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Oregon's Death with Dignity Act: Socially Constructing a Good Death

A thesis

presented to

the faculty of the Department of Sociology and Anthropology

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Master of Arts in Sociology

by

Erin Elizabeth Mauck

May 2016

Dr. Martha Copp, Chair

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Dr. Paul Kamolnick

Keywords: Death with Dignity Participation, Autonomy, Good Death, Physician-Assisted Death, Aid-in-Dying Legislation

ABSTRACT

Oregon's Death with Dignity Act: Socially Constructing a Good Death

by

Erin Elizabeth Mauck

As aid-in-dying legislation expands across the United States, this study examines the dynamics influencing participation in Oregon's Death with Dignity Act. In addition to data from secondary sources, this thesis analyzes field research data collected in Oregon, including 14 in-depth interviews with volunteers and employees of two advocacy organizations at the center of legalized physician-assisted death. Themes emerged including the conditions that motivate participation, the importance of both personal and professional autonomy, the significance of a good death, and the growth of open dialogues about end of life choices. This thesis concludes with a discussion of the impact Death with Dignity laws could have across the United States, with a specific focus on the state of Tennessee.

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DEDICATION

My research is dedicated to the memory of my mother, whose months spent in hospice made me aware of the need for end-of-life options and inspired my research. Starting early in my life, she taught me to be compassionate towards others, to help those who are less fortunate, and to enjoy the little moments the most.

Carolyn Cooper Wright

November 16, 1947 – January 12, 2013

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CHAPTER 1

INTRODUCTION

The state of Oregon first passed a law to legalize physician-assisted death in 1994, and three years later in 1997, the Death with Dignity Act was enacted (Regan and Alderson 2003). It was the first law in the United States to give terminally-ill people the option to obtain aid-in-dying from their doctor (Ganzini et al. 2009). According to Oregon's Public Health Division, physician-assisted death "allows terminally-ill adult Oregonians to obtain and use prescriptions from their physician for self-administered, lethal doses of medications" (Oregon Public Health 2016). Since 1997, a total of 1,545 prescriptions for life-ending medication have been written, of which 991 terminally-ill people have died from ingesting it (Oregon Public Health 2015).

According to the Death with Dignity Act, the Oregon Public Health Division is required to release an annual report of the previous year's statistics. The 2015 summary was released on February 4, 2016. This report includes the characteristics and end-of-life care received by the terminally ill people who have died using the Death with Dignity Act. The characteristics were similar to those from previous years: 93.1 percent were white, 43.1 percent had a bachelor's degree or higher, 90.1 percent died at home, and 99.2 percent had some form of healthcare plan. Another interesting statistic reported is that 91.5 percent of the decedents resided west of the Cascade Mountains (Oregon Public Health 2015), a region that is demographically wealthier and more urban than the rest of the state. As in previous years, the three most reported end-of-life concerns were the decreasing ability to participate in enjoyable activities (96.2%), loss of autonomy (92.4%), and loss of dignity (75.4%) (Oregon Public Health 2015).

From 1997 to 2013, the average annual increase in prescriptions written has been 12.1 percent; however, the annual percentage rise reflects only a slight increase in participation per 10,000 deaths. One cause for this is the growing population of Oregon, which is now nearly four million. From 2014 to 2015, however, the average annual increase in prescriptions written was 24.4 percent. This growth in participation over the past two years has not been explained; the increase in national media attention may have had an impact.

According to the Oregon Health Authority, a division of the Oregon Health Department, the steps a patient must take to get a prescription require full participation from a physician. After making two verbal requests which are separated by no less than 15 days, the patient must then provide a written request signed in the presence of two witnesses. At least one of the witnesses must not be related. Next, the attending physician and a consulting physician must confirm the terminal diagnosis and determine if the patient is mentally competent. A referral to a psychiatrist is only ordered if mental competency is in question. The physician is then required to discuss feasible alternatives to physician-assisted death and suggest that their patient notify their next-of-kin. It is only after all of these steps have been taken, and a second 15-day waiting period has passed, that the patient can receive their prescription (Oregon Public Health 2016).

There are two organizations in Oregon that are involved with the Death with Dignity Act: Compassion and Choices Oregon and the Death with Dignity National Center. The Death with Dignity National Center describes itself as an organization that “expands the freedom of all qualified terminally ill Americans to make their own end-of-life decisions, including how they die, and promotes Death with Dignity laws around the United States based on the groundbreaking Oregon model” (Death with Dignity 2016). Compassion and Choices Oregon is

a state chapter of the national organization, which is headquartered in Denver, Colorado. It promotes end-of-life choices and describes itself as an organization that “helps people plan for and achieve a good death and works to change attitudes, practices and policies so that everyone can access the information and options they need to have more control and comfort at the end of life” (Compassion and Choices 2016). The Death with Dignity National Center takes on a more macro-focused role with policy reform and national lobbying as its main goals. Compassion and Choices Oregon, in contrast, has a more micro-focused advocacy role with volunteers and employees who interact more with terminally ill individuals and their families.

To learn more about the Death with Dignity Act, I traveled to Portland, Oregon in July of 2015 to interview employees and volunteers of these two organizations. My trip was partially funded by a research grant from ETSU’s School of Graduate Studies. While in Oregon I conducted 14 interviews, collected secondary data from both organizations, and spent time visiting each organization’s office, including observing a volunteer meeting in Corvallis, Oregon. The main themes that emerged in my interviews were what motivates terminally-ill people, physicians, volunteers, and employees to participate; the importance of personal and professional autonomy; and the importance of a “good death” for dying people, their family, friends, and physicians.

Before I give a detailed analysis of my findings in Chapter 4, I provide context with relevant literature on legalized aid-in-dying, the importance of autonomy, the patient-physician relationship, and the Oregon law in Chapter 2. This is followed by a detailed description of my methods in Chapter 3. My thesis concludes in Chapter 5, where I discuss future possibilities of Death with Dignity laws on a local and national level.

CHAPTER 2

LITERATURE REVIEW

Physician-assisted death has been debated in the United States for decades and is considered one of the “most legally complex and culturally sensitive areas of civil rights to emerge in our time” (Park 1998, p. 277). Assisted death of any form has been a source of controversy for hundreds of years, as both an issue of morality and legality (Morrow 2013). The first major advancement for supporters in the U.S. came on October 27, 1997 when the state of Oregon passed the Death with Dignity Act, which legalized physician-assisted death (Regan and Alderson 2003). Oregon’s Death with Dignity Act allows a physician to prescribe a short-acting barbiturate to a competent, terminally-ill patient who has requested it (Ganzini et al. 2009). Since 1997, Washington and Vermont have both enacted Death with Dignity laws. There have been various arguments for and against physician-assisted death, but the public’s call for legislation is stronger than ever (Macleod, Wilson, and Malpas 2012). In a 2013 Gallup Poll, 70 percent of respondents agreed that doctors should be able to “end the patient’s life by some painless means” when the patient and family agreed with it (Eckholm 2014).

The terms “physician-assisted death,” “physician-assisted suicide,” “physician aid-in-dying,” and “voluntary active euthanasia” can be used when referring to a doctor’s involvement in a patient’s choice to end his/her own life. But what exactly is physician-assisted death? According to Regan and Alderson (2003) “it involves a terminally-ill patient obtaining a prescription from their doctor and then using the filled prescription to self-administer the lethal medicine” (p.1). For a doctor to consider this option, their patient must be expected to die from

their illness in a short period of time and their pain and distress must be substantial (Meier et al. 2003).

The “right to die” is the core principle that is debated in the issue of assisted dying. For supporters of Death with Dignity Acts, freedom of choice is the argument. Those who oppose such legislation argue that the “sanctity of life” is more important than freedom of choice (Menon 2012). There are many arguments in favor of physician-assisted death, most focusing on patient rights and the idea that humans have the right not to suffer. Three major arguments include a person’s right to self-determination, that it is the compassionate thing to do, and that it has been successful in Oregon where it is legal (Orr 2006). The right to self-determination means that even if it leads to their death, a person has the right to refuse or accept any treatment, and this should include medical assistance in bringing about death (Orr 2006).

