- or medically-assisted death as either a “first resort” or as one end-of-life option among many morally equivalent options. These conventional last resorts offer respect, control, relational closure, and quality of dying for the vast majority of dying persons. Even in Oregon, the state with the most extensive longitudinal experience of utilization of physician-assisted death by terminally ill patients, studies indicate that less than 0.2 percent of all deaths occur through recourse to the medical procedures available by the state’s Death with Dignity Act [20].

The purported ethical equivalence of treatment refusals with physician-assisted death and medical-assisted dying also invites critical scrutiny. This double moral equivalence presumes that the only ethically relevant consideration is informed patient choice, but it neglects to situate such choices within ethically important matters of causation, human agency, intention, and responsibility for outcomes. The negative right to refuse or withdraw medical treatment involves an understanding that terminal diseases and mortality are matters ultimately beyond human control and professional mastery. The implicit in-
The fallacy of ethical equivalence between physician-assisted and medical-assisted death is also evidenced by a broadened and subjective interpretation of futility. The moral logic of the right to die was initiated by judgments that certain medical interventions were futile in terms of patient recovery. The practice of medical-assisted dying expands the concept of a professional judgment of futility regarding extending life to futility in relieving physical or mental suffering according to patient criteria. The Canadian law is very clear in its intent to shift the criteria for medical-assisted dying away from a professional judgment of a terminal diagnosis (as with the US statutes) to an individualized and necessarily subjective patient assessment of their illness experience. It follows that if a patient determines that their suffering from a non-terminal condition is irremediable and cannot be relieved, the professional responsibility to relieve suffering is ironically fulfilled by ending the life of the suffering person.

It is incumbent on the medical profession to be able to offer more to patients with a serious or terminal illness than either aggressive and invasive medical interventions or hastening the patient’s death. As argued by physician Eric Cassell, the “test of a system of medicine should be its adequacy in the face of suffering,” even if identifying and being present to patients who are suffering is a very elusive experience [21]. Physicians assume a critical ethical responsibility for compassionately and empathetically hearing the narratives patients tell as they are faced with suffering, critical illness, dying, and mortality, stories that often reflect themes of restoration, chaos, journey, and identity [22,23]. A reliance on the art of healing and the wisdom of generations of professional care in the midst of the ordeal of suffering is part of what physician Paul Kalanithi designated as the “mortal responsibility” physicians assume as healers [24].

Professional Integrity

Part of the catalyst for the moral logic of the right to die that aims to expand patient choices in end-of-life care is that medical technologies, professional control of dying, and medicalization have made it harder to die in the contemporary era [25]. The ascendant medicalization of dying is intimated in the language of medical assisted dying selected by advocates to portray what occurs when a patient makes a request of a health care professional for a prescription or the direct administration of a lethal medication to hasten death. The medicalizing language reflects and extends the domain of medicine over the dying process rather than extracting patients from technological, institutional, and professional control. However, integrating physician-assisted or medically-assisted dying as part of the best practices that medicine has to offer in end-of-life care symbolizes something powerful and also perplexing about the nature of medicine.

Medicine has historically been represented as a “healing profession,” with “healing” as the defining feature of the professional vocation [26], as manifested through purposes of caring, curing, preventing premature death, promoting health, and relieving unnecessary pain and suffering. The distinctive “profession” or promise of medicine is defined by goods and values internal to the professional ethos and practice. However, physician-assisted and medical-assisted dying inevitably make the caring, curing, relieving, and healing purposes of medicine subservient to other goals, especially those defined by patient preferences, extrinsic to medicine’s profession. What medicine is valued for primarily in physician- and medical-assisted dying is technical proficiency and functionality in providing an effective and expedient means (a lethal pharmacologic agent) to achieve the patient’s end of a hastened death. The healing vocation of the physician is diminished to the role of efficient, and morally neutral, technician.

