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Patient Rights at the End of Life

The Ethics of Aid-in-Dying

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ABSTRACT

Purpose/Objectives: The end-of-life needs and desires of patients, whether it is related to a terminal illness or age-related end-of-life physiological function, can vary from patient to patient. Each dying patient's case should be approached in an individual and patient-centered fashion while supporting the dying patient's desired preferences related to end–of-life treatment. This serves to recognize the dying patient's individual rights related to self-determination of preserving his or her dignity during the end-of-life process. As the U.S. population continues to age at the fastest pace in history, it is vital for end-of-life patients and their family members, health care providers, and lawmakers to consider how health policy can drive legislation that supports the dying patient's right to express his or her dignity and own end-of-life desires related to aid-in-dying by allowing health care providers to legally provide physician-assisted health (PAD) and death with dignity (DD) the end-of-life care dying patients prefer.

Primary Practice Setting(s): Palliative, hospice, and long-term care.

Findings/Conclusions: When state laws do not support a terminally ill person's ability to make his or her own end-of-life decisions based on his or her own preferences and desires related to PAD and dignity in dying, there can be moral conflictions with the existing ethical principles that can contribute to additional distress and anxiety in the terminally ill patient. Not allowing the terminally ill patient the legal right to choose his or her preferences and desires at the end of life goes against the freedom of the patient to choose. The aging population is growing quickly, and people are living longer, which means the frail elderly in their final stages of death due to multisystem organ failure might also desire to have the option of PAD that supports dignity in dying.

Implications for Case Management Practice: Case managers are an instrumental and integral part of the end-of-life care team. They are held to the same standard of practice as clinical care providers when it comes to promoting the biomedical ethical points autonomy, beneficence, nonmaleficence, justice, and fidelity. Following these ethical principles is critical for case managers to consider when supporting the desires and preferences of terminally ill patients. Case managers should be involved in all the patient-centered decision making for a terminally ill patient's desire for DD and PAD. It is critical for case managers to follow their organization's defined code of professional conduct as well their specific professional organization and professional certifying body's defined code of ethics and conduct despite their personal convictions.

Key words: *advocacy, death with dignity, end of life, ethics, physician-assisted death, terminally ill*

The end of life can be a difficult and challenging time for patients, family members, and health care providers. In many cases, patients at the end of life often experience excruciating pain, unimaginable suffering, and poor quality of life in which the dignity and preferences of the dying patient take a back seat to administering treatments and medications in an attempt to minimize the patient's subjective experience of pain and suffering (Smith, Acker, & Torres, 2017; Torres, Lindstrom, Hannah, & Webb, 2016). The current climate of interventions at the end of life is often conflicting to the patient's wishes (Snyder & Mueller, 2017). The end of life is a personal experience for each patient; therefore, it is vital for lawmakers and health care providers to understand that the end of life phase is a unique and subjective experience for each individual. This article will discuss the debatable and ethical aspects of aid-in-dying with the terms physician-assisted death (PAD) and dying with dignity (DD) when it comes to honoring a patient's end–of-life desires from the medical, legal, and legislative perspectives in the United States.

BACKGROUND

With the baby boomer population aging, our current health care system may not be ready to meet their needs and challenges at the end of life.

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Many states now have legislation, referred to in most states as either aid-in-dying or DD laws, that allows terminally ill adults who have the mental capacity to make informed decisions (in the absence of coercion) to request medication from their physician with the sole purpose of the medication to be aid-in-dying as the end result would be death …. However, the legislative topic aid-in-dying is debated intensely and is a very emotionally charged debate from both advocates and those who object.

The frail elderly specifically may be at risk with comorbidities that contribute to terminal illness or mortality (Smith et al., 2017; Torres et al., 2016). The frail elderly are often at a greater risk for undesired hospitalizations that result in more life-sustaining interventions that can increase health care cost for the patient, family, and the health care system that could be avoided (Biggar & Hood, 2017). The majority of terminally ill patients report their main concern to be a loss of dignity when dying and not necessarily the fear of experiencing uncontrollable pain. Therefore, for frail elderly or terminally ill patients, PAD or DD may be an option to better meet their end-of-life needs and preferences (Emanuel, 2017; Tolle & Teno, 2017).