The warning of a “slippery slope” effect with the targeting of vulnerable groups is one of the arguments against legalizing physician-assisted death. Vulnerable groups would include but are not limited to the elderly, the uninsured, people with physical disabilities, racial and ethnic minorities, and people with psychiatric illnesses (Battin et al. 2007). In her paper, Park (1998) quoted columnist Nat Hentoff who said, “When we legalize the deliberate endings of certain lives... it will eventually broaden the categories of those who can be put to death with impunity” (p. 295). However, there is no evidence in the states where assisted dying is legal that this is the case. In fact, those who have used the Death with Dignity Act to end their lives have appeared to enjoy social, educational, economic and other privileges (Battin et al. 2007).

A Social Movement

The social movement of legalizing physician-assisted death appears to be spreading across the United States and internationally. The organization Compassion and Choices, which replaced the Hemlock Society, reports that 25 states are now considering Death with Dignity laws. In addition, on February 5, 2015 the Canadian Supreme Court issued a 9-0 decision that will allow terminally ill people to obtain medication from their physician that will end their life (Sanburn 2015). On January 27, 2015, Colorado introduced Bill 1135. This act would protect a terminally-ill person's freedom to make their own end-of-life choices, which 68 percent of Colorado voters favor. State Representative Joann Ginal stated, when speaking on behalf of the terminally ill supporters, "They want to choose the what, the where, the when and particularly the with whom so that they have comfort when their journey ends" (Compassion and Choices 2015).

On September 11, 2015, lawmakers in the state of California approved a bill to legalize physician-assisted death (Compassion and Choices 2015). California governor Jerry Brown signed the law into effect in October 2015 (CNN 2015). There had been early doubts that the Catholic governor would sign the bill, and he had declined all comments until the day he signed it. In a signing statement, the governor stated "I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill" (Brown 2015). Before the law was signed into effect, an effort from the Catholic Church had been made to encourage the governor to veto it (Brown 2015).

The social construction of a good death is part of the social movement for not only legalizing physician-assisted death, but for the social acceptance of it. The term social movement refers to “the collection of individuals who organize together to achieve or prevent some social or political change” (Sandstrom, Martin, and Fine 2003). Social movements can vary in their methods, goals, and ideology; some even resort to violence to obtain the desired results. Others use more peaceful avenues such as letter writing, legislation, and persuasion (Sandstrom et al. 2003). These are the methods used by proponents of the Death with Dignity movement.

The Importance of Personal Autonomy

Health care professionals in Oregon, where physician-assisted death is legal, generally agree that the main reason patients request assistance in their death is to maintain control of themselves and end their dependence on others (Ganzini, Goy, and Dobscha 2008). In a study of people’s reasons for requesting assisted death, the desire to control their circumstances, worries about their loss of dignity, loss of independence, and quality of life were the highest ranked concerns (Ganzini et al. 2008). The loss of autonomy, or the ability to care for oneself, has been reported in 100 percent of all cases in Oregon (Morrow 2014). This clearly shows the significance of autonomy in a person’s choice to seek a physician’s assistance under Oregon’s Death with Dignity Act. The control of pain is not mentioned as a top concern at the time of request, but the consequences of pain management and future pain increase are mentioned (Ganzini et al. 2008).

One of the arguments against legalization of physician-assisted death is that with the advancements in medicine, pain is more controllable and palliative care is sufficient for the majority of terminally ill people. However, if pain is not a person’s top consideration, then this

objection has less merit. It is thus important to understand the meaning of autonomy for a terminally ill person who considers physician-assisted death (Ganzini et al. 2008). Historically, common law has failed to extend autonomy to the right to take one's own life. It has however recognized people's right to refuse treatment and thus cause their own death (Menon 2012). Advocates of physician-assisted death thus focus on the central goal of maintaining one's autonomy.

The Importance of Professional Autonomy

The word "autonomy" can be traced back to Immanuel Kant, an 18th century German philosopher, whose view of professional autonomy states, "physicians as professionals discipline themselves on the basis of conscience, and engage in medical care to their patients with the spirit of positive freedom" (quoted in Hashimoto 2006). Professional autonomy for physicians includes the nature and volume of tasks, which patients they accept, care evaluation, diagnosis, and treatment (Culbertson and Lee 1996). However, in recent years, physicians' degree of professional autonomy has been declining. Dr. Richard A. Robbins (2011) writes "Ultimately, the loss of control over their own professional lives is what irks doctors the most... decisions are often based on financial or political considerations by non-physicians or under-qualified clinicians" (p. 50).

An example of diminishing physician autonomy can be observed in Compassion and Choices Oregon's "Campaign for Access." This campaign is in response to the difficulty for terminally ill people to access the law because an alarming number of physicians, who would otherwise participate in the Death with Dignity Act, are now forbidden to do so by their employers (Compassion and Choices 2015). The prohibition of a physician to provide a legal

medical service to their patient is in direct violation of their professional autonomy (Robbins 2011).

The Physician's Role

The state of Oregon established strict legal guidelines that physicians who participate in physician-assisted death must follow. These guidelines are mandated by the state of Oregon and regulated by the Oregon Public Health Division, which publishes an annual report about the patients and physicians who participated in the Death with Dignity Act (Oregon Public Health 2015). One of the pioneers in the Death with Dignity movement, Dr. Peter Goodwin, ended his own life in 2012 after an illness left him with no treatment or cure. Dr. Goodwin, a retired physician and associate professor at Oregon Health and Science University, was the first doctor to publicly campaign for a terminally ill person's right to end their life. In his final interview he stated that the Death with Dignity Act was his most significant public legacy, one which drew fierce criticism from other Oregon doctors in the early 1980s (Saker 2012). During this interview Dr. Goodwin also revealed that in 1972 he helped a patient with terminal cancer by prescribing Nembutal, which the patient used to end his life. With this admission, he pointed out that the reason he supported and sought to legalize physician-assisted death was that doctors were already helping patients end their lives. They were just doing it in secret (Saker 2012).

One of the concerns of permitting physician-assisted death is that it will pose an ethical dilemma for the physician who is asked to assist in the death of a patient (Park 1998). This concern is based on how many interpret the Hippocratic Oath and the famous four words that people associate with it: "first, do no harm" (Tyson 2001). One of the issues that many physicians face is determining what constitutes harm. For one doctor, assisting a patient in death

would be considered the ultimate form of harm. For another doctor, *not* assisting a patient in death would be the ultimate form of harm (Sonfield 2005).

The subjective description of what harm means to physicians and patients seems to be at the heart of the physician-assisted death debate. Defining harm may have to be reduced from the macro level and examined at the individual level between a physician and his or her patient (Macleod 2012). According to Dr. Cody Morris, an oncologist featured in a documentary about physician-assisted death in Oregon, each patient is going to have a different idea of what harm is and physicians must let them decide (Morris 2012). In situations involving the issue of doing no harm, patients' autonomous choices may conflict with their physicians' personal values and professional duties. Each of these situations present different ethical principle challenges (Pantilat 2008).

The Patient-Physician Relationship

Many consider the physician-patient relationship an alliance that can have considerable healing power. When the physician honors specific obligations, patients' health and quality of life can improve significantly when they are able to work together with their physician (Ludwig 2014). There are several obligations that a physician must adhere to in building a strong relationship with their patient: shared decision making, respecting the patient's autonomy, letting patients weigh the benefits and risks, making the patient's concerns be the focus of every visit, and building trust by being personable and honest (Ludwig 2014).

In the debate over physician-assisted death, some say that it destroys the trust between a patient and physician. This argument more specifically addresses the instances where a physician

might suggest assisted death as an option for a terminally ill patient when all other options have been exhausted. This can have a debilitating effect on a person who once trusted their physician, but now feels he or she has completely devalued their life (Stevens 2004). For this reason, states that have Death with Dignity Acts require that patients first make a request to their physician, not the other way around (Oregon Public Health 2015). In 2014, eighty-three physicians wrote 155 prescriptions, but only 105 were used. Of the 105 people who ingested the medication, fourteen prescribing physicians attended at the time of their death and six non-prescribing physicians attended a patient's death. The length of a patient-physician relationship ranged from one week to twenty-five years, and the number of prescriptions written by a physician ranged from one to twelve (Oregon Public Health 2015).

Religion and the Death with Dignity Act

When debating physician-assisted death, there are concerns that go beyond the ethical and legal realm and cross into the area of religion. A person's religious beliefs is one of the most important factors affecting their opinion about physician-assisted death, and findings show that people who are strongly religious are the most likely group to oppose its legalization (Bachman 1996). The belief that God should dictate the time, place, and manner of death is in clear opposition to the idea of physician-assisted death (Hamil-Luker and Smith 1998).