The construction of medicine as a morally neutral technical practice that serves ends determined by patients is reinforced by cultural shifts that emphasize the character of medicine as a “business,” health care as an “industry,” and relationships of patient and physician as a “retail” transaction between “consumers” and “providers” [27,28]. Advocates of legalization have appropriated the consumerist construction of the relationship because it presupposes the primacy of patient preference and choice. However, as with any retail-oriented relationship, the moral valence of the patient-physician relationship is diminished to an impersonal transactional exchange between strangers in which the central ethically binding feature of mutual trust is ethically peripheral. The ethical implication of the business construction of medicine and the consumerist transactional relationship between patient and physician is that medicine’s integrity and moral identity is dependent on cultural factors extrinsic to the healing promise of the profession.
The sense that medicine and medical professionalism has its own ethic independent of societal considerations, political influences, or patient choices in part explains why American jurisdictions that have legalized physician-assisted death have refrained from adopting (for now) a Canadian-style medical-assisted death procedure. Physicians have reasoned that by providing a prescription, their personal involvement and responsibility for a patient’s death is indirect at best, insofar as a patient assumed additional responsibilities, including obtaining the prescription and deciding whether or not to ingest the medication by self-administration. While diminishing the physician’s role to that of technician, this professional distancing from responsibility for a patient’s death cannot be retained when a physician (or nurse practitioner) participating in clinically-administered medical aid in dying brings about the patient’s death through direct administration of the lethal agent. Furthermore, the professional commitment that medicine is morally more than a consumer-directed retail transaction is why all jurisdictions (including Canada) that have legalized some form of physician-assisted or clinically-administered aid in dying have allowed physicians (and other health care professionals) to exercise claims of conscientious refusal and decline to participate in the patient request or procedure. The incorporation of physician- and medical-assisted dying practices as one service the profession now offers patients entails a transformative re-conceptualization in medicine of its professional integrity and ethics.

Social Responsibilities

It is a puzzle why there is greater public advocacy for the right to die and legalized physician-assisted death and/or medical-assisted death in a society that has continually fallen short of guaranteeing its citizens universal access to basic health care. It appears ethically perverse to advocate equal access to death in the absence of equal access to health care. Significantly, every nation that has legalized medical-assisted dying and physician-administered euthanasia, including not only Canada, but also Belgium, the Netherlands, Switzerland, and states in Australia, has a system of universalized access to health care. The US failure to provide this safety net of basic health care for all, while proceeding to legalize physician-assisted death and consider proposals for medical-assisted death is further evidence that American health care is neither healthy, nor caring, nor a system [29].

Annual health care expenditures in the US have reached a staggering $3.4 trillion dollars [30], a stunning 18 percent of the nation’s GDP. The substantial portion of these expenses are devoted to what can be designated as “sick care,” that is, treatments or interventions intended to restore a sick person to good health and quality of life rather than preventive care that promotes a person’s health and keeps them out of the clinical or hospital setting in the first place. Furthermore, studies indicate that over 25 percent of total Medicare costs, or approximately $170 billion, are devoted to medical care and interventions during the last six months of a person’s life [31], often with minimal medical benefit to the patient, even if this provides psychological benefit to family members who are assured they have “tried everything.”

This cost-ineffective spending pattern has made end-of-life medical care and interventions a prime area for proposing cost-containment processes. In this context, efforts to legalize physician-assisted death or medical-assisted death may seem to provide a utilitarian-oriented resolution by providing an alternative for patients to end their life and spare their families and the society of significant medical expenses during their dying process. It is important in general to commend persons who make sacrifices of their interests to benefit the common good. However, the value and dignity of human life morally should not be reduced to an economic calculation. A firewall must be maintained between decisions about ending life, be it through refusing treatment or a life-ending medication, and the costs of care. In the absence of such a firewall, what has been advocated as a right to die can be experienced as a duty to die on behalf of other persons or broader communities.

Commitments in End-of-Life Care

Ethical, professional, and legal controversies will continue to emerge as physician-assisted death becomes more socially prevalent and portends a transition to medical-assisted dying. Ethical critique of these new practices, and the new interpretations of medicine in which they are embedded, does not imply callousness to patient needs. Patients with a serious or terminal illness have legitimate interests in controlling their own dying process and calls for professional and communal responsiveness in caring at the end of life. The most valuable and meaningful aspects of dying include the presence of a community of care that witnesses to the dying person that they will never be abandoned. This requires reclaiming the historical tradition that medicine is a professional vocation oriented by commitments to healing, a dynamic process that can occur even when curing is not possible, and resistance within medical professionalism of the economic and bureaucratic reduction of the patient-physician relationship to a commercial transactional exchange. The primary professional responsibility in end-of-life care is to relieve patient pain and suffering, utilizing medical knowledge, empathy and compassion, and comfort care interventions to relieve suffering without ending the life of the person that suffers.
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