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## Autonomy and the Patient's Perspective on Physician-Assisted Suicide

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*Autonomy and the Patient's Perspective on Physician-Assisted Suicide*

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### **Abstract**

*Introduction:* Physician-assisted suicide (PAS) is an end of life (EOL) option that involves a patient ingesting a lethal medication that has been prescribed by a physician after a complex vetting process. In certain countries and the United States (US) where PAS is legal, patients avoid EOL suffering and may have more control over the dying process.

*Scholarly Inquiry Question:* Do patients who seek end-of-life care by means of PAS have a greater sense of control of their dying process versus those patients who do not or are not allowed to participate in PAS?

*Supporting Evidence:* Physical and emotional suffering are significant motivators for terminally ill patients to desire PAS (Nissim et al., 2009; Johansen et al., 2005; Maessen et al., 2009; Regan et al.). Through PAS, patients are also able to control the circumstances of their death, including the time of death, location, rituals, and individuals present (Maessen et al., 2009; Smith et al., 2011). Healthcare providers play a critical role in treating terminally-ill patients and upholding patient autonomy; non-judgmental and timely communication are the foundation for discussing PAS (Georges et al., 2007; Pasman et al., 2013). Suffering while dying is subjective (Dees et al., 2010); PAS is an EOL option that upholds the ethical principle of autonomy (Nissim et al., 2009).

*Theory and Conceptual Framework:* The Theory of Relational Autonomy was used to guide this integrative literature review. The goal of this theory is to build social relationships and institutions that encourage individuals to lead self-governing lives (Mackenzie, 2015).

*Conclusions:* Terminal illness is life-altering. PAS contributes to a better quality of death and upholds patient autonomy by allowing the patient to die on their own terms: deciding who is present, where and when their death will take place, and ultimately ending the process of painful and undignified lingering.

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## Introduction

In 1994, Oregon was the first state in the United States to legalize physician-assisted suicide (PAS) for terminally ill adults with a voter-supported initiative called the Death With Dignity Act (Volker, 2007). The 2018 annual report from the Oregon Health Authority (OHA) has been summarized by the organization Death with Dignity (DWD); this report revealed that 168 people in Oregon used lethal medications obtained under the law in 2018, with a death rate of 49.5 of 10,000 deaths. Of the people who participated in physician-assisted suicide, the majority had cancer (62.5%), were actively in hospice care (90.5%), and died at home (88.6%). With regard to end-of-life concerns motivating them to participate in PAS, patients reported the loss of autonomy (91.7%), decreased capability to be involved in activities that made life enjoyable (90.5%), and loss of dignity (66.7%) were prime factors (DWD, 2019). Oregon will be referenced frequently throughout this paper; it is considered the “laboratory” of the U.S. with regard physician-assisted suicide legislation (Volker, 2007).

In 1997, the Supreme Court of the United States ruled that each state may independently decide to legalize physician-assisted suicide (Volker, 2007). Since this ruling, several other states have chosen to pass legislation similar to Oregon’s Death with Dignity Act; in June 2019, Maine became the eighth state to legalize PAS (Villeneuve, 2019). With 18 states also considering PAS (Villeneuve, 2019), the discussion surrounding physician-assisted suicide is acutely relevant to the medical community in the United States. Despite the possible discomfort surrounding a medical option that shortens rather than prolongs life, understanding and forming an opinion about PAS is vital for healthcare providers who participate in conversations with their patients about end-of-life options.

## Background

Physician-assisted suicide (PAS) is defined as the use of a lethal prescription medication from a licensed physician that is ingested by the patient on their own power with the intent of ending their life (Shibata, 2017). PAS differs from euthanasia for which euthanasia is defined as an event when a medication is administered by a third party with the intention of ending the person's life at his or her request (Chapple, Ziebland, McPherson, & Herxheimer, 2006). Some studies use "aid-in-dying" as an umbrella term for both PAS and euthanasia; aid-in-dying is also used to simply reference the act of the medical community assisting in shortening the life of the patient.

Using Oregon as an example, patients who are interested in PAS must meet specific criteria, according to the Physician Aid-in-Dying Clinical Committee and Oregon Death with Dignity Act of 1994, Chapter 127. Per the Act, the patient must be over the age of 18, show proof of residency in the State of Oregon (via a driver's license, lease agreement, tax return, or voter registration), be capable of making major medical decisions as determined by their physician, and have a terminal diagnosis or a type of medical condition for which the outcome would be death within six months or less (1994). Capable is defined as "in the opinion of a court or in the opinion of the patient's healthcare provider or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available" (Oregon Death with Dignity Act, 1994, p. 1). Healthcare provider (HCP) will be used to include any physician or advanced practice provider primarily caring for the patient during end of life.

Upon a patient's request for PAS, the healthcare provider is required to ask questions to assess for any physical, psychological, financial, social, and spiritual issues that could be influencing the patient's request. The goals of the initial assessment by the HCP are to prevent premature action by the patient, ensure the patient is making the request free from external pressure, and to make certain that the patient is considering or has considered alternatives to PAS. The decision to participate in PAS must be voluntary and intentional, meaning the patient understands that their participation of such acts will result in the ending of their life. If the healthcare provider is concerned for the presence of mental health conditions influencing the patient's decision, the physician shall refer the patient to a licensed psychiatrist for a thorough evaluation (Oregon Death with Dignity Act, 1994; Orentlicher, Pope, & Rich, 2016).

According to the Oregon Death with Dignity Act, the attending physician is the primary physician (healthcare provider) who is caring for and treating the patient's terminal illness (1994). The HCP is not required to obtain a special license to prescribe lethal medications for PAS. Should a patient request PAS, the healthcare provider has the right to refuse to participate in such events. If the primary healthcare provider declines to be involved in PAS, the patient's care and medical records would be transferred to a new healthcare provider who provides services associated with PAS (Oregon Death with Dignity Act, 1994). When patients are seen and evaluated by a healthcare provide, this evaluation serves as clearance for the patient to make this type of serious decision. Thus, healthcare providers are participating in good-faith compliance with Oregon's Death with Dignity Act, and they are protected from any criminal liability or professional disciplinary action (1994).

As with other major medical procedures, the healthcare provider must establish informed consent. This is accomplished by the healthcare provider making the patient aware of other end-

of-life options such as hospice care, aggressive symptom management, the voluntary cessation of oral intake, discontinuing life-sustaining treatment, and palliative sedation (Oregon Death with Dignity Act, 1994; Orentlicher et al., 2016). The healthcare provider must also inform the patient that the lethal prescription medication will almost certainly cause death; the medication potentially induces vomiting, which can, rarely, result in failure to cause death; the patient can refuse PAS at any time; the HCP will care for the patient regardless of the patient's decision to participate in PAS; and the patient must be physically able to ingest the medication independently or inject the medication in their feeding tube. Family may only help the patient by mixing the medication in a cup but are not allowed to administer the lethal dose of medication. The healthcare provider must document the patient's understanding of each item to show proof of informed consent (Oregon Death with Dignity Act, 1994; Orentlicher et al., 2016).

The healthcare provider is required to refer the patient to a consulting healthcare provider who is qualified by specialty or experience to assess the patient and make both a prognosis and diagnosis about the patient's disease. "A consulting physician shall examine the patient and his or her relevant medical records and confirm, in writing, the [healthcare provider's] diagnosis that the patient is suffering from a terminal disease, and verify that the patient is capable, is acting voluntarily and has made an informed decision" (Oregon Death with Dignity Act, 1994, p. 4).

Continuing to use Oregon as a model, the patient must make two verbal requests for PAS to their healthcare provider, at least fifteen days apart (Orentlicher et al., 2016; Volker, 2007). The patient must also present a written request (see Appendix), witnessed by two individuals who sign the request for PAS form in the presence of the patient and attest to the patient acting voluntarily, having the mental capacity, and not being coerced into signing the request for PAS (Oregon Death with Dignity Act, 1994). The witnesses cannot be a relative, a financial

beneficiary, the healthcare provider, or a staff member of the institution where the patient is receiving care (Oregon Death with Dignity Act, 1994). Encouraging the patient to include his or her family in the decision-making process is recommended but not required (Oregon Death with Dignity Act, 1994). If the patient qualifies for PAS, the healthcare provider writes the prescription for the lethal medication, which is then dispensed by a pharmacist or the healthcare provider (Volker, 2007).

In Oregon, over one-third of patients who receive a lethal prescription choose not to ingest the medication, for reasons that are not documented (Orentlicher et al., 2016). A literature search performed by Willem, Groenewoud, and van der Wal looked at the various medications used in physician-assisted death, which includes PAS and euthanasia (1999). This study found that over forty medications had been used in physician-assisted death. Most of the literature in this study came from the Netherlands, and the medication regimen for PAS varied across HCPs and institutions. Thirty percent of patients received one medication, either an opioid or barbiturate; 57% received two medications, typically a barbiturate or a benzodiazepine with a neuromuscular relaxant. Other medications that have been utilized include propofol, ketamine, insulin, and potassium. However, the recommendation for PAS is 9g of a short-acting barbiturate, either secobarbital or pentobarbital, which is what has been used in the United States (Orentlicher et al., 2016; Willem, Groenewoud, & van der Wal, 1999).

In physician-assisted suicide, the patient must take the medication independently. The ingestion process starts with the administration of an anti-emetic such as Reglan (metoprolamide) or Zofran (ondansetron) to prevent nausea. About an hour later, the patient mixes eight ounces of water with the barbiturate. The patient then must ingest the entire mixture quickly to prevent falling asleep and risk not getting the full dose of the medication; the patient

goes into a comatose state which leads to respiratory suppression with the end result of death.

In Oregon and Washington State, the healthcare provider cites “respiratory failure” as the cause of death on the death certificate to maintain patient confidentiality (Orentlicher et al., 2016).

The Netherlands is seen as the global leader in setting the precedent for physician-assisted suicide and euthanasia. According to Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, and van der Heide, the history of aid-in-dying in the Netherlands began in 1973, when a physician’s mother repeatedly requested assistance in dying following a debilitating stroke (2009). The physician chose to help her mother die via lethal medication; the physician was subsequently prosecuted and found guilty of committing murder. This case initiated the conversation about the medical community’s conflicting role in relieving suffering while doing no harm (Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, & van der Heide, 2009). Physician-assisted suicide and euthanasia were regularly practiced in the Netherlands throughout the 1980s and 1990s, but the fear of prosecution caused an absence of transparency from the medical community regarding end-of-life treatment. Each reported case was scrutinized closely, and the court decided whether to prosecute the healthcare provider. The Euthanasia Act was passed in 2002 to officially legalize the practice of aid-in-dying and protect healthcare providers, but mainly legalized an existing practice. Since passing The Euthanasia Act in 2002, most healthcare providers in the Netherlands report an increase in legal certainty and care in the dying patient (Rietjens et al., 2009).