Fairbanks (1980) states that "most efforts to regulate morality are based on religious beliefs, and measures of religious culture provide the single best predictor of the type of morality policies a state will pursue" (p. 104). Bob Dent, an Australian fighting for legalized aid-in-dying, challenged before his death on September 22, 1996, the issue of religion in legal and political issues (Dent 2000). Dent declared "The Church and State must remain separate. What right has

anyone because of their own religious faith to which I don't subscribe, to demand that I behave according to their rules?" (p. 121). Bob Dent was the first person to choose physician-assisted death under the Rights of the Terminally Ill Act in Australia (Fraser and Walters 2000).

In May of 1997, the Catholic led group Physicians for Compassionate Care unsuccessfully challenged Oregon's Death with Dignity Act. The judges in the Ninth Circuit Federal Court of Appeals (2000) issued this statement:

Those who believe strongly that death must come without physician assistance are free to follow that creed, be they doctors or patients. They are not free, however to force their views, religious convictions, or their philosophies on all other members of a democratic society, and to compel those whose values differ from theirs to die painful, protracted, and agonizing deaths. (P. 124)

Impact on End-of-Life Care in Oregon

There have been positive benefits for end-of-life care in Oregon as a result of the Death with Dignity Act. According to a study in the new England Journal of Medicine, Oregon has become a leader in excellent palliative care (Quill 2004). Some examples of this include the high number of hospice referrals in the state, along with the public awareness of end-of-life options. In fact, more than three-fourths of the terminally ill people who die using the Death with Dignity Act are in hospice at the time (Quill 2004). Data support the idea that legalizing physician-assisted death can actually improve palliative and hospice care, not diminish it. High numbers of Oregon physicians and other medical professionals, including hospice nurses, attend training courses on end-of-life decision-making (Quill 2008). According to Dr. Timothy Quill, "Overall, Oregon appears to be among the leaders in comparison to other states in virtually all aspects of palliative and end-of-life care, including allowing open access to physician-assisted death, subject to safeguards" (Quill 2008). When Oregon passed the Death with Dignity Act in 1994,

“It established a civil, criminal, and disciplinary safe harbor for physicians and others who followed its eligibility criteria and procedural protocol” (Coombs Lee 2014).

CHAPTER 3

RESEARCH METHODS

This research explores the importance of legalized physician-assisted death, the impact of the Death with Dignity Act in Oregon, and the motivation behind those who participate in the process. Three modes of data collection were used: in-depth interviews, field research, and secondary data analysis, including archival research. In order to obtain the data necessary for this topic of research, my data collection was completed primarily in Portland, Oregon between July 10, 2015 and July 21, 2015. I conducted fourteen personal in-depth, semi-structured interviews using an open interview guide (Lofland 1971). All of the interviewees were employees and volunteers of two organizations in Oregon: Compassion and Choices Oregon and the Death with Dignity National Center. My initial contacts were made with the directors of each organization and then interviews with additional employees and volunteers were arranged. I also visited both organizations' offices and attended a Compassion and Choices Oregon volunteer meeting in Corvallis, Oregon.

Interviews were conducted at the offices of both organizations, a local coffee shop, a small Portland restaurant, homes, and two over Skype. Open-ended questions were employed to allow respondents to provide full and detailed responses about their experiences in the area of physician-assisted death and their organizational role. All of the interviews were audio recorded, fully transcribed, and coded, and they ranged from 26 minutes to one hour and 40 minutes in length. Coding included an initial phase of open coding on all fourteen interviews, followed by focused coding on ten of those interviews (Emerson, Fretz, and Shaw 1995). This stage of analysis revealed several main themes including the importance of autonomy, personal

experience as motivation to participate, and the importance of semantics. Several sub-themes also emerged. These included the feeling of peacefulness, access issues due to religious-based opposition, and the positive impact of the law. These themes were confirmed with the coding of my 96 pages of field notes taken during the July 2015 research trip.

The ages of my interviewees ranged from 21 to 69 with an average age of 45. There were seven females and seven males, and all were Caucasian. The participants included three retired physicians, two of whom are currently the national medical directors for Compassion and Choices; directors of both organizations; six volunteers; and three paid employees. The education levels of the fourteen participants included three MDs, two PhDs, two RNs, two master's degrees, three bachelor's degrees, and two currently attending college. Of the fourteen interviewees, three gave me permission to use their real name because of their public advocacy roles: Dr. Peg Sandeen, Dr. Peter Reagan, and Dr. David Grube. For the remaining eleven, I assigned each a pseudonym to ensure anonymity, and all identifiable data were removed for confidentiality purposes.

When my research began, the main focus was on the employees and volunteers of both the Death with Dignity National Center and Compassion and Choices Oregon. The opportunity to interview retired physicians who were now employed by or volunteering for Compassion and Choices had not been considered. Both of the national medical directors for Compassion and Choices reside in Oregon, including the physician who wrote the state's first prescription after the Death with Dignity Act was passed. As employees of Compassion and Choices, they were added to my list of eligible interviewees for this research. A third physician who is also retired, is now a volunteer for Compassion and Choices and was also interviewed. Because of this added

factor in the pool of eligible interviewees, I adapted my interview guide to allow for physician-related questions.

In addition to interviews and field research, secondary data analysis was incorporated. This included but was not limited to peer-reviewed journal articles, relevant archival materials of the Death with Dignity and Compassion and Choices organizations, literary data such as legal history, the paperwork the state requires for a person to obtain physician-assisted death, and any additional organizational documentation that would be relevant to my research. Books, magazines, newspapers, websites, media, and documentaries were also analyzed.

Initially, my proposed research methods included interviews with terminally ill people in Oregon who expected to use the Death with Dignity Act. Unfortunately, due to the limited duration of my research trip, the specific dates, and demographic limitations, this did not come to fruition. However, interviews with the three physicians and the six volunteers provided me extensive first-hand accounts of experiences with those who have used the Death with Dignity Act. These interviews include detailed conversations with indirect quotations from terminally ill people who had used the Death with Dignity Act and provided data that could not be obtained directly (Emerson et al. 1995).

CHAPTER 4

FINDINGS AND DISCUSSION

In this chapter, I examine the themes that emerged from my interviews, field notes, and analysis of secondary data. These themes include: conditions that prompt an individual to participate, the importance of autonomy, experiencing a good death, and the “death conversation.” All of these themes include the perspective of the terminally ill participant, the prescribing physician, and the volunteer or employee of an aid-in-dying organization.

Conditions That Prompt Involvement

Motivation for involvement with the Death with Dignity Act varies for the terminally ill people who use it, the physicians who write the prescriptions, and the volunteers and employees of both Compassion and Choices Oregon and the Death with Dignity National Center. These motivations are what I refer to as “conditions that prompt involvement.” These conditions include a meaningful experience with death, and for the terminally ill participant, a fear of diminished quality of life.

According to the Oregon Health Authority’s “Oregon Death with Dignity Act Data Summary,” the top three conditions that prompt terminally ill people’s participation are the loss of autonomy, the loss of dignity, and loss of the ability to participate in enjoyable activities (Oregon Public Health 2016). These have been the three most reported conditions every year since Oregon’s first summary was released in February of 1999. In an account reported to me during my interview with Compassion and Choices volunteer Carolyn, another reason a terminally ill person may choose this option is that “people know of it, they’ve heard of it, they

have friends that did it,” or, as volunteer Lester shared, “hospice workers have experienced it and it gets around. There are personal stories like ‘it worked out for them, maybe I could do that.’” Others only think about the option after they are diagnosed as terminally ill. Compassion and Choices volunteer Janet, whose husband used the Death with Dignity Act to end his life in 2012 explained:

He had lost his voice so he could only whisper. He was in great pain because the cancer had spread to his bones and he couldn't get comfortable. He had no energy and no appetite. When he first mentioned using Death with Dignity he said he loved me and then he said ‘I just don't want to keep living this way. I'd like to explore the Death with Dignity law.’

For a terminally ill person in Oregon who chooses to use the Death with Dignity Act to end their life, the decision to hasten death connects several areas of life including physical, social, emotional, spiritual, ethical, and economic factors (Jamison 1996). Together, all of these factors influence whether or not a person uses the Death with Dignity Act.