The Physician Orders for Life Sustaining Treatment (POLST) was instituted to replace advance directives, which allows patients to make their end-of-life preferences known while being reflected in the medical orders (Tolle & Teno, 2017). A patient with an unavailable advanced directive in a hospital or emergent setting will most likely be subject to standard protocols with life-sustaining interventions. Clinicians, case managers, social workers, and the nursing professionals all participate in a collaborative, team-based approach when assisting patients in the completion of POLST (Hickman, Keevern, & Hammes, 2015; Thomas & Sabatino, 2017).

Many states now have legislation, referred to in most states as either aid-in-dying or DD laws, that allows terminally ill adults who have the mental capacity to make informed decisions (in the absence of coercion) to request medication from their physician with the sole purpose of the medication to be aid-in-dying as the end result would be death. Nationally in the United States, there has been a sociocultural push, from the terminally ill population and DD advocates in particular, to allow terminally ill patients the right to self-determination of how they die, while allowing them to end the pain and suffering they are experiencing in a manner that is peaceful and dignified. However, the legislative topic aid-in-dying is debated intensely and is a very emotionally charged debate from both advocates and those who object.

KEY DEFINITIONS

In debating the two sides of aid-in-dying, it is critical to understand the terms most often discussed and the definitions associated with each one. The most commonly discussed terms are PAD, DD, and "physician-assisted suicide." Before debating and discussing the ethical points of these individual terms, it is important to note how they are defined in both health care and legislative realms (see Table 1). The term of passive euthanasia must also be highlighted as it refers to the withholding of life-sustaining treatments at the patient's request that either hasten death or serve to prolong death (Garrard & Wilkinson, 2005). The term "physician-assisted suicide" is also referred to as active euthanasia and involves voluntarily terminating one's own life by self-administering a lethal medication prescribed by a physician (USLegal, 2019). "Physician-assisted suicide" is different from the withholding or discontinuation of medical treatment in circumstances where death is imminent as this was defined previously in this section as passive euthanasia. The terminology of passive euthanasia is more generally accepted in society but not without controversy. This is especially so in the United States when it comes to an individual's right to refuse life-sustaining medical treatments (USLegal, 2019).

TABLE 1
Key Definitions Associated With Patient's Rights at the End of Life

Physician-assisted death (also referred to as physician-assisted suicide and voluntary euthanasia)—Physician prescribes a lethal dose of medications per the patient's request that the patient self-administers (Snyder & Mueller, 2017).

Passive euthanasia—The withholding of life-sustaining treatments at the patient's request that either hasten death or serve to prolong death (Garrard & Wilkinson, 2005).

Dying with Dignity (also referred to as a "Good Death" [Beckstrand et al., 2006])—Maintenance of control over one's choices or comfort, which is a process and not an event with the four main components being life completion, treatment preferences, dignity, and family (Meier et al., 2016).

Physician-assisted suicide (also referred to as active euthanasia)—Voluntarily terminating one's own life by self-administering a lethal medication prescribed by a physician (USLegal, 2019).

Advocates for dignity in dying use the term "PAD" as it suggests compassion and respects patient's preference. The term "PAD" also supports the biomedical ethical principles of autonomy, nonmaleficence, beneficence, and justice while considering the profession of medicine's Hippocratic oath, which specifies to do no harm (Beauchamp & Childress, 2012; Snyder & Mueller, 2017). The term PAD in some states is often legally defined as physician-assisted suicide whereas proponents of PAD most often use the term "dying with dignity," which is also known as a "good death" (Emanuel, 2017; Meier et al., 2016). Unfortunately, there is a lack of standardized and uniform terminology and corresponding definitions when it comes to the use of key terms related to patients' rights at the end of life to aid them in the preactive and active phases of dying (Meier et al., 2016).