Physician-assisted suicide is also legal in Switzerland, Belgium, and Canada (Hurst, Zellweger, Bosshard, & Bopp, 2018). In Switzerland, assisted suicide has been legal since 1918, if altruism is the motivation for helping someone end their own life (Hurst & Mauron, 2003). In Canada, PAS was legalized in 2015 following the British Columbia Supreme Court Case, *Carter*

*vs Canada*, in which two terminally ill women were granted the right to end their own lives (Supreme Court of Canada, 2016). Like the Netherlands, aid-in-dying was regularly practiced and considered a patient's right in Belgium decades before it was formally legalized in 2002 (Saad, 2017). In the United States, PAS is legal in Oregon, Maine, Vermont, Washington, Montana, California, Washington D.C., and Bernalillo County in New Mexico (Shibata, 2017; DWD, 2019).

The criteria to qualify for PAS in both the Netherlands and Belgium are similar to Oregon, except the healthcare provider must also believe the patient is suffering unbearably and hopelessly (Pasman, Willems, Onwuteaka-Philipsen, 2013). Suffering as a motivation to participate in aid-in-dying is frequently cited in the data surrounding end-of-life decision-making. An integrative review by Dees, Vermooij-Dassen, Dekkers, and van Weel concluded that a true definition of patient suffering in the context of a request for PAS or euthanasia does not exist due to its subjectivity (2010). For the purposes of this paper, their conceptual definition of suffering will be used: "Unbearable suffering in the context of a request for euthanasia or physician-assisted suicide is a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind" (Dees, Vernooij-Dassen, Dekkers, & van Wheel, p. 350, 2010). While family members and medical professionals may also undergo suffering, this paper will focus on the patient experience up until death.

During the dying process, suffering and relief from suffering vary between different terminal illnesses, as do the motivations for desiring a hastened death. Pierson, Curtis, and Patrick found that patients dying from AIDS longed for a "good death," wanting complete pain control, avoiding prolonged dying via life support, and desiring intact bodily functions (2002).

Patients with amyotrophic lateral sclerosis (ALS) in the Netherlands feared choking to death as their bodies slowly lost control of basic, involuntary functions (Maessen et al., 2009). After witnessing their loved ones deteriorate and die from the same genetic disease, individuals in the early stages of Huntington's disease also feared suffering through losing physical function and a sense of self (Regan et al., 2017). Patients with advanced cancer viewed the option of hastening death in the future as reassuring for the present, allowing them to imagine a sense of control and autonomy (Nissim, Gagliese, & Rodin, 2009).

Upholding the ethical principle of autonomy is a frequently cited reason for ensuring access to physician-assisted suicide. In *Principles of Biomedical Ethics*, Beauchamp and Childress define personal autonomy as “self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (p. 58, 2001). In medicine, the right to autonomy has been used by competent patients to refuse or request treatment (Shibata, 2017). Personal autonomy is often referenced with regard to physician-assisted suicide, because limiting a patient's ability to choose aid-in-dying is forcing the patient to participate in a dying process that is usually filled with pain and suffering. Denying anyone relief from this type of suffering could be considered violation of the patient's ethical principle of autonomy (Shibata, 2017). PAS is illegal in most states and countries around the world, severely limiting patient's access to this end-of-life options. Some patients do travel in order to participate in physician-assisted suicide in places where it is legal. However, in a qualitative study exploring Huntington's disease, participants in the United Kingdom report the mutually conflicting conditions of being healthy enough to go to Switzerland but ill enough to meet the criteria to qualify for PAS, in addition to difficulties of needing the money to travel and

dying in a strange country without a large number of friends or family present (Regan, Preston, Eccles, & Simpson, 2017).

As modern medicine evolves, discussing end-of-life options such as physician-assisted suicide become increasingly relevant. Some may consider PAS to be healthcare providers “playing God;” however, with medical marvels such as chemotherapy, intubation and ventilator support, feeding tubes, antibiotics, and vasopressors, life is being extended beyond its previous natural endpoint. In addition to focusing on keeping people alive, the medical community must also ask the uncomfortable questions about their role in helping patients die with dignity and respect.

### **Purpose**

The purpose of this scholarly inquiry paper is to explore the patient-experience surrounding physician-assisted suicide, particularly with regard to the ethical principle of autonomy. A large body of research has been performed on the moral dilemma nurses and healthcare providers face surrounding PAS, focusing on the healthcare professionals rather than the patient. As PAS continues to be introduced to state legislatures across the United States, misinformation and moral outrage also eclipse the patient perspective. In keeping with the practice of medicine, the patient’s end-of-life wishes and experience should drive the discussion surrounding physician-assisted suicide.

### **Scholarly Inquiry Question**

To guide the literature search for this topic, a clinical question was developed using the Population (P), Intervention (I), Control (C), Outcome (O), PICO, method. The clinical question is as follows: Do patients who seek end-of-life care by means of PAS have a greater sense of

control of their dying process versus those patients who do not or are not allowed to participate in PAS?

### **Method Used for Inquiry**

A traditional, or narrative, literature review was the method used to guide this inquiry; this type of review is used to synthesize and summarize a large volume of data on a specific topic (Cronin, Ryan, & Coughlan, 2008). The purpose of a traditional literature review is to not only provide a thorough background on a specific subject but also reveal areas requiring further research (2008). The steps to writing this type of literature review include selecting a review topic, searching the literature, analyzing and synthesizing the literature, and writing the review (2008). Following the completion of this paper, the interpretations of the literature review will provide further recommendations and will be presented to faculty at Winona State University in April, 2020.

### **Literature Review**

#### **Database Search**

A literature search was conducted through CINAHL/Ebsco World Host and The Cochrane Library (Table 1) using the following key words: Patient experience, physician-assisted suicide, quality of life, and quality of death. Data was limited to publication between the years 2000 and 2019. Excluded sources include those articles that were not in English language, duplicates of previously found articles, or articles in which physician-assisted suicide or euthanasia occurred in the event of diseases which were not terminal (i.e. Alzheimer's disease, dementia, or chronic mental illness). Articles from the perspective of healthcare professionals such as nurses or healthcare providers were excluded, and those from the perspective of the patient or the patient's proxies were included. Articles from proxies were included only if the

researcher was examining the patient's dying experience from the perspective of the patient proxies. Excluded were articles with low levels of evidence, specifically those based on expert opinion or discussions of the legal and ethical dilemmas facing providers participating in physician-assisted suicide as they are not relevant to the patient experience of PAS. Of the remaining articles, 37 were reviewed, and 13 were included due to their quality, relativity to the patient perspective on the use of physician assisted suicide, and diversity of data from the United States and countries in Europe.

### **Review of the Literature**

Thirteen articles were reviewed, in-depth (Table 2), and the information has been organized by themes. Each heading within this section will reference a theme, and the evidence from the included studies will be synthesized accordingly. Of note, the data is limited by two factors: 1) Due to the nature of the topic, the patient is unable to be interviewed about his or her experience posthumously and 2) Studying physician-assisted suicide is restricted to the few countries and states where it has been made legal; thus, the evidence is limited to specific cultures, religions, and geographic areas. The results may not be generalizable.

Some of the articles from countries where both PAS and euthanasia are legal do not differentiate between the two practices. In addition, participants in the study performed by Pierson et al. have a terminal diagnosis of AIDS. This study was published in 2002; medical advancements over the last eighteen years have remarkably improved outcomes for patients living with HIV/AIDS. Though dying of AIDS is unlikely in 2020, the results of the patients' dying experience in this qualitative study are still relevant to this paper.

### **Themes from the Literature**

#### **Patient motivations for participating in physician-assisted suicide.**

*Physical suffering.*

Avoiding physical suffering was a frequent motivation for patients with terminal illnesses who desired a hastened death. This section will be divided by disease process.

Patients with neurodegenerative diseases such as amyotrophic lateral sclerosis (ALS) and Huntington's disease primarily experience physical suffering related to loss of voluntary and involuntary muscle functioning. Patients in the early stages of Huntington's disease reported witnessing close relatives die slowly, which caused them to view participating in PAS for themselves as an imperfect but necessary solution until a cure is found. They describe the process as being "locked in," existing but unable to speak, eat, or do anything for one's self (Regan et al., 2017). "They have in no way been able to sustain her quality of life. And, as a result I don't see it as a triumph that she is still breathing" (Regan et al, p. 711, 2017).

Maessen et al. found that the most common physical reason (70%) for ALS patients to participate in PAS was a fear of choking. Pain was not cited as a reason for hastening death (2009); however, in a study measuring patient interest in PAS as reported to the caregiver, Ganzini, Silveira, and Johnston found that choking episodes and severity were not significant motivations, rather severe insomnia, frequent pain, and discomfort other than pain as statistically significant motivations for discussing PAS (2002). A limitation to the study by Ganzini et al. is the accuracy of the caregivers' reports of the patients' interest (2002); thus, choking in patients with ALS is still considered a physical motivation for participating in PAS.

Patients with a terminal cancer diagnosis describe fear of future pain and experiences with present or past pain as motivations for participating in aid-in-dying. During a study exploring the attitudes of dying cancer patients toward euthanasia or PAS, Johansen, Hølen, Kaasa, Loge, and Materstvedt found that patients had a significant fear of pain, and previous

exposure to pain caused a fear of future pain (2005). “It is the pain that I am most afraid of... My only hope is to have no pain” (Johansen, Hølen, Kaasa, Loge, & Materstvedt, p. 456, 2005). A longitudinal study of patients with advanced lung and gastrointestinal cancers found that 89% of participants contemplated hastening death through PAS or euthanasia as a future exit plan based on fears of experiencing severe pain during the final dying phase (Nissim et al., 2009).

When pain is severe, it consumes all of the attention of the patient (Johansen et al., 2005), leaving the patient unable to focus on anything but the pain (Nissim et al., 2009). A desire for PAS would surface, as death is preferable to a prolonged state of severe pain (Johansen et al., 2005; Nissim et al., 2009). However, when the pain was alleviated, the motivation for a hastened death would diminish (Johansen et al., 2005). Thus, desire to participate in PAS could fluctuate with the patient’s pain level. “[When the pain is alleviated] then I want to live a little bit longer” (Johansen et al., p. 457, 2005). Severe pain also triggered the patients’ feelings of despair (Nissim et al., 2009; Johansen et al., 2005).

Only one study in this review of literature focused on patients dying from AIDS, a qualitative study exploring patients’ perceptions of a good death. Severity of pain was correlated to the degree of the patient experiencing a “bad” death, and absence of pain was the most commonly mentioned factor identifying a “good” death. None of the patients were indifferent to the domain of symptom control. Several of the participants mentioned physician-assisted suicide as a method of escaping unbearable pain and ensuring a “good death” (Pierson, Curtis, & Patrick, 2002). “There’s no point in keeping people in pain, or so doped up that they’re not aware of anything, because that’s the only way you can keep them from being in pain, you know, alive, just to be alive. That’s not living” (Pierson et al., p. 594, 2002).