In my interviews with volunteers and employees of Compassion and Choices Oregon and the Death with Dignity National Center, the motivation behind their involvement comes from a past experience with a death that left an indelible mark. Ten of my interviewees had a negative experience with the death of a loved one, friend, or patient; two of them had a good experience, and two interviewees declined to answer. One of the first questions I asked during my interviews was how the participant became involved with the aid-in-dying movement. The majority (n=12) of my interviewees had a past experience with the death of someone that influenced their current role. In my interview with the director of the Death with Dignity National Center, Dr. Peg Sandeen shared the following:

When I was 25, my husband was diagnosed with HIV. He fought with that for a couple of years and then he died. That was back in 1993 when AIDS was nearly a death sentence...

and he experienced a tremendously bad death. He suffered greatly and a lot of [people with AIDS] generally did at that time. A lot of them wanted a choice. A lot of them ended their lives in violent ways... he wanted help ending his life, so it exposed me. So after he died I became a social worker, but I remained interested in end-of-life care and had AIDS patients who experienced what he had experienced and the process just repeated itself over and over and over.... I decided to get my PhD, so I came [to Oregon] and it just happened that this job came up and it was a great fit.

Compassion and Choices Medical Director Dr. Peter Reagan reported a similar experience with a friend's death while he interned in medical school. This happened years before the Death with Dignity Act was passed, and his involvement made Dr. Reagan witness to a long, arduous death:

My seminal experience was when a really good friend of mine died of leukemia... he was only 39 years old. I was an intern and I went through the experience of his death and it really brought me up close and personal with the process of dying... As an intern you do get quite a bit of exposure and so I knew what to expect. So, he'd ask me questions and I'd say 'here's what I've seen' and then our interactions would gradually get more clinical and then I realized days before he died that I was more than an intern, I was his good buddy... I learned a lot from that whole experience and it was impressive to see his point of view. You know at some point you get to a place where dying doesn't seem like the worst thing that could happen to you.

As these and many other interviewees related, the conditions that prompt people to join the organizations I visited seem to fit a pattern. This idea is confirmed by volunteer Michael Houston, who wrote "My journey is similar to the path that leads almost all volunteers to Compassion—we want to do this work because we have experienced death, good and bad, and we know the difference" (Lee 2003: 50).

A physician's motivation

I had the privilege of interviewing three retired physicians, two of whom are now medical directors for Compassion and Choices. Each of these interviews provided insight into the motivation behind a physician's participation in Oregon's Death with Dignity Act. Each

physician had a negative death experience in their past that solidified their future involvement in physician-assisted death. Though they are now retired and no longer may prescribe medications, each had written prescriptions for life-ending medication during their careers as doctors.

In February of 1998, Dr. Reagan was contacted by his former teacher Dr. Peter Goodwin, who was instrumental in the passing of the Death with Dignity Act. Dr. Goodwin had a referral for him, a woman Dr. Reagan would come to call “Helen.” She met all the criteria that Oregon requires and as Dr. Reagan stated, “she qualified in spades.” Not only was she the first prescription for life-ending medication that Dr. Reagan wrote, she was the first Death with Dignity participant in the state of Oregon. He wasn’t aware of this at the time, as he reported to me:

I didn’t know it was the first prescription until I went to find a pharmacy... I wasn’t [at Compassion and Choices] then, but I called Compassion and asked ‘what pharmacy do you guys use?’ and they were like... ‘Oh’... they didn’t know! So there was this chase all over the state to find a pharmacy... and we found one.

In addition to witnessing the death of his friend as described above, Dr. Reagan described how, years before the Death with Dignity Act was passed, he decided he would help a patient if he ever had the opportunity. Before physician-assisted death was legal, he had an experience with a patient, a male in his 70s with a terminal lung disease, which solidified his choice to participate:

He had horrible lung disease, he had a lot of trouble breathing, and he had a lot of secretions all the time. He actually had to suction himself periodically. He was very weak... he also had a heart condition... he ends up pretty quickly in a care facility because he can’t do anything... He was nothing but gracious, nothing but considerate. The chance that he would ask you to put yourself out by giving him aid-in-dying or by asking you to give a little extra medicine or anything risky... he would never do that to a person, he was just too considerate. So... one day he was found dead by having cut his wrists with a... with scissors he found around the nurse’s desk... and what can you say... he was at the point where life was miserable for him... and there really wasn’t anything anyone, any of us could do about it. He was like ‘this isn’t living.’ So that particular... he more than anything... helped me understand the value of some option being legal.

The other Medical Director for Compassion and Choices is Dr. David Grube. During his career as a practicing physician, he wrote over 20 prescriptions. In my interview with him, he said:

I had an experience earlier before the law passed. I had a neighbor who had a battle with kidney cancer and... his son asked me to come over and help with his dad... and he had taken a shot gun and blown his head off. That was the most horrible thing I ever saw in medicine, and I said to myself 'I will never, ever, ever let any of my patients get to this place where they're so desperate that they do this.' It was so traumatic for the family... and for me. So, I had that in my background as a life experience... The law passed in 97 and I wrote my first prescription in 99. A patient said 'this is what I want to do,' so I learned about the law. I had known in my heart that if a patient ever asked, because of the experience with my neighbor, that I would help my patient.

It's a "Calling," Not a Job

Participating in the emotional journey during the dying process of a terminally ill person is usually reserved for family members and close friends. So why do individuals decide to devote time to terminally ill people they barely know? During my interviews with the volunteers and non-medical employees of the Death with Dignity National Center and Compassion and Choices Oregon, the answer to this question was made clear to me. They consider their role at the organization something they were "meant to do." The majority (n=11) consider the work they do to be a "calling" not a job. Donna, a 44-year old Compassion and Choices volunteer, shared with me, "Yes it's work and it can be hard physically and emotionally, but it's not a job to me. It's a calling." Becky, a 68-year old volunteer, echoed Donna's sentiment. "I don't get paid so I guess it's not a real job, but even if I did, I wouldn't consider it work. It's just something I'm meant to do."

Though her role as the director of the Death with Dignity National Center demands more time on policy reform and lobbying than with terminally-ill individuals, Dr. Sandeen still considers her job to be fulfilling on a larger scale:

If I can change the law, I can impact all of their lives right? I might not know who it is, I might not see them on a day to day basis, but I have much more impact I think. So I find that very fulfilling. I love doing the political work and the idea that I helped change how people die in Washington, I helped change how people die in Vermont... I helped change how people die. I gave them an option... people who I'll never meet, people who I won't know. I'm very proud of that... it's really good.

I did not get the opportunity to interview Compassion and Choices National Director Barbara Combs Lee while I was in Oregon because the organization is headquartered in Denver, Colorado; however, in a book she authored in 2003, she wrote "While I did not understand its importance at the time, a lesson from one of my first patients greatly influenced the work that eventually became my calling" (p. 8). This was the sentiment repeated to me by Compassion and Choices volunteer Becky:

I was a nurse for most of my life and I saw so many terminally ill patients lay in a hospital bed for weeks or even months... and they suffered. So when a friend of mine started volunteering for Compassion, I knew I wanted to help. It was... just the right thing to do... something I knew I had to do... you know what I mean?

During my visit at the Compassion and Choices Oregon Portland office, the Oregon state director explained why he thinks so many of the volunteers join Compassion and Choices: because they experienced a death that led them to the choice. As he said, "it's something that chooses you, not the other way around."

The Personal and Professional Importance of Autonomy

Over 100 years ago John Stuart Mill wrote "On Liberty." In this essay he declares, "Over himself, over his own body and mind, the individual is sovereign... he is the person most interested in his own well-being" (quoted in Orfali 2011). Mill's forceful argument for the right to self-determination seems like an anthem for the Death with Dignity movement. For both the

terminally ill person who chooses to use the Death with Dignity Act and the physician who is asked to prescribe the life-ending medication, autonomy is of critical importance.

In my review of the literature and analysis of secondary data, autonomy was characterized as self-government, self-rule, independence, or simply having control over oneself. The fear of losing their autonomy has been reported in 100 percent of the physician-assisted death cases in Oregon (Morrow 2014). Autonomy is defined as “an idea that is generally understood to refer to the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces” (Stanford University 2016). This definition is a perfect summary of the feelings related to me during interviews and in the stories I found during my analysis of secondary sources. In *Compassion in Dying*, a story is recounted about Richard Holmes by his son Rick Holmes (p.85):

Like many who consider aid in dying, Richard was determined to have some control over how he spent his last days. A retired salesman with a strong independent streak, he reasoned ‘I’ve lived life pretty much as I’ve wanted to and I feel I should be able to end it if I need to.’