BIOMEDICAL ETHICAL PRINCIPLES

Medical ethics defines provider duties to patients and society and is often more extensive than legislation. Bioethical principles to consider when discussing PAD and DD include the following (Beauchamp & Childress, 2012; Snyder & Mueller, 2017):

a. respect for autonomy,
b. nonmaleficence,
c. beneficence, and
d. justice.

Table 2 lists these principles and their corresponding definitions. The term "fidelity" will be addressed later in this article.

TABLE 2
Key Biomedical Ethical Principles to Consider When Discussing Physician-Assisted Death and Dying With Dignity as Defined by Beauchamp and Childress (2012)

Respect for autonomy—refers to self-governing and the patient's ability to independently make his or her own decisions that are respected by others.

Nonmaleficence—the obligation to avoid harm to include harm that is deliberate, at risk, or takes place while carrying out beneficial acts.

Beneficence—doing good and acting in ways that serves to benefit patients.

Justice—relates to treatment that is fair, equitable, and appropriate in relation to what is due or owed regardless of what has been contributed or earned.

Fidelity—relates to the faithfulness, truthfulness, fairness, loyalty, and commitment in caring for patients.

The principles of autonomy and justice have strong meaning and application when considering PAD and DD among terminally ill patients at the end of life. Respect for autonomy takes into account the right of the terminally ill patients to self-determination when in the presence of sound mind and authority to make their own decision in their death (Emanuel, 2017). When addressing PAD and DD among terminally ill patients, the principle of justice refers to a set of universally accepted principles that determine what is considered right or wrong, no matter the societal or cultural norms (Center for Economic and Social Justice, 2017). The principle of justice also focuses on treatment that is fair, equitable, and appropriate in relationship to what is due or owed to a person (Rich, 2013). When applying the biomedical ethical principles of autonomy and justice, terminally ill patients in their final phase of life should have options available promoting dignity and alleviating suffering while allowing them to make their own autonomous choices when it comes to how they die (Emanuel, 2017).

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Nonmaleficence focuses on avoiding harm or inflicting the least amount of harm possible to achieve the greatest benefit whereas beneficence deals with actions that serve to benefit others by removing harm, preventing potentially hurtful actions, or improving the current situation. Applying these two ethical principles leads to determination of what constitutes the least amount of harm for the terminally ill patient while also considering what provides the greatest benefit (Beauchamp & Childress, 2012; Snyder & Mueller, 2017).

TWO SIDES OF THE DEBATE

According to The Hastings Center (2018), PAD involves a physician providing a consenting, terminally ill patient with a lethal mixture of medication that the terminally ill patient self-administers if the decision is made by the patient to hasten death and end his or her life (Emanuel, Onwuteaka-Philipsen, & Urwin, 2016). In the United States, there are varying views from legal, ethical, and moral standpoints related to PAD. Therefore, both terms—PAD and DD—are frequently used when discussing and debating the options for terminally ill individuals at the end of life. From observational purposes, it seems as if the term PAD is used, mainly by the medical profession and

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the term DD is used by advocates for patients' rights that promote dignity in dying during the last days of life (Ganzini & Back, 2016).

The Death with Dignity National Center supports PAD that allows the terminally ill patient to die with dignity. They have also developed model legislation to promote the availability of DD among terminally ill individuals. This allows patients at the end of life the freedom to choose how they die, with PAD being one of the available options (Death with Dignity National Center, 2018). The Death with Dignity National Center and the American Public Health Association both recommend against using the terminology "physician-assisted suicide" due to it being inappropriate and inaccurate. In addition, the terminology "physician-assisted suicide" can be seen as biased as it sheds a negative light on both proposed and existing laws related to death with dignity (American Public Health Association, 2018; Death with Dignity National Center, 2018).

Opponents of PAD include the American Medical Association (AMA) and the American College of Physicians (ACP). The AMA uses the term "physician-assisted suicide" with the corresponding justification of doing more harm than good for physicians as it:

1. Goes against the physician's role of being a healer,
2. Could be challenging to control, and
3. Might potentially impose grave risks to society (Snyder & Mueller, 2017).

