

## ABSTRACT

### Dignity in Dependency: A Christian Communal Alternative to Physician-Assisted Suicide

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Physician-assisted suicide (PAS) is one manner of dying that people may choose when diagnosed with a terminal illness. Many people who pursue PAS do so because they fear the loss of autonomy that accompanies dying and believe that they will also lose their dignity in the vulnerability and dependency of dying. This thesis intends to challenge the notion that dignity is inherently tied to autonomy, a notion that devalues the lives of individuals who are living and dying with diminished autonomy, and will offer an approach toward dying that honors the dignity of the all people. The rhetoric of supporters of PAS relies on an idea of personhood in which a person is only dignified if they are autonomous. This view does not account for the dignity of all people. This thesis will examine the status of PAS in the United States, focusing on the Death with Dignity Act in Oregon and the supporters of PAS that identify with the ‘death with dignity’ movement. Next, various accounts of personhood will be discussed, and attention will be paid to their accounts of autonomy and dignity. Lastly, this thesis will propose an approach to end-of-life care based on the medieval Christian literary tradition of *ars moriendi*, or the art of dying. Aspects of the *ars moriendi*, particularly cultivation of virtues for the dying person and imitation of the life and death of Jesus, will be reclaimed to support a Christian approach to dying well within community.

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DIGNITY IN DEPENDENCY: A CHRISTIAN COMMUNAL ALTERNATIVE TO  
PHYSICIAN-ASSISTED SUICIDE

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## INTRODUCTION

Death is an experience shared by all human beings, yet the experience of dying is intensely personal and unique to the dying individual. While people are dying, the values that shaped their life come to the forefront and influence their death, determining the attitudes they have, the decisions they make, the people and ideas they cling to. The way a person dies is usually greatly influenced by the way they have lived and the values they have. This thesis was inspired by the author's interest in the ability of death and dying to bring life into such sharp relief. The ideals of an individual are often made known in their dying.

Physician-assisted suicide (PAS) is one manner of dying that people may choose in parts of the world that permit the practice, including in areas of the United States. In this practice, a physician prescribes a lethal dose of medication, and the patient takes the medication to end their life. For it to qualify as PAS, the patient must self-administer the medication; if the physician administers the lethal dose, then the practice is euthanasia, not PAS. This thesis will examine PAS and the people who pursue it as a paradigm for the preoccupation with autonomy in Western culture. Individuals who pursue PAS tend to cite concerns related to loss of autonomy that cause them to consider PAS. In a society that is fixated on autonomy as the fullest expression of being human, people facing debility and deterioration at the end of life may view their dependent state as wholly undignified. If dying strips away a person's autonomy and dignity, then opting for physician-assisted suicide rather than facing the experience of dying may appear to be a way of 'dying well.' The 'death with dignity' movement in the United States has formed

based on the premise that PAS allows people to die with dignity by allowing them to exercise autonomy in death.

The purpose of this thesis is to assert that the rhetoric of the death with dignity movement is based upon an idea of personhood, rooted in an association between autonomy and dignity, that does not honor the dignity of all people. In response to this insufficiency, the author will propose an approach to end-of-life care based on the medieval Christian literary tradition of *ars moriendi*, or the art of dying. This approach aims to honor the dignity of the dying individual *throughout*—rather than *despite*—their weakness, dependence, and vulnerability.

The first chapter will discuss a brief history of euthanasia and physician-assisted suicide in the Western world. Then, the Oregon Death with Dignity Act (DWDA) will be examined as a model for understanding PAS and its practice in the United States, followed by an analysis of the conceptual relationship between dignity and autonomy through the lens of PAS and the ‘death with dignity’ movement. Next, the second chapter will discuss philosophical anthropologies, or accounts of what it means to be human, and examine the roles of autonomy and dignity in various accounts of personhood.

The last chapter of this thesis will share a phenomenological approach to addressing dignity at the end of life, beginning with the perspectives and personal experiences of two Christian disability scholars. From there, this paper will delve into the *ars moriendi* tradition, examining the history, structure, and contemporary applications of the medieval Christian tradition. This thesis will conclude that a modified adoption of the *ars moriendi* and the example of Jesus offer Christians a model for living and dying well within community, honoring the dignity of the dying and the vulnerable.