Richard Holmes was two days from being able to get his prescription when the Attorney General at that time, John Ashcroft, declared that any doctor who prescribed medication under the Oregon law would be breaking federal law. This brought about a lawsuit in which Mr. Holmes was the first patient plaintiff for *Compassion in Oregon v. Ashcroft* (Combs Lee 2003). Holmes became a central figure in this battle. At a press conference, Richard Holmes spoke openly about his feelings:

I want the option. I want the choice – that’s all I want. When the quality of my life is not worth living, then I want to stop living... It should be my decision. I have lived the way I

want to; I should die the way I want to. I personally think it [legal aid in dying] should be a law in every state in the whole country.

The state of Oregon won this lawsuit and Richard Holmes received his prescription, though he never used it. He had said from the beginning that he didn't know if he would take it, but he just wanted the comfort to know he had the choice. He passed away at home at the age of 73 (Combs Lee 2003).

Although I never pointedly asked about autonomy during my interviews,¹ it always seemed to work its way into the answers to other questions. One question in particular triggered a response about autonomy in 12 of my 14 interviews. This question was: *Some people think improving pain management will eliminate the need for Death with Dignity laws. Will you talk about that?* From that one question, I learned that pain management has very little to do with the decision to use Death with Dignity, it is the demand for autonomy that influences that choice the most. Compassion and Choices Oregon volunteer Randy, a 58-year old male explained:

All the clients I have known... the people I've met that do this [aid in dying] ... they really don't talk about pain as the reason. They just don't want to be dependent on everyone... they want control. They want to be able to clean themselves and feed themselves and... just do things for themselves. I think if they didn't have any pain at all, they'd still want to do it.

In his answer to this same question about pain medication and whether or not it would eliminate Death with Dignity laws, Dr. Grube replied:

I think according to the records kept in Oregon, pain is a reason. You know, they don't want to suffer, but it's more about autonomy. I think if all the pain was managed perfectly and there was no pain... there would still be requests for aid-in-dying. It's more about control than anything else. It's more about the loss of pleasure... when people

¹ It was a deliberate strategy not to use the word autonomy because I did not want to invoke a word associated with movement rhetoric and assume that interviewees would define it the same way.

cannot pursue happiness, when nothing will make them happy, and they're dying from whatever they have... it's one of their rights.

In an article published in *Men's Health* in 2006, the story about a 79-year old male with liver cancer was detailed. He already has his prescription, and as his symptoms worsen he contemplates when he will decide to use it. He admits that up until a few weeks earlier he was able to walk the dogs with his wife every morning, but his condition has deteriorated to the point where now walking to the front door is excruciating because of the swelling in his ankles (Drury 2006). His wife, a pediatrician, says that the most important word for her husband is "control... control over his own destiny" (p. 3). He, "the patient," as referred to in the article, goes into more detail:

Just lying there... without the joy of memories... the memory of being alive... the memory of loving and being loved. Insensate... I see this as a clinical process. It's the teacher in me. Birth, adolescence, maturity, old age, death. Death is the end of growth. I feel it is my right to decide.

Throughout my research I have learned that autonomy is a central issue, not only for the terminally ill person who wants aid-in dying, but for the physician who wants to write a prescription for them. Professional autonomy has been defined as "the degree to which the job provides substantial freedom, independence, and discretion to the individual in scheduling the work and in determining the procedures to be used in carrying it out" (Kalleberg 2011). One of the fastest growing barriers to a physician's autonomy in Oregon is erected by the Catholic Church, which opposes any form of assisted-dying and forbids mention of it in their hospitals. A physician, nurse, or any other employee can be terminated if they refer a patient to a doctor or to another facility that offers legalized aid-in-dying. This employer-based gag rule is of great concern in states with legal assisted dying, like Oregon and Washington, because one out of every two hospital beds is in a Catholic hospital (Stewart 2015). Dr. Stephen Kerner, a physician

who practices in Florence, Oregon is the medical director at a hospital which is Catholic-affiliated. He voices his frustration about this problem: “I am not able to give my own perspective...There is no question that it affects the kind of care I am able to deliver. When my patients inquire about it, I have to say that we don’t participate in it” (p. 5).

In my interviews with the three retired physicians in my sample, this same level of frustration was repeated. The idea that a physician who discusses and makes a decision about aid-in-dying with his or her patient, will risk termination, is unacceptable to all three of them. Dr. Reagan provided further detail when I asked him about the issue of access for Oregonians who want assistance in dying:

It’s complicated... one of the things that I don’t think the patient quite gets is that...if for example, you’re hired by the hospital in Providence, they [the hospital administration] are allowed to forbid you from participating in the Oregon Death with Dignity Law. Nowadays people I used to work with, they don’t own their practice. Half of them are owned by Providence and the other half of them are owned by another [hospital or corporation] who also has objections. If I were working in that clinic setting now, I would not have the same freedom to write a prescription that I did four years ago.

You’re told you can’t obey your conscience... you have to obey theirs. And the hospital... they’re constrained by whoever is in charge... We want to give the person [terminally ill patient] what we can... what they want.

Professional autonomy for a physician means that that they should be able to make decisions based on their experience, knowledge, and authority, especially when it is a drug or treatment that is a legal option (Hodson and Sullivan 2012). As a Compassion and Choices volunteer, a 65-year old retired physician, explained to me, “It’s scary to think that with something as intimate and personal as this, a physician can’t just say yes if they want.”

A Good Death

In June of 2009 Jeri Edwards Orfali died after a battle with cancer. Her dream was to use physician-assisted death to plan her final moments, but she lived in Hawaii, a state where it is not legal. She made several calls to Compassion and Choices in Oregon and on May 7, 2008 she wrote a letter to one of the counselors there. Unfortunately, all they could provide was emotional assistance due to legal constraints (Orfali 2011). According to her husband Robert, Jeri wanted to plan her death just as she had planned things throughout her life. She did not want uncontrollable pain and she didn't want to suffer. In a book her husband wrote after her passing, he recalls a conversation he had with his wife after her diagnosis in which she described how her death would be (p. 19):

In my dream, we rent a beautiful ocean side suite at the Moana overlooking my surfing spot. We sit on the lanai and enjoy watching the surfers...Later our closest friends join us for a nice bottle of wine. We talk story and reminisce. We laugh a lot. At sunset, I say goodbye to everyone and have one more toast to the good life. Then I drink my final cocktail...

The description of how Jeri Orfali dreamed her death would be, is similar to most of the death experiences described to me during my interviews: peaceful, positive, calm, and shared with close friends and family. This theme, which I call "a good death," is closely related to autonomy in that, when a terminally ill person is able to exercise their right to choose the details of their final moments, advocates describe their death as good. Dr. Sandeen summed it up for me during our interview when she said, "It's all about autonomy and self-determination."

During my interviews, attendance at the Compassion and Choices volunteer meeting, visits at the organization's offices, and in all of the secondary data I analyzed, one idea remained constant: The Death with Dignity Act is intended to allow a terminally ill person to achieve a

good death. The definition of what makes a good death may vary in its specificity, but in general, it can be defined as “a death in which the rights of the person have been respected and during which the dying person was made as comfortable as possible and was in the company of persons he or she knew and loved” (medical dictionary 2016). This can include dying at home without stressful physical symptoms. In a 1998 national Hospice Demonstration study to determine what a good death would be for a dying person, researchers asked terminally ill people how they would ideally spend their last three days. The top five responses were as follows (death reference 2016):

- I want certain people to be with me
- I want to physically be able to do the things I want
- I want to feel at peace
- I want to be free from pain
- I want those three days to be like any other days

What constitutes a good death varies across cultures and throughout history (Jutna 2013). Ending one’s life is celebrated in some cultures as a sign of heroism or martyrdom, not stigmatized. In parts of Asia and the Middle East, a good death may include sacrificing life for the benefit of country, and may be considered the highest honor for an individual (Jutna 2013). In Chinese culture, having a good death is based on having a good life. It is called a five blossom death. The five blossoms represent life accomplishments: marriage, having a son, being respected, having a grandson, and dying in your sleep after a long life (Simmons 1999). These examples are just two of the varying descriptions of what is considered a good death, but they represent how a good death, though personal, is socially constructed.