Dees et al. performed a systematic review to create an overview of descriptions of unbearable suffering in the context of a request for euthanasia or physician-assisted suicide. The 55 articles included in the review showed that physical suffering from the patient's perspective included pain, weakness, and functional impairment as motivations to request aid-in-dying. These experiences are inevitable during the terminal phase of an illness, and the irreversible disintegration seemed to be the start of openly considering death as preferable to life (2010). These motivations are consistent with the findings from Georges et al. who performed a retrospective study into the history of the wishes of terminally-ill patients for aid-in-dying by interviewing the relatives closest to the patient. The two most commonly cited physical reasons were pain (42%) and dyspnea (26%) (2007).

Physical suffering in the terminal phase of illness is unavoidable, regardless of illness. This evidence reveals that physical suffering is a key motivator for patients to participate in physician-assisted suicide. While aggressive symptom control and palliative care are strategies to relieve patients' distress, suffering in the face of death could be prolonged and persist until the end of the patient's life.

### ***Emotional suffering.***

In addition to physical suffering, emotional suffering during the terminal phase of illness is complex, with multiple layers including anticipating death, becoming dependent on others, and feelings of hopelessness or despair. This section will also be separated according to disease process when applicable.

Ganzini, Silveira, and Johnston performed two studies in Oregon on the same patients with ALS, both studies measuring patients' motivations for aid-in-dying. The second study was performed posthumously, asking patients' relatives if the patient expressed interest in physician-assisted

suicide in the last month of illness. The second study found that 67% of patients who discussed wanting PAS in the last month of life had hopelessness scores of >9 on the Beck Hopelessness Scale during the first study (Figure 1). Only 12% of patients who did not report an interest in PAS in the last month of life had elevated hopelessness scores. Major depressive disorder did not predict a desire to participate in PAS (2002).

Figure 1. Beck Hopelessness Scale

Item	Question	True	False
1	I look forward to the future with hope and enthusiasm		
2	I might as well give up because I can't make things better for myself		
3	When things are going badly, I am helped by knowing they can't stay that way forever		
4	I can't imagine what my life would be in 10 years.		
5	I have enough time to accomplish the things I most want to do		
6	In the future, I expect to succeed in what concerns me most		
7	My future seems dark to me		
8	I expect to get more of the good things in life than the average person.		
9	I just don't get the breaks, and there's no reason to believe I will in the future		
10	My past experiences have prepared me well for my future		
11	All I can see ahead of me is unpleasantness rather than pleasantness		
12	I don't expect to get what I really want		
13	When I look ahead to the future, I expect I will be happier than I am now		
14	Things just won't work out the way I want them to		
15	I have great faith in the future		
16	I never get what I want so it's foolish to want anything.		
17	It is very unlikely that I will get any real satisfaction in the future		
18	The future seems vague and uncertain to me.		
19	I can look forward to more good times than bad times		
20	There's no use in really trying to get something I want because I probably won't get it		

Figure 1. A 20 point questionnaire to assess hopelessness and suicidality in vulnerable populations. Adapted from “Risk to self in psychiatry: Do suicide/self-harm scales help clinicians?” by A. Mitchell, 2008, a lecture conducted at the Annual General Meeting of the Royal College of Physicians, London.

Several years later in the Netherlands, Maessen et al. had similar results when researching ALS patients. Hopelessness was strongly associated with the decision to seek PAS or euthanasia ( $p = 0.04$ ), and no significant association existed between a diagnosis of depression or depressive symptoms and euthanasia or PAS (2009). This suggests that hopelessness, and not depression, is a motivator and predictor of patients desiring to participate in physician-assisted suicide during the final stages of ALS.

Other significant motivators to participate in PAS found by Maessen et al. included that the patient knew there was no chance of improvement, loss of dignity, and feeling dependent on others, though feeling to be a burden on family or friends was not reported frequently (2009). Similarly, patients with Huntington's disease also contributed emotional suffering as a reason for PAS, describing as a loss of self, explaining a fear of entering a persistent vegetative state, losing not only complete physical functioning, but also one's role, personality, meaning, and community (Regan et al., 2017).

Nissim et al. found that all advanced cancer patients in the study experienced despair and contemplated death as an escape. Many believed that hastening death was the only action that would relieve strong feelings of despair, helplessness, and panic (2009). Future worries such as pain, eventually losing hope, and potentially entering a persistent vegetative state influenced cancer patients' wishes for PAS (Johansen et al., 2005). Patients feel trapped by their disease state, "I don't want to wake up and face this... honestly I just pray that I would just die in my sleep" (Nissim et al., p. 168, 2009).

When researching the relatives' perspective on patients who died using euthanasia or PAS, Georges et al. found loss of dignity to be the most expressed reason for patients to request aid in dying (60%) (2007). Activities of daily living (ADL) dependency is also a significant

motivator, along with the feelings of being a burden and hopelessness (Georges et al., 2007; Dees et al., 2010). Dees et al. details the feelings of existential loss: independence, occupational role, sexual desire, and personal status as significant emotional burdens driving patients to participate in PAS (2010).

While many end-of-life options are focused on controlling physical suffering, these studies reveal the immense emotional suffering experienced by individuals with terminal illnesses. Physical suffering and emotional suffering are also linked; pain can influence feelings of despair and hopelessness (Johansen et al., 2005; Nissim et al., 2009). Emotional suffering in many forms is a significant motivator for patients to participate in physician-assisted suicide.

#### ***Economic Motivations in the United States.***

The United States does not have a state-financed healthcare option for all residents, potentially leading patients to desire physician-assisted suicide to avoid accumulating additional illness-related bills. Emanuel, Fairclough, Slutsman, and Emanuel explored the economic burden of terminal illness in the United States (2000). This study found a strong association between economic burden and patients with substantial needs in four areas: transportation, nursing care, homemaking, and personal care. Patients with substantial care needs were significantly more likely to report that their care was a moderate or great economic hardship for their family compared to patients with low care needs. In families of patients with substantial care needs, 10% of the household income was spent on healthcare costs other than their insurance premiums, and they or their family had to sell assets, take out a loan, or get an additional job to pay for the patient's healthcare. 14.9% of these patients had thought about or expressed a desire for PAS compared with 8.2% of patients with low care needs (Emanuel, Fairclough, Slutsman, & Emanuel, 2000).

### **Quality of Life and Quality of Death.**

In harmony with avoiding suffering as a motivation to participate in PAS, physician-assisted suicide could be an end-of-life option that can influence the patient's quality end-of-life and quality of death. 92% of relatives of patients who died using euthanasia or physician-assisted suicide in the Netherlands believed that assisted dying had increased the patient's quality end-of-life, and 100% of relatives reported that the patients were ready to die (Georges et al., 2007).

### ***Quality of Life.***

Access to PAS is instrumental in promoting quality of life in patients with terminal illness. Knowing that physician-assisted suicide is an option allows patients with terminal illness to tolerate the present suffering (Nissim et al., 2009).

As a disease progresses, patient's quality of life changes and compels many to desire physician-assisted suicide. Dees et al. gives the example of a formerly athletic and energetic 62-year-old woman who requested PAS after being diagnosed with metastatic ovarian cancer and was facing physical frailty and regular hospitalizations (2010). Severe pain also significantly effects patients' quality of life in the terminal phase of illness (Dees et al., 2010; Johansen et al., 2005; Nissim et al., 2009; Pierson et al., 2002). Patients who are refused access to PAS state that they continue to desire death because of a poor quality of life, such as being physically unable to do activities of enjoyment but are limited to sitting around and watching television (Pasma et al., 2013).

Patients can anticipate life changes due to the disease, even if in earlier stages of the disease process. These life changes can include physical changes including pain, cosmetic changes, side effects of medications; emotional changes due to the distress of the disease burden and treatment options; and overall a different perspective of their life after being diagnosed with such an illness. Patients with Huntington's disease report knowing that they would not be able to maintain their quality of life due to the impending disease progression, which caused them to embrace assisted dying when the time came (Regan et al., 2017). These same patients reported that their diagnosis also forced them to be intentional with their time and actions prior to their death (2017).

### ***Quality of Death.***

Physician-assisted suicide can play a lead role in creating better quality of death. Participants with advanced cancer perceived PAS as an option to avoid painful and undignified lingering, which would in turn cause their family to linger with them (Nissim et al., 2009). "Suicide is a way of exiting. I don't want to talk about that because I like life, and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don't want to stay" (Nissim et al., p. 168, 2009). Patients with AIDS experienced similar feelings, concerned that dying would inevitably include a long, drawn out process; physician-assisted suicide would allow them to avoid that process, creating a 'good' death experience (Pierson et al., 2002). This belief is echoed in patients with Huntington's disease, believing that assisted dying embodies an act of kindness (Regan et al., 2017). "Nan was just a vegetable by the end of it, bless her, she was literally just a case. There was nothing left inside. We were keeping her alive, but what for? She wasn't getting any joy out of life" (Regan et al., p. 711, 2017). Thirty-three percent of

patients in a study by Nissim et al. believed that physician-assisted suicide and euthanasia are part of the medical community's duty to relieve suffering (2009).

In a qualitative study exploring the lived experience of patients with AIDS, the majority of participants felt as though having family members, friends, pets, and caregivers around during the dying process would be an important contributor to creating a good death (Pierson et al., 2002). For some, a reason to request euthanasia or PAS offers an opportunity to say good-bye to their loved ones while remaining conscious (Georges et al., 2007), and patients who receive a lethal prescription are more likely to have the opportunity to say goodbye than those who do not participate in PAS (Smith, Goy, Harvath, & Ganzani, 2011). "I think dying alone, not having anyone there to help make that crossing-over bearable, that would probably be the worst" (Pierson et al., p. 591, 2002). This includes some desiring to have a religious figure present to perform last rites (Pierson et al., 2002), though patients who participate in PAS are less likely to engage in a spiritual ceremony than those who do not pursue PAS (Smith et al., 2011).

Pierson et al. found that patients also preferred to be in their own home, and this location was correlated with a desire to have their loved ones present (2002). Patients with ALS who participated in euthanasia or PAS most often died at home and with less anxiety, while patients who were receiving sedatives were more likely to die at a nursing home or hospice (Maessen et al., 2009). In a systematic review of literature by Gamondi, Fusi-Schmidhauser, Oriani, Payne, and Preston, two sub-themes emerged when anticipating the final farewell: Patients who engaged in assisted dying were able to organize end-of-life rituals, and patients were allowed to choose the location of death (2019). Family members rated the quality of the moment of death as higher in patients who engaged in PAS compared to those who did not (Smith et al., 2011).

Physician-assisted suicide promotes dying with dignity, and patients view PAS as more dignified than suicide (Nissim et al., 2009). In patients who did use euthanasia or PAS, dignity in dying contributed to the patient having a better death experience, with 93% of relatives reporting that their loved ones died peacefully (Georges et al., 2007). Physician-assisted suicide can significantly influence the quality of life and death in patients with terminal illnesses.