However, the AMA states that, instead of actively engaging in PAD, physicians should diligently respond to the needs of the terminally ill patient at the end of life by respecting the patient's right to autonomy (AMA, 2018).

The ACP also uses the terminology "physician-assisted suicide" and reaffirmed its opposition to it in 2017 due to the potential for altering the role of physician as healer and comforter while also potentially harming the societal role of the medical profession. However, at the same time, the ACP also affirmed the physician's responsibility to promote the betterment of care among terminally ill patients at the end of life, while at the same time calling for improvement in the delivery of hospice and palliative care (American College of Physicians, 2017).

Neutrality of the two sides of this debate can be noted in the stance taken by the Stanford School of Medicine (2018), as it states that it is not for or against PAD, but it does have a strong stance when it comes to considering a patient's request and desires related to the alleviation of his or her own end-of-life suffering. Stanford School of Medicine states that terminally ill patients at the end of life become extremely distressed and worried due to feeling out of control when it comes to how they die and they worry about dying alone, dying in distress, or dying in pain (Stanford School of Medicine, 2018). It is important to keep in mind that early and effective palliative care being patient and family-centered can serve to alleviate this anxiety felt by patients during the end-of-life experience (Torres et al., 2016). By supporting the patient and his or her desired end-of-life choices, we are providing patient-centered care that is patient and family driven (Beckstrand, Callister, & Kirchhoff, 2006).

MORAL CONFLICTIONS

Morals, as contrasted with ethics, focus on beliefs, behaviors, and actions that are a result of human action and character. Therefore, terms of PD and DD would not be complete without discussing the moral conflicts often involved with these two terms. The moral compass of societies in more southern and northeastern states may differ from those in northwestern and southwestern states, which may also serve to explain the lack of legislation related to PAD and DD (Ganzini & Back, 2016). The individual states in the United States that do not have PAD legislation often have a strong moral presence from a religious standpoint that supports views of PAD and DD as taking away innocent human life or even a form of murder (Mason, Kim, Martin, & Gober, 2017). Religions that oppose legislation for PAD often point to advances in medicine that alleviate pain and suffering at the end of life; therefore, PAD is unnecessary (Mason et al., 2017). However, this is where one should recall the main reason patients request PAD, which is to exercise their right of autonomy and to alleviate pain and suffering (Emanuel, 2017).

CURRENT CLIMATE

In the United States, the legal use of PAD is decided upon in each individual state (Ganzini & Back, 2016). The Supreme Court has ruled that PAD is not a right protected by the constitution. In some states, it is allowed by state law and in others, it is an option that is granted by decision of the court (Emanuel, 2017; Pormeister, Finley, & Rohack, 2017). There are many states where PAD is not supported by the law and is therefore considered illegal. Currently, in the United States, seven states and the District of Columbia have legalized PAD at the end of life (see Figure 1). California, Colorado, Hawaii, Oregon, Vermont, and Washington allow for PAD through legislation; the state of Montana allows for it through court ruling only (ProCon.org, 2018). Figure 1 shows a map of the United States and states where PAD has been allowed since 1997, where there are new laws against PAD, where PAD is banned, where there are no clear statutes related to PAD, and where PAD laws are awaiting court decision.

All states that legally allow PAD have a 2-week waiting period after two oral requests from a patient and an additional 48 hr after a written request and the subsequent prescription. In addition, patients must have a terminal prognosis of 6 months or less to live but are not required to have "unbearable pain" (Emanuel et al., 2016). It is noted that the more conservative southern states do not have legislation that supports PAD whereas many western states have legislation in place that supports PAD. The legislatures in the southern states, which make up the so-called "Bible Belt," are historically believed to more likely look at the moral side of issues rather than the medical or self-determination argument in support of DD (Mason et al., 2017). This point highlights the important influence culture of morality has on ethically debated topics such as PAD and DD (Snyder & Mueller, 2017).