In the United States, the contemporary construction of a good death in the death with dignity movement reflects American ideals of individualism and self-determination. Thus, for a

person who uses the Death with Dignity Act, a good death isn't only about the final hour, it's about the entire process. It's from the moment the prescription is written until the final moments after the medicine is taken. For example, all of the volunteers I interviewed relayed to me their experience with the relief terminally ill people expressed after they filled their prescription.

Compassion and Choices Oregon volunteer Donna explained the reaction of one client:

She called to say she had gotten her prescription. I almost felt like I was talking to a different person because her voice sounded so much lighter. The process of finding a doctor had been stressful for her and going through the process too... but once she had her medicine... it was like a load had been lifted. She sounded relaxed.

The stories were the same with all of the volunteers I interviewed, with descriptions that echoed what Donna had told me. Their expressions included: "a relief," "a weight was off their chest," "they could just relax now." The idea that just having the prescription could bring great sense of relief to the terminally ill person who received it was explained specifically by Dr. Sandeen:

I think what it is, is that when you have that prescription you get to just live your life. If the suffering is bad tomorrow, you have the opportunity to hasten your death... but if it's fine tomorrow, you can spend time with your family or do your bucket-list thing or travel. I think that's what it is. It's a day to day basis decision where 'If the suffering gets so bad...I have it. If not, I'm just going to continue living'... and I think that's what it is. For those people, that prescription offers peace of mind.

Compassion and Choices volunteer Carolyn explained how getting the medicine was such a big moment for the clients she had worked with:

Just having the prescription in their hand, or in their bedside table drawer, or in the bathroom medicine cabinet... I don't know... there's just something about knowing you have it if you need it. There is this anxiety going through the process, I mean, they have already gone through being told they are terminal... so once all the paperwork and waiting time is over, they have the medicine. The last step is theirs to decide.

Another aspect of achieving a good death for those who use the Death with Dignity Act is that they have the opportunity to say their goodbyes and plan their final moments. For some it

will be a quiet, private moment with close family, for others it may be a large group of friends and family. The larger events have been called “final gatherings,” “life celebrations,” and “transition ceremonies,” among others. In 2002, an Oregonian named Roger, with the help of a friend, planned his final gathering. He had been diagnosed with colon cancer in 1999 and by 2002 it was terminal. In January, he and 30 of his friends gathered in his apartment to celebrate his life (Lee 2003). During a videotaped message, Roger said the following (p. 19):

Many of you I've been friends with since I was a little child, some of you I have been good friends with for 45 years. There are other friends here who I've known only a few days, but I've gotten close to you.... To have all of you in the same room at the same time and of the same mind—and to sit down and talk with the people I love is incredible... When you have a life-threatening disease you know life is going to be finite, it brings you to the Now. If you have issues—good or bad—tell people that you love them... That is why I wanted to gather all of you here today. I want to tell you how much I love all of you...

The smaller, more intimate gatherings at the time of death are usually attended by family and possibly one or two friends. Volunteers and physicians I interviewed recalled how they had been asked to attend events like this. The one thing that was similar in each of their recounted examples was the peaceful atmosphere during the taking of the medication and the passing of the person.

In addition to saying their goodbyes and getting things in order, a terminally ill person using the Death with Dignity Act also gets to plan the details of their death. This can include where they want to be when they take the medication, what time of day they want to take it, and who they want to be there with them. For some, the time planned for taking the life-ending medicine can actually be considered a special event. It provides opportunities for closure, moments of sharing with friends and family, and gatherings that honor the person's life and their passing (Jamison 1995). These acts can be ritualistic or symbolic for some, especially those who

hold religious beliefs. Dr. Reagan shared an experience during our interview about one of the deaths of a patient that he attended:

I had one case that Compassion referred to me... I actually met her about a year before she died. She wanted to know who she was going to be asking, and then about a year later we went through the process. I didn't know anything about her religion when I went to her house... I was going to her death. First of all, I couldn't find any parking... I was like 'Wow! Something's happening here.' I go up to the house and it's very obviously a religious household. There were different quotations from different saints as you're walking up the path to the door, and when I get to the front door I see it's shoulder to shoulder with about 60 people in there... who are all in this sort of wake mood... she's there in the bedroom which is the "inner sanctum" ... and her son and daughter and me. So then she dies... and we do what we do...

Dr. Reagan's story is an example of how even when a large group of people gather together, there is usually a private area designated as the place where the medication will be taken.

The Final Moments

Dr. Reagan's reference to the "inner sanctum" points to another important element of a socially-constructed "good death": the highly meaningful moment when the prescribed medication is ingested. Other interviewees described this moment as "an amazing experience," "triumphant," or "humbling." Janet, a Compassion and Choices volunteer, recalled her husband's final moments:

We had invited our closest friends and there were Compassion volunteers there too. We sang and talked... someone read a poem. He spoke individually to everyone. The volunteer mixed his medicine in orange juice and he [her husband] drank it. The last thing he said was 'thank you.' I won't ever forget those moments.

Compassion and Choices Medical Director Dr. Grube shared an experience he had while attending the death of a patient. She had been a patient of his for years and he described her as "a

very smart and highly educated woman, very autonomous, very opinionated.” He explained that she had actually interviewed him to see if she wanted him to be her doctor. According to Dr. Grube, she was diagnosed with emphysema and eventually she couldn’t do the things she wanted to do. She ended up being on “oxygen, big machines, and tons of medicine.” He summed it up by saying “she had absolutely no joy in her life.” She qualified for the Death with Dignity Act, and when it was planned, she asked Dr. Grube to attend. He recalled the experience to me:

She talked to her family, and asked me as her doctor to come to [her death] ... It was just me and her family... Then she went to her bedroom and took her medication and her daughter was there and her son, and she died in their arms. Very gently... very beautiful... That was probably the most powerful experience I had. I think it’s such an intimate experience and I’m not a stranger to them... I’m their doctor.

For the interviewees who attended at least one death of someone (n=7) using the Death with Dignity Act, the experience was described in a very similar way. I had initially assumed it would be very depressing and dark, something that would leave a permanent mark or keep them from wanting to participate again. Their words indicated the opposite is the case. Though they all agreed that it was an “emotional” and “tearful” experience, they all expressed that it was also “positive” and “peaceful.” In my interview with Compassion and Choices volunteer Lester, he explained this:

Of course it’s sad... it’s sad because the person is dying... that they have whatever it is that they have, like cancer. It’s sad because their life is ending. But... at the same time it’s not sad because they are passing away in a way they choose, a peaceful way you could say. They get to say goodbyes and fall asleep. It was one of the most special things I’ve ever been a part of.

During his career, Dr. Reagan was asked to attend the death of four or five patients, however he had some apprehension when he was asked to attend the first. Not only was it his

first time to attend a patient's assisted death, it was Helen, his patient who received Oregon's first life-ending prescription:

I was a little nervous about going to the first one because I didn't want to appear to myself or others that I was putting pressure on the patient. Then I was asked 'would you please come?' and I thought 'yeah, but I want you to know that if you decide not to take the medicine it's totally fine' ... but I'd be lying if I didn't say it's an amazing experience.

If I'm trying to describe what happened when Helen... when she took the medication... Everyone is there and there is all this communication all around and... she knows what's going on and... the ending is almost more of a triumph than a catastrophe and the feeling is totally resolved... and the family is fine.

Dr. Reagan shared that he had attended several deaths and his stories were the same in the way that he described the atmosphere and the feeling afterwards. During our interview he recalled the prescription he wrote for the one patient he had known for many years. This story was in response to my question: *Other than the first prescription you wrote, was there any other case that stood out.* Here is what he shared:

Well, all the ones that I went to really... well one of them was a patient of mine. The only one that was a patient of mine... a 50-year old man with ALS, Lou Gehrig's disease. I delivered his babies. I mean, I knew this family for a bunch of years and... when he died, his 19 and 21-year old kids were there... his wife was there... it was a really deep experience... a little different than being with someone you just met... It was just me and his wife and the two kids... very intimate... fascinating, amazing, deep.