**Patient-physician communication about end-of-life wishes.**

Healthcare providers licensed to prescribe lethal prescriptions are the gateway to participating in physician-assisted suicide. Therefore, open communication and building a positive relationship between patient and HCPs is central to ensuring patient input about their end-of-life wishes. Having a good relationship with one's HCP increases the patient's feeling that they are receiving quality medical care (Pierson et al., 2002). In addition, the HCP is responsible for ensuring patient understanding of every available end-of-life option, and miscommunications could result in missed opportunities to relieve patient suffering.

***Timing.***

As explained in the introduction, there is a complex process that takes place between a patient's request for physician-assisted suicide and receiving the prescription. Understanding the patient's wishes as early as possible will help to guide the provider and ensure the patient receives care in a timely manner. Many patients will disclose their wish for a hastened death to their loved ones earlier than to their healthcare provider. Ganzini et al. found that ALS patients made explicit requests for PAS to their HCPs in the last month of life but had discussed considering PAS as an end-of-life option to their caregivers in previous months (2002). A study by Georges et al. reports that 79% of patients expressed their wishes about end-of-life decisions to their partners (69%) or children (38%) before they became terminally ill, but only 33% of

patients spoke to their physician about their wishes prior to becoming terminally-ill (2007). Most explicit requests were made within three months of the patient's death, with 29% of requests being made in the last week of life (Georges et al., 2007). A study by Pasman et al. revealed that patients who make a request for PAS before reaching the terminal phase of illness will be refused, and many of these patients will then no longer discuss their desire for PAS with their healthcare provider, despite an ongoing wish to die (2013).

Patients in the early stages of Huntington's disease worried that they would be physically unable to participate in PAS upon reaching the point in the dying process when they would desire it. This caused them to wonder when they should formally document their wishes (Regan et al., 2017). "If I am declining gradually, am I losing the ability to make those decisions? So do I need to make that decision long before I am symptomatic in order to ensure that I don't miss my opportunity? (Regan et al., p. 712, 2017).

### ***Miscommunications.***

Like any relationship, good communication creates a positive outcome; conversely, miscommunications add stress and contribute to negative outcomes. Miscommunications between patient and healthcare providers about end-of-life wishes are common, often leading to unintended consequences.

Under-communicating is a form of miscommunicating and leads to a lack of knowledge. In a study by Silveira, DiPiero, Gerrity, and Feudtner interviewing 728 outpatients at various outpatient clinics in Oregon, only two-thirds of patients accurately identified that competent patients in Oregon can legally refuse life-saving or life-sustaining treatment (2000). Knowledge of end-of-life options was found to be associated with a college education and being Caucasian (Silveira, DiPiero, Gerrity, & Feudtner, 2000) Experiencing death or illness of a loved one was a

statistically significant association with better knowledge of end-of-life options. One-third of participants had authored an advanced directive, but authoring an advanced directive was not a statistically significant association (Silveira et al., 2000). In this study, patients' knowledge was coming from sources other than their healthcare provider or was simply absent.

Miscommunications are common when an explicit request for aid-in-dying is made by the patient, and the healthcare provider's response can negatively influence the patient's experience. Georges et al. found that 74% of patients found their HCP's reaction to their request for euthanasia or PAS to be satisfactory, because they felt like their physician had insight (2007). However, 16% of patients were disappointed in the HCP's response to their request, and 10% of patients were undecided due to the healthcare provider's ambivalence (Georges et al., 2007). Pasma et al. explored the patient experience when requests for PAS were refused, with the reason for refusing being that the patient did not meet the criteria to participate in PAS or euthanasia (2013). These patients reported still wanting aid-in-dying, even if it was not possible at that moment; they might not bring it up again if they believe that aid-in-dying was not possible for their condition or if the provider's response appeared irrevocable (Pasma et al., 2013). "I've told him several times, and once he said: 'You mustn't keep talking to me about euthanasia, because you know what I can do and what I can't do, so forget about it'" (Pasma et al, p. 316, 2013). Several of the HCPs in this study were unaware that their patients still wished to die, and some even admitted to purposefully not bringing up the subject of aid-in-dying with the hope that the patient would not bring it up either (Pasma et al., 2013). No appointments were made to evaluate the patient's situation after the refusal, despite the possibility of the patient's condition changing to meet the PAS criteria in the future (Pasma et al., 2013).

A systematic review by Dees et al. found that the factors motivating patients to participate in euthanasia or physician-assisted suicide varied between the patient and the physician perspective, with little overlap. The patients reported that their reasons for wanting to die included “pain, weakness, functional impairment, dependency, being a burden, hopelessness, indignity, intellectual deterioration, loss of oneself, loss of autonomy, and being tired of life” (Dees et al., p. 342, 2009). The HCPs pointed to only general weakness, loss of dignity, and pain as patient motivations for PAS (Dees et al., 2009). Healthcare providers may lack a clear understanding of the patient’s desire for PAS.

***Stigma of talking about death.***

Patients with advanced cancer report difficulties in discussing their impending death, noting that family and friends avoided the topic (Nissim et al., 2009). Similarly, patients with Huntington’s disease reported little communication with their loved ones because of a cultural taboo of death (Regan et al., 2017). This discomfort can even spread to conversations with their healthcare providers, “It’s the same with family and friends as well as medical professionals. It’s kind of like people wanting to talk to you about it enough so that you feel heard, but not wishing to distress you by bringing it up at times when it feels uncomfortable” (Regan et al., p. 713, 2017). These participants felt as though they were left to manage their disease on their own, but the healthcare provider should be the one to guide the conversation about death (Regan et al., 2017).

***Good communication.***

Patients dying from AIDS felt as though they had a good relationship with their HCP based on feeling like they were treated as a whole person and receiving quality care (Pierson et al., 2002). According to their relatives, 74% of patients who died by euthanasia or PAS in the

Netherlands were satisfied by how their HCP handled their request for assisted dying (Georges et al., 2007).

### **Patient autonomy.**

Having access to PAS allows patients to maintain autonomy and a feeling of control until the very end of their life (Nissim et al., 2009). Smith et al. found that the patient having control of his or her surroundings contributed to a better quality of dying (2011). A desire to control one's own death was the only psychological motivation for euthanasia or PAS that was shared by relatives, patients, and healthcare providers (Dees et al., 2010). This includes being involved in treatment decisions and having the option to cease treatment whenever the patient desires (Pierson et al., 2002). Patients with Huntington's disease held the central belief that an individual has the right to autonomy, and assisted dying is a way of exercising this right (Regan et al., 2017). A study by Gamondi et al. found that when a loved one's desire for assisted dying was not fulfilled, family members felt as though the patient's right to choose PAS was disrespected (2019).

### **Subjectivity.**

Suffering is subjective (Dees et al., 2010) as are the patients' decisions on how and when to participate in the dying process. "By having the choice to prolong or end suffering when there is no cure for certain illnesses, we as adult human beings should have the right to decide how much pain and suffering that we can endure. Only we know that, not the doctors or the state or the government. We should have that choice" (Pierson et al., p. 593, 2002). Patients in the early stages of Huntington's know that the suffering may eventually be too much, but each patient should be able choose that point for themselves (Regan et al., 2017).

### **Family experience.**

As mentioned previously, having one's community present throughout the dying process is important to many (Pierson et al., 2002). A systematic review of literature by Gamondi et al. reveals that family members who are involved in their loved one's dying process have close bonds with the patient (2019). Playing a role in the patient's end-of-life care brings comfort to family members and contributes to family members feeling at peace with the patient's decision (Gamondi, Fusi-Schmidhauser, Oriani, Payne, & Preston, 2019). Smith et al. found no statistically significant differences in connectedness between patients and family in those who participated in PAS versus patients who did not (2011).

Witnessing the patient's suffering worsen was a key motivator for families to embrace the patient's request for assisted dying (Gamondi et al., 2019). Some patients dying from AIDS believe that a 'good' death would include their families' acceptance that they were going to die (Pierson et al., 2002). Patients with Huntington's disease admit that they would delay dying if their families were not in agreement (Regan et al., 2017). Gamondi et al. found that few families experienced regret about the patient's cause of death when the patient did participate in euthanasia or PAS, though some family members wished the decision had been postponed (2019).

A 'good' death includes having a sense of resolution, having said good-bye, time to prepare, and peace with self and others (Pierson et al., 2002). This preparedness represented positive components for the family's bereavement and contributed to higher quality preparedness and symptom control ratings than those who did not die from assisted dying (Gamondi et al., 2019).

### **Summary of themes.**

As previously stated, significant gaps exist in the literature due to the nature of the topic. Physician-assisted suicide is limited to the few countries and states where it has been made legal; thus, the ability to openly study this topic is constrained. The results from the abovementioned studies are not necessarily generalizable across cultures, religions, or healthcare delivery systems. Additionally, as noted in the review of literature, suffering at the end-of-life is subjective, and therefore subject to subject variation cannot be measured. Within subject variation also cannot be measured, since the subjects are no longer alive following the intervention. Due to these limitations, studies about physician-assisted suicide are more likely to be qualitative versus quantitative, as with the research included in this paper.

For patients in the terminal phase of illness, end-of-life suffering is a personal, subjective experience. Social stigma surrounds the topic of discussing one's suffering and death; knowing this, the patient's healthcare provider bears the responsibility of creating an open conversation about all end-of-life options with the patient. Physical, emotional, and economic factors motivate terminally-ill patients to desire to participate in physician-assisted suicide, and the motivations can vary by diagnosis. Physician-assisted suicide upholds the ethical principle of autonomy by allowing the patient to choose the timing, location, and context of their own death. Through avoiding suffering related to the dying process such as entering a persistent vegetative state, painful lingering, or loss of dignity, PAS contributes to a better quality of life and quality of death. With physician-assisted suicide as an end-of-life option, patients can die on their own terms.

### **Conceptual Framework**

When discussing autonomy in *Principles of Biomedical Ethics*, Beauchamp and Childress report a misplaced criticism of respect for autonomy taking precedence over all moral

considerations (2001); others view autonomy as a cardinal moral value that should guide both politics and healthcare practices (Mackenzie, 2008). Patient autonomy is central to the conversation about access to physician-assisted suicide as an end-of-life option, and relational autonomy theory provides a framework for the discussion of the patient experience with PAS in this paper. In this section, “relational autonomy theory” will be used interchangeably with “relational autonomy.”

Relational autonomy theory is a rooted feminist theory, “motivated by feminist concerns about the impacts of oppression and social injustice on women’s (and men’s) opportunities to lead self-governing lives” (Mackenzie, 2015, p.278), moving beyond the concept of “self-governance” found in other theories of autonomy toward analyzing the social, political, and relational aspects of autonomy. The goal of relational autonomy theory is to build social relationships and institutions that encourage individuals to lead self-governing lives (Mackenzie, 2015). Four key principles of relational autonomy theory and how it relates to the patient experience surrounding physician-assisted suicide will be explained in the subsequent paragraphs.