In a study conducted by Emanuel et al. (2016), it was found that in the United States, Canada, and Europe, more than 70% of patients who chose PAD had some form of cancer, were typically older, and were white patients who were well-educated; the reasons for making this choice were the fear of losing autonomy and dignity, lack of quality of life, and avoidance of mental and emotional distress. A large number of these patients were also enrolled in either hospice or palliative care programs. This research also concluded that legalization of PAD is increasing nationally and internationally and mainly involves patients with terminal illnesses such as cancer (Emanuel et al., 2016).

Data on PAD

As PAD has been legalized in several states, it is important to review current statistics in those states. The four points made by Emanuel (2017) regarding PAD in states where it has been legalized are as follows:

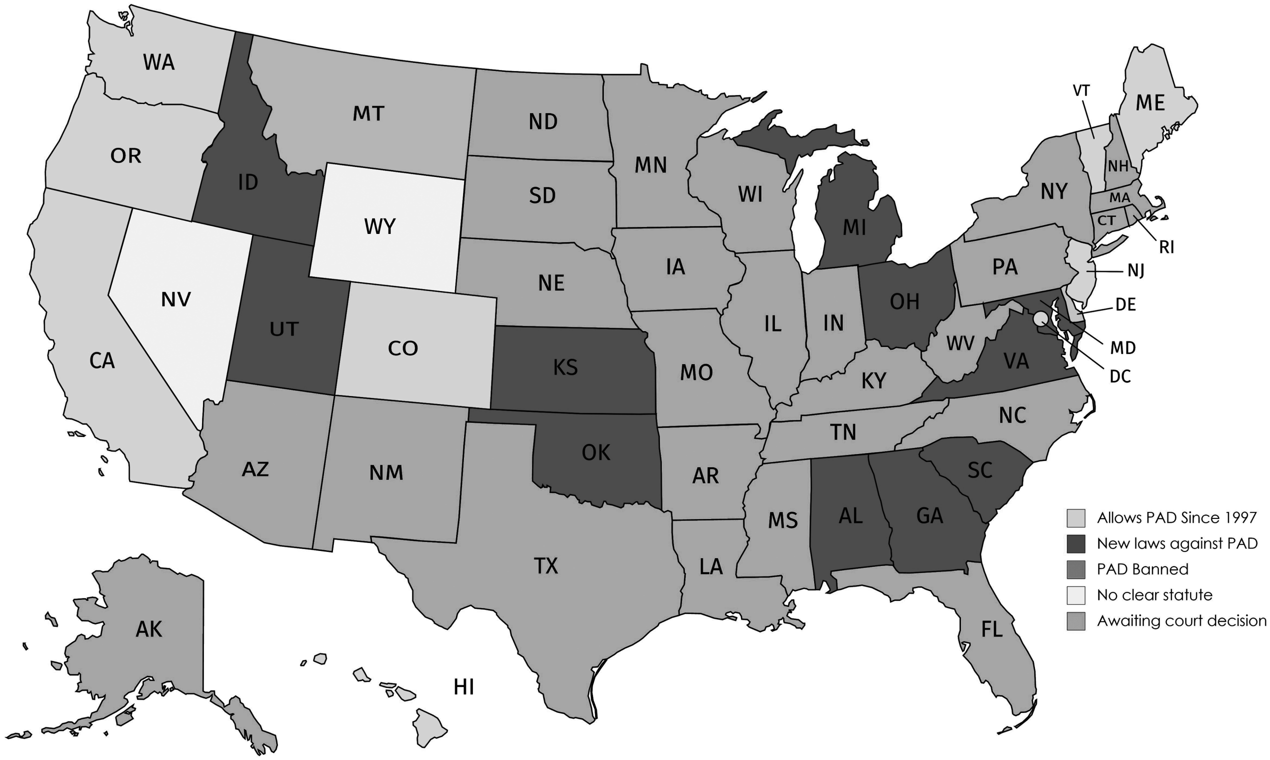

FIGURE 1

Map of the Current Climate for PAD in the Individual States (Charlotte Lozier Institute, 2019; Emanuel et al., 2016; ProCon.org, 2018).