One of the ways that the final moments are able to be peaceful, serene, and calm, is the physical symptoms before and after the medicine is ingested. The steps are typically the same for each person. First, they are instructed to take a drug that will coat their stomach and help them keep the medicine down when they take it. This is usually done an hour before they intend to take the lethal medication. After the hour has passed they will take a barbiturate, usually secobarbital. The medicine is bitter tasting and unpleasant, so it is usually mixed in orange juice or applesauce to make it more palatable (Kirkey 2015). The terminally ill person taking it is

instructed to ingest it fairly quickly so they don't fall asleep before they finish it. The time between ingestion and unconsciousness has ranged from one minute to 38 minutes, with a median of five minutes (Lee 2014). After falling asleep and becoming unconscious, the person stops breathing first and then, because there is no oxygen in the blood, the heart stops (Kirkey 2015). Dr. Grube stressed to me that "It's like falling asleep. It's a rapid falling asleep and generally takes a few minutes. It's extremely simple."

According to the Oregon Death with Dignity Act 2015 Data Summary, 90.1 percent of the Oregonians who used the Death with Dignity Act to end their lives died at home (Oregon Public Health 2016). This statistic has remained steady since 1997. In fact, of the 991 people who have died using Oregon's law, 928, or 94 percent, have died at home (Oregon Public Health 2016). This is one of the things that, according to the survey mentioned at the beginning of this section, is desired to achieve a good death. The Compassion and Choices Oregon State Director explained to me that one of the things a terminally ill person wants when they use the Death with Dignity Act is to be able to die at home:

They want to die at home with their family and their friends. They don't want to end up in a hospital hooked up to machines for days, weeks, or months... and they don't want to end up sedated and unable to do the things they want. With the Death with Dignity Act, they have the chance to decide where they want to die and for the most part, that is where they choose... at home.

A good death for those who use the Death with Dignity Act in Oregon is thus one where they have peace of mind, the opportunity to say goodbyes to family and friends, plan their final moments, and know that they will fall asleep painlessly. It is also a death where they get to die at home. In all of my interviews, these sentiments were repeated in different stories, about different

people. In each case, the person with a terminal illness had succeeded in achieving what most Americans today consider a good death.

The Death Conversation

While I conducted my field research in Oregon, it became clear that there was something different about Oregonians' attitudes towards death and dying. This assumption has been corroborated through secondary data analysis, the interviews I conducted, and from visits I made to the Compassion and Choices Oregon office and the Death with Dignity National Center. As the first state in the United States to pass an assisted-dying law, Oregon citizens spent years fighting for the Death with Dignity Act. It was first passed in 1994, but it took three years for it to be enacted in 1997. During this time, news about the Death with Dignity Act was on television, in local magazines, and in the newspaper. According to Compassion and Choices volunteer Randy:

Talking about death became the norm. I remember talking about it with colleagues, friends... you know... everyone was talking about it. I guess you could say it was dinner time conversation. You couldn't go 24-hours without hearing the word death... so now it's not weird or... uncomfortable to talk about.

Part of the conversation about death, and more importantly the Death with Dignity Act, is the terminology used to describe aid-in-dying. The appropriate terminology used is "physician-assisted death"; terms invoking the word "suicide" are frowned upon. According to the Oregon Death with Dignity Act section 2.06, "The Oregon Death with Dignity Act does not constitute suicide, assisted-suicide, mercy killing or homicide" (Goldberg 2011). Thus, the State of Oregon sanctions "physician-assisted death", and "aid-in-dying" due to the stigma attached to the word suicide. I learned through my interviews that terminology can impact the opinion of participants,

physicians, legislators, and the public. The word suicide carries with it a negative connotation that advocates deem harmful. In my interview with Dr. Sandeen, she expressed the following:

The idea that they [terminally ill who use the Death with Dignity Act] are suicidal... they want to live but they are going to die... they think it's harmful and hurtful that people put that label on them, that they're suicidal, because they're really not. They want to live but that's not an option for them... And so for me it's profoundly personal and... I think it's very hurtful that our opposition uses language like that for political gain to try and influence people.

During my visit to the Compassion and Choices Oregon office I learned about Death Cafés. A death café is an event where people get together, drink coffee, and talk about death. I had never heard of these before, but it was clear that it is a common occurrence in Oregon. I was also impressed to learn that Compassion and Choices volunteers attend local farmer's markets and provide end-of-life information to people who request it. This includes advanced directives and other end-of-life planning materials. These are just two examples that reflect the openness about death that Oregon residents have developed. This openness has translated into a healthy dialogue between a doctors and patients, a terminally ill person and their family, and healthy individuals planning for the "what ifs." The importance of having an open conversation about death, and more specifically, a discussion of what one's end-of-life preferences are, was explained to me during my interview with Dr. Reagan. In his story about the patient who killed himself violently before the Death with Dignity Act passed, he explained the importance of being able to talk openly about one's death:

Point being, he did this and I knew a number of people who were friends with him and they all asked 'how come he never talked to us about this... how come we never had the chance to say goodbye?' ... and that's what it was all about... not being able to be honest, being able to be open, because it was against the law. That taught me why there should be some legal option... not just so you could use it, but so you could talk about it. So you can say to your friends 'I don't want to live anymore' ... and you can talk to your doctor about it 'Here's what I'm thinking about... how do you feel about it?'

In the *Letters to the Editor* section of The Washington Post, a letter was written about Dr. Ken Stevens. Dr. Stevens had a patient request aid-in-dying in 2000, but after discussing options and counseling her, she didn't use the Death with Dignity Act, and 14 years later she was still alive (The Washington Post 2014). The letter states:

Because the law was in place, the patient was comfortable bringing up the topic with her physician, who then appropriately dissuaded her. But what if the patient had just chosen suicide, instead of aid-in-dying, without the benefit of discussions with her doctor and family? The law helped Dr. Stevens and his patient. The value of the law for all of us in Oregon is that it takes some of the loneliness out of the dying process because it facilitates healing conversations. For the vast majority of us, it's not about taking a drug to die; it's about being able to share our deepest fears and most poignant concerns with our doctor and our family.

Impact on End-of-Life Care

Another area in which the Death with Dignity Act has been credited is the high level of end-of-life care that Oregonians receive. Oregon has one of the highest hospice referral rates in the United States and has become a leader in palliative care (Quill 2008). Oregon also has a high number of physicians and other medical professionals who attend training courses in end-of-life decision making. These data suggest that legalizing physician-assisted death doesn't undermine end-of-life care, it enhances it (Quill 2008). According to the 2015 Oregon Death with Dignity Act Data Summary, 118 people, or 92 percent of the people who died using the Death with Dignity Act were enrolled in hospice at the time of their death. Since 1997, 865 or 90.5 percent of all Death with Dignity Act recipients were enrolled in hospice (Oregon Public Health 2016). This is a clear confirmation that physician-assisted death works with hospice and palliative care, not against it. Dr. Sandeen underscored this point in our interview:

I think that when [someone]... is positing this type of thing, that hospice and palliative care are mutually exclusive, that they're two different options, the Oregon data shows

that's not true... 90 percent of the people who participate in the Death with Dignity Act are also enrolled [in hospice]. So they are receiving good quality end-of-life care, including pain management. They also choose Death with Dignity... it's not one or the other.

Oregon is rated one of the best in the states in terms of palliative care... and depending on what statistic you're looking at... pain management, number of patient beds, and number of oncologists.

According to surveys given to families of terminally-ill Oregonians, just having the option of assisted dying reduced anxiety for both the terminally ill person considering aid-in-dying and their family. In addition, many healthy Oregonians find it reassuring psychologically to have the Death with Dignity Act as an option if they ever need it (Orfali 2011). There is also data that reveals that in some areas, according to family members, the quality of death for those who use physician-assisted death is better than those who do not. One of the highest ratings was related to preparedness for death and the ability to say goodbye to loved ones (Smith et al. 2010). There is also data that supports the positive effect the Death with Dignity Act can have for surviving family members--specifically that they are more prepared for their loved one's death (Ganzini et al. 2009).

Some may argue that legalized aid-in-dying in Oregon has only helped the 991 terminally ill people who have used it. Others may argue that it has helped the 1,545 people who have received prescriptions, whether they used them or not. The Death with Dignity Act seems to have helped all of them; however, it goes much farther than that. Oregon has a population of four million people, and I would argue it helps every single resident. With the open dialogue it has created in regards to death and dying, to the highly rated hospice and palliative care, to the training doctors take on making end-of-life decisions, the Death with Dignity Act offers resources to Oregonians that residents of most other states lack.