First, relational autonomy theory states that a person must have a series of self-reflective skills in order to achieve autonomy competence, “self-control and motivational decisiveness; emotional skills, such as the capacity to interpret and regulate one’s emotions; imaginative skills, required for understanding the implications of one’s decisions and envisaging alternative possible courses of action; and capacities to reflect critically on social norms and values” (Mackenzie, 2015, p. 286). As explained in the review of literature, in seeking autonomy when considering physician assisted suicide, the terminally ill patient has been reflective on his or her

physical and emotional suffering, other courses of action such as simply withdrawing cares, and social values, for example, avoiding the subject of their own death due to social stigma.

Secondly, relational autonomy theory is particularly relevant to medicine as it acknowledges a person's vulnerability and dependence, in contrast to the popular belief that autonomy equals self-sufficiency (Mackenzie, 2015). This is especially true during the terminal phase of illness, and the patient's healthcare provider must recognize the patient's vulnerable state. As mentioned in the previous section, the provider's role in promoting patient autonomy includes fostering a positive provider-patient relationship, communicating effectively about the patient's end-of-life options, and being attentive to the patient's wishes throughout the course of their disease.

Thirdly, relational autonomy identifies that autonomous decision-making is sustained through significant social relationships, and one's autonomy is not free from social influence (Mackenzie, 2015). The literature reveals patients' families embracing the patient's request for PAS after witnessing the suffering brought on by the patient's terminal stage of illness (Gamondi et al., 2019). These social relationships can also be oppressive to the patient, corroding the patient's sense of self-esteem (Mackenzie, 2015), such as patients dying from AIDS needing their families to accept their death in order for them to consider it a "good" death (Pierson et al., 2002). The patient's healthcare provider also becomes a significant social relationship in the terminal phase of illness. Regan et al. details the patients' experiences of social stigma surrounding the conversation about their death, even when talking with their HCPs (2017). Patients are especially vulnerable to the attitudes and judgments of their HCP, which can aide in restricting their autonomy (Mackenzie, 2015).

Finally, relational autonomy considers the impact of societal oppression that restricts a person's autonomy. To live an autonomous life, all people from all social groups must have access to genuine opportunities and a range of options (Mackenzie, 2015). Thus, the social distribution of autonomy must also be considered, for example, patient populations in some historically liberal U.S. states have access to physician-assisted suicide while those in other states do not. Health and social policies have the capacity to both limit and increase patient autonomy.

### **Conclusions, Implications, and Recommendations**

The purpose of this paper is to explore the patient experience with physician-assisted suicide to determine if participants in PAS have more control over their end-of-life care. This section will be organized by stating the author's conclusions based on the review of literature, ending with implications for nursing and recommendations.

#### **Conclusions**

Though limited to the states and countries where it has been legalized, physician-assisted suicide is an end-of-life option that allows patients to avoid parts of the physical and emotional suffering that accompany dying of a terminal illness such as cancer or a neurodegenerative disease. Terminal illness is life-altering, and PAS contributes to a better quality of life and quality of death by allowing the patient to die on their own terms: deciding who is present, where and when their death will take place, and ultimately ending the process of painful and undignified lingering. Suffering during the terminal phase of illness is subjective; each patient's experience will be different, and the patient is the only one who can decide when he or she no longer wishes to suffer. Healthcare providers play a lead role as a patient advocate by guiding

both the conversations surrounding the patient's end-of-life wishes, informing the patient of all available end-of-life options, and assisting the patient carry out his or her death plan.

### **Recommendations**

Further research should be performed surrounding the patient experience of physician-assisted suicide in the United States and abroad. This research will likely be limited to qualitative studies, which should delve deeper into the themes found in this paper: patient motivations for participating in PAS, the influence of the patient-HCP relationship on the patient's experience with PAS, and patient autonomy during the dying process. In addition, other terminal illnesses should be included when studying PAS such as congestive heart failure, chronic obstructive pulmonary disorder, end-stage renal disease, Parkinson's disease, or multiple sclerosis.

Healthcare providers have a responsibility to uphold the patient's autonomy. Knowing that the dying experience is subjective, HCPs must adopt the role of student and learn the patient's personal definitions of suffering and dying well. Building a trusting relationship with the patient will assist in identifying terminally ill patients who may be interested in PAS as an end-of-life option. All treatment options should be discussed frequently throughout the course of the patient's illness, and the HCP should encourage the patient to choose the end-of-life option that best matches the patient's values and desires. If the HCP does not feel confident with having EOL discussions, the HCP should either invest in continuing education about all available EOL options or refer the patient to a different provider.

In keeping with Relational Autonomy Theory and with the patient's consent, the healthcare provider should include the patient's significant social relationships when discussing end-of-life options with the patient. This will provide a framework for the patient to maintain an

ongoing dialogue with his or her community and assist the patient's loved ones in embracing the patient's EOL decision. Including these significant relationships will ultimately uphold autonomous decision making.

In the U.S., physician-assisted suicide is illegal in 41 states as of 2019 (Villeneuve, 2019). The majority of American terminally ill patients do not have access to PAS, an option that has been shown can contribute to better quality end-of-life. Without permission to use physician-assisted suicide, patients are forced to endure end-of-life processes that are often drawn out and overwhelmed with suffering; this violates the ethical principle of autonomy: the patient's right to request a specific treatment. Thus, physician-assisted suicide should be legalized in all 50 states, giving every American access to all end-of-life options.

### **Implications for Nursing**

Nurses need to thoroughly analyze their own biases regarding physician-assisted suicide, educate themselves on the latest information on the subject, and promote open discussions about physician-assisted suicide amongst their peers. An integrative literature review of American nurses' opinions toward PAS found that the majority of nurses in four of the studies supported PAS primarily due to relieving the patient's suffering, while nurses in six of the studies were against PAS primarily for religious and moral issues as well as the potential for the misuse or abuse of PAS (Pedersen & Tariman, 2017). Nurses who do not support physician-assisted suicide should not be shamed for their opinions, but this does exhibit the propensity of healthcare providers to be unsupportive of a treatment based on their own values rather than those of the patient. The nurses should support their patients whose values differ from their own by referring patient who are interested in PAS to a different nurse.

Pedersen and Tariman report that of the six studies finding nurses to be against PAS, three revealed that nurses might become supportive of PAS if they had more knowledge on the subject (2017). Educating all nurses by adding curriculum or on the job training about physician-assisted suicide could garner support from nurses previously opposed to PAS. If nurses remain unsupportive of physician-assisted suicide, particularly in states that legalize PAS, significant ethical dilemmas will be present while treating terminally ill patients.

### **Summary**

According to the literature included in this paper, suffering and dying are profoundly personal experiences. For patients with terminal illnesses such as advanced cancer and neurodegenerative diseases, physician-assisted suicide is an end-of-life option that allows the patient to avoid prolonged emotional and physical suffering, thereby contributing to a better quality end-of-life. Working with patients in this terminal phase, medical professionals such as healthcare providers and nurses have the unique role of providing end-of-life care, upholding patient autonomy, and advocating for patients to be granted access to all available end-of-life options, including the legalization of PAS in all fifty states. Though the concept of physician-assisted suicide can make some healthcare professionals uncomfortable, the legalization of PAS in several countries and U.S. states makes this issue relevant. The Hippocratic Oath reads, “Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty” (Tyson, 2001). Physician-assisted suicide brings this tension to the forefront of the conversation: When to preserve life and when to let it go? Based on the research in this paper, only the patient can answer this question.

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Appendix

REQUEST FOR MEDICATION TO END MY LIFE IN A HUMANE AND DIGNIFIED MANNER

I, \_\_\_\_\_, am an adult of sound mind.

I am suffering from \_\_\_\_\_, which my attending physician has determined is a terminal disease and which has been medically confirmed by a consulting physician.

I have been fully informed of my diagnosis, prognosis, the nature of medication to be prescribed and potential associated risks, the expected result, and the feasible alternatives, including comfort care, hospice care and pain control.

I request that my attending physician prescribe medication that will end my life in a humane and dignified manner.

INITIAL ONE:

\_\_\_\_\_ I have informed my family of my decision and taken their opinions into consideration.

\_\_\_\_\_ I have decided not to inform my family of my decision. \_\_\_\_\_ I have no family to inform of my decision.

I understand that I have the right to rescind this request at any time.

I understand the full import of this request and I expect to die when I take the medication to be prescribed. I further understand that although most deaths occur within three hours, my death may take longer and my physician has counseled me about this possibility.

I make this request voluntarily and without reservation, and I accept full moral responsibility for my actions.

Signed: \_\_\_\_\_ Dated: \_\_\_\_\_

DECLARATION OF WITNESSES

We declare that the person signing this request:

- (a) Is personally known to us or has provided proof of identity;
- (b) Signed this request in our presence;
- (c) Appears to be of sound mind and not under duress, fraud or undue influence; (d) Is not a patient for whom either of us is attending physician. \_\_\_\_\_ Witness

1/Date

\_\_\_\_\_ Witness 2/Date

NOTE: One witness shall not be a relative (by blood, marriage or adoption) of the person signing this request, shall not be entitled to any portion of the person's estate upon death and shall not own, operate or be employed at a health care facility where the person is a patient or resident. If the patient is an inpatient at a health care facility, one of the witnesses shall be an individual designated by the facility.

(Oregon Death with Dignity Act, 1994)

Table 1

*Database Search*

Date of Search	Keywords Used	Database/Source Used	# of Hits		
			Listed	Reviewed	Used
09.01.19	Patient experience	CINAHL/Ebsco	127,984		
09.01.19	Physician assisted suicide	CINAHL/Ebsco	2,897		
09.01.19	“Patient experience” AND “physician assisted suicide”	CINAHL/Ebsco	131	16	5
09.11.19	Quality of life	CINAHL/Ebsco	173,424		
09.11.19	Quality of death	CINAHL/Ebsco	14,895		
09.11.19	“quality of life” AND “quality of death” AND “physician assisted suicide”	CINAHL/Ebsco	59	15	5
09.24.19	Physician assisted suicide	The Cochrane Library	2	2	1
09.24.19	Emanuel, Ezekiel AND physician assisted suicide	Incremental search of references	16	3	1
09.24.19	Ganzani AND Silveira	Incremental search of references	1	1	1