Like other health care providers, such as physicians, case managers working with terminally ill patients may encounter conflicting ethical or moral dilemmas related to the end of life. However, case managers must follow their organization's defined code of professional conduct as well their specific professional organization or professional certifying body's defined code of ethics and conduct despite their personal convictions.

1. Although PAD has been legal in some individual states, in the United States and other countries such as Belgium and the Netherlands, statistically it is not considered to be the main cause of death.
2. Recent data show very low utilization of PAD in the United States (see Table 3).
3. When a patient requests PAD in states where it is legal, it is not always granted.
4. More than three-quarters of terminally ill patients who are granted PAD have some form of terminal cancer.

These data can provide many assumptions as to why PAD is not utilized at a greater rate in the United States when compared with other countries. Using these quantitative data provided by Emanuel (2017) can assist with conducting further research from both quantitative and qualitative standpoints to determine benefit and existing challenges of PAD use in the United States.

IMPLICATIONS FOR CASE MANAGERS

Case managers are an instrumental and integral part of the end-of-life care team. They are held to the same standard of practice as clinical care providers when it comes to promoting the previously discussed biomedical ethical points autonomy, beneficence, nonmaleficence, and justice. However, there is another key biomedical ethical principle that case managers should abide by when it comes to advocating for a terminally ill patient's rights at the end of life and it is the principle of fidelity (Code of Professional Conduct for Case Managers [CCMC], 2015). According to Beauchamp and Childress (2012), fidelity is the display of commitment to faithfulness, truthfulness, fairness, and loyalty when caring for patients. This is a critical ethical principle to consider when supporting the desires and preferences of terminally ill patients.

TABLE 3
Percentage Associated With Physician-Assisted Death^{a}

Country/State	Time Frame	Percentage of All Deaths
Netherlands, European Union	2010	6.70
Belgium, European Union	2010	6.00
Washington, United States	Since 2008	0.24
Oregon, United States	Since 2002	0.30

^{a}From research conducted by Emanuel et al. (2016).

It is evidenced that case managers should be involved in all patient-centered decision making regarding POLST as well as the terminally ill patient's desire for PAD during the assessment and ongoing care coordination (CCMC, 2015). Like other health care providers, such as physicians, case managers working with terminally ill patients may encounter conflicting ethical or moral dilemmas related to the end of life. However, case managers must follow their organization's defined code of professional conduct as well their specific professional organization or professional certifying body's defined code of ethics and conduct despite their personal convictions (CCMC, 2015).

CONCLUSION

When state laws do not support a terminally ill person's ability to make his or her own end-of-life decisions based on his or her own preferences and desires related to PAD and dignity in dying, there can be moral conflictions with the existing ethical principles that can contribute to additional distress and anxiety in the terminally ill patient. Not allowing the terminally ill patient the legal right to choose his or her preferences and desires at the end of life goes against the freedom of the patient to choose. In 2008, the American Public Health Association published its standpoint that terminally ill patients have the right to self-determination at the end of life to include the personal and subjective option of death based on what the terminally ill patient feels a "good death" entails (American Public Health Association, 2008).

This purpose of this article focused on the terminally ill patient's right to choose his or her preferences at the end of life, but the frail elderly must not be forgotten about when it comes to personal preferences at the end of life. The aging population is growing quickly, and people are living longer, which means the frail elderly in their final stages of death due to multisystem organ failure might also desire to have the option of PAD that supports dignity in dying. In the health policy arena, it must be remembered that there is a difference in a terminally ill individual's subjective decision on how to die "a good death" and the termination of health, viable person's life, regardless of age. This fact gets lost, more often than not, in the ongoing debate because of the focus on morality and ethics, as opposed to an individual's right to choose.

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Registration Deadline for Nurses: February 28, 2021

Disclosure Statement:

The authors and planners have disclosed that they have no financial relationship related to this article.

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