At the end of my interview with Dr. Reagan, he shared more details about the final moments he shared with Helen, Oregon's first Death with Dignity Act participant. Hearing how he described her spirit and tenacity is inspiring. It is an excellent example of the importance of Oregon's law and the impact it has had on many lives:

She was the ideal person. She... she knew that she was asking me to go out on a limb for her... and she did everything she could to help me feel good about it. She would say things like 'When you go to bed tomorrow night, you're going to feel good because you're going to know that you did the right thing.' I didn't ask her to... she just came up with it... She was spectacular... You know when you're going to go on vacation? You're looking forward to getting on the plane and it's exciting and you're looking forward to it? Then when you're coming back from vacation it's like 'Oh God... I want to stay. I don't want to go back...' Well, she was going on vacation... she was all about getting out of here! She was not longing or looking back... and that was quite inspiring. It was a little shocking actually... just to see how she handled it.

The people who want this tend to be very used to being in charge of their lives... they make things happen all their lives, and they're going to make this thing happen too. And... they're pretty darn positive. They know what they want... and they want it really bad... and they're really effective at getting what they want. They can do all the hoops and talk to the right people. So, all the people that I met were pretty impressive people. They were all people you just hate getting to know... then unknowing.

CHAPTER 5

CONCLUSION

Oregon's Death with Dignity Act has touched the lives of many people. Based on my analysis of field data and in-depth interviews with people involved in legalized aid-in-dying in Oregon, several sociological themes emerged: the social conditions that prompt people's involvement, the personal and professional importance of autonomy, the meaning of a good death, and the growth of conversations about death and end-of-life care. This research contributes to our understanding of the impact that legalized aid-in-dying can have on individual participants and on the entire population of a state. There are several areas of future research that my thematic analysis identifies as deserving further consideration.

While conducting research in Oregon, I learned that Compassion and Choices is currently campaigning for improved access. It was surprising to learn that in a state where physician-assisted death has been legal for nearly 20 years, being able to use the Death with Dignity Act is harder today than ever before. This lack of access, particularly for those living in rural, eastern parts of Oregon which has fewer hospitals, is a product of the tremendous effort by the Catholic Church to inhibit aid-in-dying for potential participants. This religiously motivated barrier is a growing concern due to the increase in the Catholic Church's hospital ownership and the consolidation of corporate and church ownership of clinics and hospitals. Limited access inhibits personal autonomy and diminishes professional autonomy for physicians and other medical personnel. The conflict over access thus merits further investigation.

Another topic that needs to be explored further is in the area of what constitutes a good death and the changing meaning of death as a social process. As life expectancy continues to

increase for most Americans,² so does their desire to control when, how, and in whose presence they die. The current meaning of a good death suggests that more people wish to avoid heroic medical efforts, expensive treatments, and long-term hospital stays too sedated to say goodbye to loved ones and get their affairs in order. The desire for a “good death” or “quality exit” does not mean that terminally ill people refuse medical care; instead, it signals an invitation for more physicians to recognize the social importance of death and dying.

A third area of research could study how medical schools and teaching hospitals plan to approach the topic of physician-assisted death. As Death with Dignity and related laws expand across the United States, how will these agents of medical socialization broach this topic? As I discussed in Chapter 4, the state of Oregon offers courses to physicians and other medical personnel on making end of life decisions and death and dying. Will other states follow this path and extend training in these areas for all healthcare workers? As more states pass death with dignity legislation, medical curricula on death and dying will need to adapt. They will need to address dying in a humane manner as a process, rather than assume that death should be conquered at all costs.

Expansion of Legalized Aid-in-Dying as a Social Movement

It has been 22 years since Oregon’s law was passed, and over 18 years since it was enacted. It took 10 years after the enactment of Oregon’s legislation for another state—Washington—to pass a similar law that legalized aid-in-dying. After Washington passed its Death with Dignity Act, Vermont and California followed suit. Since 2014, nearly half of the states in America are now considering Death with Dignity laws. These states include:

² Life expectancy is not increasing for all Americans. Current reports indicate that the mortality rates of white Americans with low levels of education have worsened (Case and Deaton 2015).

Connecticut, Colorado, Delaware, Florida, Indiana, Iowa, Kansas, Maryland, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, Oklahoma, Pennsylvania, Tennessee, Utah, Washington D.C., Wisconsin, and Wyoming (Compassion and Choices 2015). This activity shows a marked increase in the movement to pass aid-in-dying legislation.

Most experts agree that the fight for individual states to pass laws legalizing physician-assisted death will be slow-going. According to University of Pittsburgh law professor Alan Meisel, high-profile cases like Brittany Maynard's play an important role in sparking national attention, but they do not necessarily change the opinion of those who oppose legislation (Sneed 2014). Maynard drew national attention in 2014, when at the age of 29, she moved to Oregon from California to use the Death with Dignity Act. She had been diagnosed with terminal brain cancer and wanted the option of aid-in-dying (Schierhorn 2015). The median age of Oregonians who use the Death with Dignity Act is 71, so Brittany Maynard's story stood out, especially among younger generations. In a U.S. News and World Report article, Dr. Sandeen explained "It brings the debate to a younger crowd. It brings the debate to a group of individuals who don't normally think about dying every day" (p. 2). Having the support of people in their 20s and 30s could play a crucial role in the future of the legalization of physician-assisted death across the United States (Sneed 2014).

Proponents of the legalized aid-in-dying movement have compared the issue with other controversial legislation, such as same-sex marriage, and they hope the issue takes a similar legislative path (Ollove 2015). This is one of the reasons why having the support of younger generations could be critical in passing laws in individual states (Sneed 2014). Same-sex marriage advocates won victories on a number of fronts such as referendums, the courts, and

state legislatures. Advocates agree that using these same strategies may be necessary to pass Death with Dignity laws across the United States (Ollove 2015).

The approval of physicians on the issue of legalized aid-in-dying has been increasing. According to a national 2014 Medscape survey of over 21,000 physicians, 54 percent of the physicians surveyed believe that physician assistance in dying should be allowed. This percentage is 15 percent higher than reported in the 2010 survey Medscape conducted. This increase is a significant indicator that the acceptance of Death with Dignity laws is increasing among physicians (Schierhorn 2015). Whether this increase in physician approval is based on the increase in public approval is unknown.

One of the most recent states to propose a Death with Dignity bill is Iowa. The bill is being co-sponsored by two Democratic Senate members, including Dick Dearden. Senator Dearden lost a friend to a terminal illness last year, and this experience stressed the importance of having a Death with Dignity law (Tauscheck 2016). Iowa is among several Midwestern states considering aid-in-dying legislation. In fact, the majority of the states that are considering it are in the Northeast and the Midwest. The only state considered culturally southern with any current Death with Dignity legislation is Tennessee (Death with Dignity 2016).

On March 31, 2015, Representative Craig Fitzhugh introduced HB 1040 with two co-sponsors (Tennessee Gov 2016). This bill was named the Tennessee Death with Dignity Act, and it was the first time in the Tennessee legislature that a Death with Dignity bill was considered (Nolo Press 2015). The advocate behind this legislation was John Jay Hooker, a Tennessee resident and attorney who was diagnosed with terminal cancer in January 2015. In a statement to the Tennessean, a Nashville newspaper, Hooker stated, "I want Tennesseans to have the right to

choose how they die, and I want that to be the legacy I leave.” Representative Fitzhugh has said that although he has deep misgivings about the law on a personal level, his fight on behalf of civil rights outweighs his personal feelings (Tennessean 2015). On January 24, 2016 John Jay Hooker lost his battle with cancer. Based on a court declining to hear the case in November of 2015 and Hooker’s passing in January, some commentators feel the Tennessee Death with Dignity bill will fade; however, it remains on the docket for 2016 (Nashville Scene 2016).

My research on Oregon’s Death with Dignity Act has shown that having legalized physician-assisted death has many positive attributes. This in no way implies that there are no negative impacts, but according to the data I collected, the pros outweigh the cons. Aid-in-dying legislation is spreading across the Midwest and the Northeastern United States, and with Tennessee as the lone Southern state, each section of the country has pending Death with Dignity bills. This is strong evidence of the relevance and importance of continued research on this and other end-of-life issues.

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