Table 2

Literature Table

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
1	Dees, M., Vernooji-Dassen, M., Dekkers, W., & van Weel, C. (2010). Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: An integrative review. <i>Psycho-Oncology</i> , 19, 339-352. doi: 10.1002/pon.1612	To provide a systematic overview of descriptions of unbearable suffering and current views on suffering of patients in the context of a request for EAS (euthanasia or physician-assisted suicide) as suffering is a requirement of due care and difficult to assess	*Patients who request EAS *Literature from January 1, 1980- June 30, 2007 *Literature search in English, Dutch, and Flemish of the databases PubMed, Embase, Cinahl, Web of Science, Psych Info, and the Royal Dutch Medical Association  *55 articles were included *20 articles with definitions of suffering of patients, 35 empirical studies about suffering of patients with a request for EAS	*Concept analysis of an integrative review *All included literature had a description of suffering of patients with an actual request for EAS or a definition of suffering was included *Two authors independently the full text articles *Articles were categorized by who reported the patient suffering, i.e.: patients, HCPs, or family *A third and fourth researcher helped analyze the qualitative data	*Every study referred to suffering or “unbearable suffering” but no generally accepted definition *Four themes of suffering emerged: physical, psychological, existential, or spiritual, which all contributed equal numbers of motivations *Suffering in the context of dying is generated by factors undermining the quality of life *Themes in qualitative suffering: Caused by: pain, weakness, functional impairment, dependency, being a burden, hopelessness, indignity, intellectual deterioration, loss of autonomy, tired of life *Motivations for EAS differed between the patients, physicians, and family *Pt motivations: pain, Weakness, dependence on others, humiliation	*Suffering is subjective to each person *All forms of suffering are potentially unique to the death experience versus other experiences that may cause suffering *Important for HCPs to bring up the conversation of suffering with the patient, because the motivations that lead people to request EAS are complex *Research on the patient experience requesting EAS is limited to countries where it is legal; “illegal” motivations may be missing	*Individual patient perspective is the most important *Suffering involves the patient as a whole *Patients must be involved in suffering in order to meet criteria for PAS by physicians in Oregon and the Netherlands, yet it cannot really be measured *Motivations differed between the patients/ families/HCPs, but the patient’s motivations should be the most important *EAS being legal/illegal is complicating the ability to research what is best for end-of-life care	V

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
2	<p>Emanuel, E., Fairclough, D., Slutsman, J. &amp; Emanuel, L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. <i>Annals of Internal Medicine</i>, 132(6), 451-459.</p>	<p>To determine the cause of economic and other burdens in terminally ill patients and identify possible interventions</p>	<p>*Terminally ill patients (N=988) without HIV/AIDS with &lt;6mos. to live, able to sign consent, and spoke English as well as their primary caregiver (N=893)                      *Six different locations were randomly selected across the USA based on metropolitan statistical areas: Worcester, MA; St. Louis, MO; Tucson, AZ; Birmingham, AL; and Brooklyn, NY.                      One rural setting as well: Mesa County, CO.                      *Physicians in those areas were randomly selected and asked to identify patients</p>	<p>*In-person interviews of patients and their caregivers                      *Survey was developed following a lit. search, pilot study, focus groups, and expert consultation, contained 135 questions, caregiver survey contained 118 questions adapted from seven different survey instruments                      *Measured social supports, communication with HCPs, personal and spiritual meaning, care needs, EOL care plans, economic burdens, euthanasia, and PAS                      *Patient care needs ranked “low” to “high” on a four point scale</p>	<p>*Mean age: 66.5, leading cause of terminal illness: cancer (51.8%), heart disease (18%), and COPD (10.9%)                      *Pt’s with moderate or high care needs were significantly more likely than those with low care needs to report the cost of their illness was a moderate or great economic hardship (44.9% compared with 35.3%, <math>p=0.005</math>), that 10% of their household income was spent on healthcare costs other than insurance premiums (28% compared to 17%, <math>p&lt;0.001</math>), and that they had to sell assets, take out a loan or mortgage, or obtain an additional job (16.3% compared to 10.2%, <math>p=0.004</math>)                      *In patients requiring substantial assistance, 14.9% had seriously thought about or discussed PAS compared to 8.2% of patients with few care needs, <math>p=0.001</math></p>	<p>*Terminally-ill patients in the USA with substantial care needs experience significant economic and other burdens                      *Best to create interventions that help with patients’ needs but do not add cost                      *Important to take cost into consideration when treating terminally ill patients                      *HCPs need to talk with patients AND families about cost                      *Sample may be biased; physicians may have selectively referred patients                      *21% of referred patients died or became incapacitated</p>	<p>*Cost of terminal illness is more than emotional                      *Terminal illness takes a toll on the entire family, particularly the financial health of the family                      *Sad that families have to take out additional loans/mortgages or get other jobs just to pay for the care of their loved one instead of spending time with the terminally ill                      *Study takes place in the USA                      *Difficult to obtain data on this topic d/t the patients dying or being mentally unable to participate                      *With PAS being illegal in most states, is the family unduly forced to carry a heavier economic burden?</p>	<p>IV</p>

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
3	Gamondi, C., Fusi-Schmidhauser, T., Oriani, A., Payne, S., & Preston, N. (2019). Family members' experiences of assisted dying: A systematic literature review with thematic synthesis. <i>Palliative Medicine</i> , 1-15. doi: 10.1177/0269216319857630	To offer an understanding of the experiences of family members of patients who died using assisted dying in jurisdictions where it is legal	<p>*Direct family members of patients who participated in euthanasia or PAS, over the age of 18</p> <p>*Countries where assisted dying is legal: Netherlands, Canada, Switzerland, and USA (Oregon, Washington, Vermont only)</p> <p>*Articles from Jan 1992-Feb 2019</p> <p>*Databases used: Medline, Embase, CINAHL, AMED, PsychINFO</p> <p>*N=19, 11 articles were qualitative, and 8 were quantitative</p> <p>*Patients primarily had cancer or ALS</p>	<p>*Primary research. Quantitative and qualitative</p> <p>*Thematic synthesis using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocol guidelines</p> <p>*Articles screened in two phases by three reviewers</p> <p>*Quality appraised using structured checklist with higher scores indicating better quality</p> <p>*Three step process: articles were coded inductively, descriptive themes were developed, and then analytical themes were generated</p>	<p>*Family members involved in assisted dying had strong, open, positive, and supportive relationships with the pt.</p> <p>*Family members occasionally excluded members who opposed assisted dying</p> <p>*Witnessing the patient suffer motivated family members to agree with the pt's request</p> <p>*Family members who shared the values of the patient saw the decision as the patient's right</p> <p>*Positive emotions were experienced such as being at peace, accepting the patient's choice, and having felt included</p> <p>*Few experienced regret</p> <p>*Family members perceived a fast decision-making pace as being problematic</p> <p>*Some wished it had been postponed</p> <p>*Death rituals were intentional and planned</p> <p>*Family thought assisted dying contributed to the pt's QOL</p>	<p>*Families can be very involved in supporting pts interested in PAS</p> <p>*PAS could aide in promoting QOL/QOD</p> <p>*Assisted dying may challenge family value systems</p> <p>*Conversation with family members may be more open in countries where assisted dying is legal</p> <p>*Family members are important patient advocates during the dying process</p> <p>*Western countries only; other cultures/religions may have different experiences</p> <p>*Proxy perspective vs patient perspective</p>	<p>*PAS has the potential to increase QOL/QOD under the right circumstances</p> <p>*Patient suffering as a reason to participate in PAS</p> <p>*What about the family members who felt uncomfortable with assisted dying? Potentially divisive</p> <p>*Family members are potentially taking on legal risks if they are actively involved in the patient's EOL plan; legal protections should be in place for family members</p> <p>*Family members are important players in the pt death experience and should also have their needs met such as counseling services</p>	V

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
4	Ganzini, L., Silveira, M., & Johnston, W. (2002). Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. <i>Journal of Pain and Symptom Management</i> , 17(3), 312-317.	To understand more about ALS patients' interest in physician-assisted suicide throughout the terminal phase of their illness, particularly the final month of life	*Terminally ill patients with ALS *N=50 family caregivers of patients with a confirmed diagnosis of ALS from Oregon and Washington who had died between 1995-1999 *Patients cared for in the Oregon Health Sciences University neuromuscular clinic or Portland Veterans Affairs Medical Clinic or had participated in a previous study (N=38) *Convenience sample	*Descriptive *Caregivers were recruited by mail *Surveyed in person or over the phone *An interview (median of 11 months between patients' death and interview), and a survey (median of 36 months between pt death and survey) *Results from caregivers compared to pt results from previous study *Caregivers rated suffering on a 6 point scale measuring pain, suffering, anxiety, depressed mood, dyspnea, confusion, insomnia, choking episodes, difficulty communicating *Questioned about interest in PAS	*Caregiver knew patient for median of 34 years *16 (32%) explicitly discussed wanting PAS in the last month of life *Patients who requested PAS had frequent insomnia ( $p=0.003$ ), pain ( $p=0.01$ ), severe discomfort ( $p=0.03$ ), and distress at being a burden ( $p=0.02$ ) *No difference between those who did and did not want assisted suicide in the last month of life in prevalence of depression *The patient having indicated interest in assisted suicide in the previous study (OR: 11.7, 95% CI: 1.1-130.7) and a hopelessness score of >9 on the Beck Hopelessness Scale (OR: 12.5 (1.9-83.2) were predictors of pt continuing to request PAS *50% of patients initially interested in PAS had a persistent interest throughout the illness	*Patients interested in PAS in the final month of life may be identified earlier *HCPs should screen for hopelessness in patients with ALS *Interest in PAS persists over time; important to continue to reassess *Controlling pain and sleeplessness may help the pt avoid wanting assisted dying *Small sample size, convenience sample *More research before death (on patients) and after death (on those pts family) should be performed)	*Death with Dignity Act was enacted in 1997; thus only four patients were eligible for PAS *Open communication between pt and provider about EOL desires is profoundly important; should drive terminal illness management *Symptom management can drive patient emotional state *Newly legal in both states at the time of the study; what about recently?	VI

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
5	Georges, J., Onwuteaka-Philipsen, B., Muller, M., Van der Wal, G., Van der Heide, A., & Van der Maas, P. (2007). Relatives' perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: A retrospective cross-sectional interview study in the Netherlands. <i>Death Studies, 31</i> , 1-15. doi: 10.1080/07481180600985041	Gain understanding of the background and history of patient requests for EAS and the significance of EAS on the patient's EOL	<ul style="list-style-type: none"> <li>*Studying patients who used EAS to end their lives</li> <li>*Interviewed most involved relative of patient</li> <li>*Nationwide, across the Netherlands</li> <li>*N=87</li> <li>*October 2001-January 2002</li> <li>*Mean period of time between the patient death and interview: 17.6 months</li> <li>*Interviewed in their home</li> </ul>	<ul style="list-style-type: none"> <li>*Descriptive, cross sectional</li> <li>*Random sampling of 167 physicians with patients who used EAS approached patients' family members</li> <li>*Interviews were 2 hours long</li> <li>*Semi-structured interview focused on pt's illness, motivations for EAS, end of the pt's life, and the dying process</li> <li>*Multiple interviewers, trained specifically to participate in study</li> <li>*Descriptive statistical analysis</li> </ul>	<ul style="list-style-type: none"> <li>*85% had cancer, 15% had other diseases, mostly neurologic such as ALS</li> <li>*79% of pts had voiced their wishes prior to being terminally ill</li> <li>*67% of wishes directed at unbearable suffering and heavy dependence on others</li> <li>*84%: explicit requests made w/in 3 mos. of death</li> <li>*74% satisfied with how the physician dealt with the request</li> <li>*Patients &lt;68yrs were concerned about missing an important life event (<math>p=0.031</math>)</li> <li>*92% of relatives believed EAS contributed to the patient's quality of the end-of-life by avoiding further suffering (37%), respecting the pt's wish (29%), dignity would be preserved (18%), ending current suffering (16%)</li> <li>*23% thought EAS came too late, causing more pain/suffering</li> </ul>	<ul style="list-style-type: none"> <li>*Close relatives of the dying patient should be part of the care plan</li> <li>*Patients may have EOL wishes before becoming terminally ill</li> <li>*Discuss patient's personal definitions of dignity and being burdensome</li> <li>*Ask patient about possible life events that they want to attend</li> <li>*Taking time to sort through the patient's request may prolong pt suffering</li> <li>*Retrospective study, also only getting the perspective of pt's proxies, could be biased or withholding information</li> </ul>	<ul style="list-style-type: none"> <li>*Explore possible alternatives to relieve suffering and pts feeling like a burden; they may not even feel like they need PAS if their motivations are relieved</li> <li>*Proxy relations are part of the patient, when thinking about or planning the patient's dying process; must build positive relationships with relatives.</li> <li>*Illegality of PAS may be unnecessarily prolonging suffering in certain patients</li> <li>*Thinking about EAS is different than making an explicit request</li> <li>*EAS is respecting the patient's wishes and feeling in control</li> </ul>	VI

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
6	Johansen, S., Hølen, J., Kaasa, S., Loge, J., & Materstvedt, L. (2005). Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. <i>Palliative Medicine</i> , 19, 454-460.	To explore and describe attitudes and wishes for euthanasia/PAS in a group of patients with advanced cancer on a palliative unit	*Patients with advanced, terminal cancers: lung (n=2), prostate (n=5), GI (n=5), breast (n=2), head/neck (n=2), and unknown primary cancer (n=2). Total: N=18, cognitively intact *Estimated life expectancy: <9 mos. per MD *Convenience sample on the Palliative Medicine Unit, Department of Oncology and Radiotherapy, University Hospital of Trondheim, Norway *Survival from time of interview: 3 days – 9 mos.	*Qualitative *Research RN used interview guide with 8 issues + sub questions *RN did not work at the hospital *One, 45 minute face to face interview *Euthanasia/PAS defined to patients prior to interview *Interviews were recorded and transcribed *Interpreted according to grounded theory *Analyzed by pooling concepts, inter-case analysis to compare interviews, and central concepts were grouped *Two investigators reviewed and interpreted all transcripts with few divergences	*Positive attitude toward Euthanasia/PAS: Fear of future pain and/or poor quality of life; right to choose when suffering should end *Negative attitude: Religious and ethical arguments such as the wrongdoing of taking life *Possibility of wishing for euthanasia/PAS; none of the patients wished for euthanasia/PAS at the time of the interview, always future oriented *Factors influencing wishes for euthanasia/PAS: Fear of future pain, worries about future poor QOL, worries about future lack of hope *Experiences of previous pain caused fear of future pain attacks in the future *Will to live decreased with unbearable pain; wish to die disappeared with pain alleviation *Most patients expressed hope for the future, such as attending a family event	*Controlling patients' pain throughout the course of their illness may influence whether they desire euthanasia/PAS *Pain is an indicator of QOL if cancer patients *More research on the patient perspective/ experience should be performed *Only one interview that was relatively short *Validity may be limited due to the variability in survival time after the interview *Euthanasia/PAS is illegal in Norway; patients may not have answered honestly	*Cancer is very painful; much different motivation than patients with neurologic terminal illnesses such as ALS *Wishes for euthanasia/PAS fluctuate *Difficult to research the terminally ill cancer patient because there is not a universal timeline or course of disease *Whether or not PAS/Euthanasia is legal in the study's country could influence results *Hope for the future influences the decision to desire to participate in PAS; can hope be cultivated? *A wish for PAS is different than a request for PAS, could be ambivalent	VI

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
7	Maessen, M., Veldink, J.H., Onwuteaka-Philipsen, B.D., de Vries, J., van der Wal, G., & van den Berg, L. (2009). Trends and determinants of end-of-life practices in ALS in the Netherlands. <i>Neurology</i> , 73, 954-961.	To determine which factors influence end-of-life practices in patients with ALS and whether rates of this population using euthanasia or PAS are changing over time	<p>*Patients with a possible, probable, or definite diagnosis of amyotrophic lateral sclerosis (ALS)</p> <p>*University Medical Center of Utrecht, Netherlands, a national referral center for ALS patients</p> <p>*Patients who died between January 2000 – June 2005</p> <p>*Involved patient's physician (N=204) and informal caregiver (N=209) for 209 individual patients</p>	<p>*Cohort study</p> <p>*Questionnaire was sent to the patients' physician and informal caregiver</p> <p>*Physician questionnaire: need for interdisciplinary consultation, palliative care, patient depression</p> <p>*Informal caregiver questionnaire: patient's social structure, feelings, religion, depression using DSM-IV, feelings of hopelessness</p> <p>*Data was compared to the questionnaire results from a study from 1994-1998</p> <p>*Other EOL practices mentioned: withdrawing/withholding treatment</p>	<p>*35 (16.8%) patients participated in euthanasia/PAS from 2000-2005, not a significant change previous data</p> <p>*PAS/EAD patients had higher level of education (<math>p=0.03</math>), did not think religion was important (<math>p=0.04</math>)</p> <p>*No association between PAD/EAD and depression</p> <p>*No significant differences between quality of care for patients with PAS/EAD and other patients</p> <p>*Reasons reported by informal caregivers for PAS/EAD: fear of choking, no chance of improvement, loss of dignity, dependence on others, fatigue.</p> <p>Infrequently mentioned: pain, feeling like a burden</p> <p>*PAS/EAD: More likely to die at home (<math>p=0.007</math>) vs hospice /nursing home</p> <p>*All deaths considered peaceful by physician</p>	<p>*Numbers of patients participating in PAS/EAD did not increase (not a slippery slope)</p> <p>*Patients were able to be at home</p> <p>*All deaths were peaceful: important implication when HCPs are talking with patients approaching EOL</p> <p>*Euthanasia and PAS were combined; unclear how many patients participated in PAS</p> <p>*Data is post-humous and from the physician/informal caregiver, not the patient.</p>	<p>*Patient motivations for PAS seem to be consistent; perhaps pain wasn't an issue because it was ALS versus cancer or other terminal diagnoses</p> <p>*Interesting that there was not a relationship between depression and hastening death</p> <p>*Dying at home versus going into a SNF: might also be specific to ALS</p> <p>*Unable to ask the patient how his/her experience was; data is limited to patient proxies</p>	IV

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
8	<p>Nissim, R., Gagliese, L, &amp; Rodin, G. (2009). The desire for hastened death in individuals with advanced cancer: A longitudinal qualitative study. <i>Social Science and Medicine</i>, 69, 165-171. doi: 10.1016/j.socscimed.2009.04.21</p>	<p>To contribute to the understanding of the desire for hastened death (DHD) in patients with advanced cancer</p>	<p>*Patients with Stage III or IV lung or Stage IV GI cancer, &gt;18 years old, no cognitive impairment</p> <p>*Patients were recruited from a large cancer center in Toronto, Ontario, Canada</p> <p>*Patients were already participating in a quantitative study measuring DHD</p> <p>*N=27, 20 with GI and 7 with lung cancer</p>	<p>*Qualitative, longitudinal design</p> <p>*Grounded theory method</p> <p>*Baseline scale Schedule of Attitudes Toward Hastened Death</p> <p>*Semi-structured, discovery-oriented interviews</p> <p>*Most interviewed at least twice (Range: 1-6), follow-up interviews were every 2-4 months during illness stability</p> <p>*Interviews audiotaped and transcribed</p> <p>*Analyzed by a nursing doctoral student using the “hermeneutic circle,” and broken down into “meaning units”</p> <p>*Findings discussed biweekly with team members</p>	<p>*Mean age: 61</p> <p>*19 participants died during study; mean final interview timeline: 3 months before death</p> <p>Three categories:</p> <p>*DHD as a hypothetical exit plan: Common and persistent (89% pts), future plan when all else had failed, provided reassurance of autonomy until the end, enhanced ability to tolerate present, 9 patients wished PAS were legal and is morally justifiable to relieve suffering, rarely discussed with others</p> <p>*DHD as an expression of despair: Pts feel emotionally trapped in despair and hopelessness, experienced by all pts but transient, for a few days. Often triggered by pain</p> <p>*DHD as letting go: Emerged in final weeks, recognition that death is imminent, welcomed, refused treatments, reached “limit”, difficult to discuss dying with family and friends</p>	<p>*Being able to hasten death allows patients to feel in control in all stages of terminal illness, not just at the end</p> <p>*DHD is natural, not a crisis</p> <p>*HCPs need to discuss EOL options with patients, regardless of legal access to PAS</p> <p>*Controlling pts symptoms, particularly pain, could help them avoid feelings of despair/hopelessness</p> <p>*Treatments interfere with final stage of dying</p> <p>*Only one interviewer who also analyzed tapes; results could be biased</p>	<p>*Access to PAS helps patients bear current suffering, PAS being legal may enhance QOL in the present, even if pts do not participate in PAS</p> <p>*PAS being illegal prolongs suffering and limits pt autonomy</p> <p>*Nonmaleficence is potentially being violated by forcing patients to suffer who wish to hasten their death</p> <p>*Rare to have data about the patient experience in the final stage of illness</p> <p>*Not talking about death with HCPs or family/friends is a common theme</p> <p>*Talking about death options, including PAS, may give the pt “permission” to talk about EOL preferences</p>	<p>VI</p>

No.	Citation / Search Engine Used	Purpose/ Objectives	Study population/ Sample/ Setting	Study Design/ Methods/ Major Variables/ Instruments and Measures	Result(s)/ Main Findings	Implications/ critique	Themes/ Comments	Level of Evidence
9	Pasma, H., Willems, D., & Onwuteaka-Philipsen, B. (2013). What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives, and physicians. <i>Patient Education and Counseling</i> , 92, 313-318.	To obtain in-depth information from both patient and physician about the situation when EAS is refused	<p>*Patients who had been refused EAS or a relative of a patient who had been refused and died prior to study</p> <p>*N = 12, 3 of these were relatives of a patient who had died after being refused, interviewed in their home</p> <p>*10 people consented to their physician being interviewed (N=11; one patient had two physicians), interviewed in their office</p> <p>*EAS refused &gt;6mo prior to interview</p> <p>*Netherlands, Dec. 2005-Sept 2007</p>	<p>*Qualitative, cohort study, explorative</p> <p>*Random sampling from an advanced directive database received a questionnaire asking if the patient (or relative of a decedent) had been refused EAS in the last 3 years</p> <p>*Single interview, patient: 60-120 min., MD: 30-60 min</p> <p>*Topic list: Reason for refusal, physician-patient communication, situation after refusal; physician-specific: attitude toward EAS</p> <p>*All interviews recorded and transcribed, used open coding, organized using inductive coding; two researchers were involved in coding</p>	<p>*None of the pts were in disease terminal phase</p> <p>*All MDs had &gt;5 years of experience, most had performed EAS</p> <p>*MDs all denied request because lawful criteria had not been met; 6/11 had doubts that the pt's suffering was unbearable, 5/11 thought there were treatment alternatives, 3/11, thought pt was not sincere because the pt only mentioned it once</p> <p>*All 9 pts and 3 relatives: wish to die remained after being denied, even after alt. treatments; most thought no longer an option after being refused</p> <p>*None decided to switch physicians after being refused</p> <p>*Several cases, the MD had a different perspective than the pt about patient's wishes</p>	<p>*HCPs must follow legal criteria before approving EAS (+PAS)</p> <p>*Must keep the conversation open and continue to discuss EOL options and patients' wishes to die</p> <p>*A pt no longer mentioning their wish to die does not mean that it does not exist</p> <p>*HCP's role to initiate conversation about EOL/death</p> <p>*Euthanasia, not PAS</p> <p>*Only one interview session</p>	<p>*Suffering is subjective and unmeasurable, yet a HCP is supposed to measure it to fulfill the legal criteria? This seems unfair to both patients and physicians.</p> <p>*Mis-communications between pts and MD about EOL care are common and can have serious outcomes</p> <p>*Talking about death with patients may open up conversations about specific EOL options</p>	VI

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10	<p>Pierson, C., Curtis, J., &amp; Patrick, D. (2002). A good death: A qualitative study of patients with advanced AIDS. <i>AIDS Care</i>, 14(5), 587-598. doi: 10.1080/0954012021000005416</p> <p>CINAHL/Ebsco World Host</p>	<p>To understand and determine what patients with advanced AIDS would consider a “bad” or “good” death</p>	<p>Patients diagnosed with an AIDS-defining illness and a CD4 count &lt;100cells/ml, English speaking, no diagnosis of dementia</p> <p>N = 35</p> <p>Convenience sample; recruited through advertisements at university and community clinics in the state of Washington, USA</p> <p>Sample size was decided when no new themes emerged</p>	<p>Qualitative</p> <p>Analyzed based on grounded theory</p> <p>Face to face interview in a quiet setting with only the interviewer and the patient present</p> <p>All interviews were audiotaped and transcribed, open and selective coding was used to identify themes and domains</p> <p>Two investigators independently reviewed and coded the transcripts; discrepancies were discussed, and a third investigator acted as an arbitrator if an agreement could not be reached</p>	<p>*15 domains were identified as defining a “good”/”bad” death</p> <p>*The most mentioned domain influencing a “good death” was symptom control; absence of pain was the most stated concern, and degree of pain correlated with a death being labeled as “bad”</p> <p>*The second domain was “quality of life,” specifically avoiding a prolonged dying experience, fear of becoming a “vegetable” or living on machines</p> <p>*PAS was the tenth most common domain contributing to a good death, with several patients stating that PAS would ensure the “good” death that they desired and escape unbearable pain</p>	<p>*Important to discuss the patient’s end-of-life perspectives, philosophies, and wishes with their provider as each patient perspective is different</p> <p>*PAS may play an important role in creating a good quality death</p> <p>*Interview lacked structure by only asking two open-ended questions</p> <p>*Patients were only interviewed once</p> <p>*Unclear which stage of the dying process each patient was in</p>	<p>*The death experience is subjective; each patient may have different priorities</p> <p>*The provider plays an important role in drawing out the patient’s wishes, particularly discussing patient’s fears and concerns</p> <p>*Patient perspective could change, depending on the stage of death</p> <p>*Nice that the interview focused on practical details</p>	VI

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11	Regan, L, Preston, N., Eccles, F., & Simpson, J. (2017). The views of adults with Huntington's disease on assisted dying: A qualitative exploration. <i>Palliative Medicine</i> , 32(4), 708-715. doi: 10.1177/0269216317741850  Cinahl/Ebsco	To explore the perspective of people who live with the inevitability of developing Huntington's disease, on assisted dying	*People who had a diagnosis of Huntington's disease or tested positive for the mutant gene  *N=7; 5 women, 2 men  *Median age: 35 years, pre-symptomatic or in the early stage of the disease  *Great Britain	*Qualitative, exploratory research *Individual semi-structured interviews following an interview schedule *Recruited via advertisements on social media/charity events *Single interview, median length: 47 minutes. 5 via telephone and 2 in-person interviews *Interviews were recorded and transcribed, then analyzed in five steps: familiarizing self with data, generating initial codes, searching for themes, reviewing themes, defining themes	Four identified themes: 1) Autonomy: Assisted dying as a way to take control as well as an act of kindness. A point would be reached when life would no longer be meaningful, each person should choose that point for themselves 2) Huntington's disease emphasizes death: Suffering was more about loss of self than pain; many witnessed their relatives die from Huntington's, which influenced views on PAS 3) Dilemmas in decision-making: No cure for Huntington's; PAS is an imperfect solution. Might be too physically/ cognitively impaired to participate in PAS. Illegal in Britain, so would have to be well enough to travel 4) Absence of explicit conversation about death: Difficult topic of conversation, often avoided with family and HCPs, feel lonely	*HCPs should talk honestly about pt's thoughts and feelings r/t death from the very beginning of a diagnosis such as Huntington's; the patient is already thinking about it. Patients may otherwise not know EOL options *Patients have to be physically able to participate in PAS but might not be emotionally ready *Early in the disease process, not terminally ill; views may change as disease progresses *Patients self-selected to participate	*Patient autonomy *Many excellent patient quotes *Point at which life is not meaningful is subjective *Suffering was less about pain and more about loss of self; similar to ALS study *PAS is not a solution or a cure, just a way to ease suffering *Huntington's disease process is long and drawn out; likely will not qualify as terminally ill (<6 mo), likely would not qualify for PAS (unable to physically/mentally meet criteria once they are deemed terminally ill) *Illegal in many states, thus forcing people to have to be well-enough to relocate	VI

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12	Silveira, M., DiPiero, A., Gerrity, M., & Feudtner, C. (2000). Patients' knowledge of options at the end-of-life. <i>Journal of the American Medical Association</i> , 284(19), 2483-2488.	Estimate the percentage of outpatients who are aware of 4 areas related to end-of-life care: refusal and withdrawal of life-saving treatments, physicians-assisted suicide, active euthanasia, and the doctrine of double effect	<ul style="list-style-type: none"> <li>*Outpatients going to a routine clinic appointment</li> <li>*English-speaking, &gt;18 years old</li> <li>*N=728</li> <li>*4 primary care sites around the state of Oregon, USA: Internal Medicine Clinic at Oregon Health Sciences University, Portland; 3 family practice/internal medicine clinics in Beaverton, Sellwood, and Tigard, Oregon</li> <li>*May and June 1999</li> </ul>	<ul style="list-style-type: none"> <li>*Cross sectional survey</li> <li>*Self-administered survey, sixth-grade reading level, written by researcher and pilot-tested prior to study</li> <li>*Pts were invited to participate independently during check-in with PCP</li> <li>*Questionnaire presented vignette of a hypothetical patient who dies from cancer</li> <li>*Assesses pt experience with EOL dilemmas and experience of personal illness, writing an advanced directive, experiencing death or terminal illness of a loved one, and participating in proxy decision-making</li> </ul>	<ul style="list-style-type: none"> <li>*69% understood that competent pts can refuse treatment</li> <li>*46% identified that pts can legally withdraw care</li> <li>*23% identified PAS as an option in Oregon for competent pts with terminal illness</li> <li>*32% reported that euthanasia was illegal</li> <li>*41% recognized double effect as legal (giving pain meds knowing that it could end the patient's life)</li> <li>*64% of respondents who knew PAS was legal also thought that euthanasia was legal</li> <li>*89% thought survey was clearly worded</li> <li>*63% were confident in their responses; confidence was associated with experience of death of loved ones (<math>p&lt;0.01</math>)</li> <li>*Personal experience with illness and authoring an advanced directive were not significantly associated with better knowledge</li> </ul>	<ul style="list-style-type: none"> <li>*Misunderstanding of EOL options; important to discuss with pts, regardless of disease, particularly option to withdraw life-sustaining care and the differences between PAS and euthanasia</li> <li>*Going through EOL cares with a family member is one of the main ways to learn about it</li> <li>*Possible selection bias (survey)</li> <li>*No information on non-responders</li> <li>*Only surveyed outpatients in Oregon; results may not be generalizable</li> </ul>	<ul style="list-style-type: none"> <li>*Survey conducted after the 1997 referendum confirming the Death with Dignity Act; even with all of the public discussion surrounding PAS, pts still lacked knowledge about EOL options</li> <li>*Many options shows that EOL is a complex legal, medical, and ethical issue; important to discuss with HCPs</li> <li>*How to best educate the public about EOL options?</li> <li>*Should not be the case that people are more educated about EOL only because they witnessed their family member's experience</li> </ul>	VI

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13	Smith, K., Goy, E., Harvath, T., & Ganzani, L. (2011). Quality of death and dying in patients who request physician-assisted death. <i>Journal of Palliative Medicine, 14</i> (4), 445-450. doi: 10.1089/jpm.2010.0425  CINAHL/Ebsco World Host	To determine if there was a difference in the quality of the dying experience using the perspective of family members of patients who participated in physician-assisted suicide, requested PAS but did not receive a lethal prescription, and patients who did not participate in PAS	*Family members of terminally ill patients who participated in PAS (N=52), patients who requested but did not receive PAS (N=32), and patients who did not partake in PAS (N=63) *Convenience sample; recruited in NW Oregon from 2 medical centers, 3 hospices, the Amyotrophic Lateral Sclerosis Association of Oregon, and Compassion for Choices of Oregon *2004-2007	*Cross-sectional survey *Used a validated instrument: Quality of Death and Dying, a retrospective 33-item survey measuring the time period immediately preceding the death (7 days if responsive, 30 days if unresponsive), from the family members' perspective *Assessed symptom control, social connectedness, preparation for death, and transcendence	*PAS patients had more control over their surroundings and ability to feed self than the other two groups ( $p < 0.01$ ) and control of bladder/bowel and energy than the group who requested but did not receive PAS ( $p < 0.05$ ) *No significant items in the connectedness + transcendence domains *Those who received a prescription were more likely to say good-bye to loved ones ( $p = 0.003$ ) and less likely to engage in a spiritual ceremony ( $p = 0.002$ ) than those who did not pursue PAS *No significant differences between groups were found in family member's perception of overall quality of life in the week before death *Family members rated the quality of the moment of death higher in PAS patients ( $p < 0.001$ )	*Better quality of death in PAS patients d/t avoiding physical symptoms and being able to prepare for death *By preparing, PAS patients are able to say good-bye to loved ones *PAS allows for a potentially positive dying experience *PAS should be legal in all states, allowing the patient to have options  *Family perspective, not the patients'; unknown how the patient perceived his/her experience *Used valid instrument	*Able to avoid a "state worse than death" by avoiding physical suffering using PAS *Dying is a subjective experience; unable to truly make broad recommendations *Important to discuss every available options when a patient is terminally ill to allow the patient to choose what is best for them *PAS meets the patient's desire to control their death experience and avoid suffering	IV