## CHAPTER ONE

### Physician Assisted Suicide and ‘Death with Dignity’

#### *Introduction*

Physician-assisted suicide, or PAS, goes by a number of names, including physician aid in dying, physician-assisted death or physician-assisted dying, and medical aid in dying, among others. Terms such as PAS and assisted suicide frequently appear in literature and are prominent in the cultural consciousness in the United States surrounding the topic. This paper will use the term ‘physician-assisted suicide,’ while recognizing that ‘suicide’ is a loaded term with significant social and legal implications. The Death with Dignity National Center (DWDNC), an American group that promotes legislation to legalize PAS, advocates for adopting value-neutral language such as physician-assisted dying, physician-assisted death, aid in dying, and death with dignity. They caution that physician-assisted suicide “is an inaccurate, inappropriate, and biased phrase” and that the word ‘suicide’ “implies a value judgement and carries with it a social stigma.”<sup>1</sup> The term ‘suicide’ can potentially introduce bias into conversation surrounding the ethics of physician aid in dying. Despite this recognition, this paper will use the term suicide as it is the most accurate term to describe the self-administration of a prescribed lethal dose of medication.

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<sup>1</sup> “Terminology of Assisted Dying,” Death With Dignity, August 15, 2020, <https://www.deathwithdignity.org/terminology/>.

Though the DWDNC and the ‘death with dignity’ movement disapprove of the term ‘physician-assisted suicide’ for its value-laden language, the first term on the DWDNC’s list of “accurate, value-neutral language” is “death with dignity.”<sup>2</sup> ‘Death with dignity,’ despite the claims of the DWDNC, is far from value-neutral language. This paper will use the term ‘death with dignity’ in reference to the death with dignity movement, a movement that consists of PAS supporters who identify with that terminology. However, this paper will not use the terminology of ‘death with dignity’ as an acceptable, value-neutral substitute for PAS. Contrary to what the DWDNC might suggest with their list of ‘value-neutral language,’ human dignity cannot be discussed without making value claims about human life. As such, this chapter will challenge the DWDNC’s claim that ‘death with dignity’ is a value-neutral term and will explore the values inherent in the language of the death with dignity movement in the United States.

In an effort to examine the significance of the ‘death with dignity’ language of the physician-assisted suicide movement, this chapter will examine the values and the conception of human dignity at the heart of the death with dignity movement. To begin, the history of assisted dying,<sup>3</sup> including PAS and euthanasia, in the Western world will be traced from classical antiquity to the modern United States. Next, the legal context of PAS in the United States will be examined, with particular interest paid to Oregon’s Death with Dignity Act, a seminal piece of American PAS legislation. Lastly, this chapter

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<sup>2</sup> “Terminology of Assisted Dying,” Death With Dignity.

<sup>3</sup> The term “assisted dying” will be used in this paper to refer broadly to euthanasia and physician-assisted suicide as they are understood in a modern context. Though euthanasia and PAS are relatively distinct issues in the current legal environment United States, they did not always bear the same distinction historically. Assisted dying will therefore be used to refer more ambiguously to aid in dying, whether it is a lethal measure directly administered by a physician (what we now call euthanasia) or one prescribed by the physician to be self-administered (what we now call physician-assisted suicide).



will discuss the topic of autonomy in light of statistics gathered from PAS practices in Oregon.

### *Euthanasia and Assisted Suicide in the Western World*

To understand physician-assisted suicide, this paper will begin with euthanasia, PAS's conceptual origin. Euthanasia's meaning in classical antiquity was quite distinct from the modern bioethical definition of this term. Rosenfeld explains that the Romans and Greeks viewed euthanasia, or 'good death,' as referring to a person's state of mind and quality of being in their final moments. To them, "euthanasia implied a happy or easy death, but not necessarily a hastened one."<sup>4</sup> Though the ancient understanding of euthanasia did not necessarily involve assisted dying, suicide was deemed acceptable in various contexts, particularly when quality of life was lacking.

In fact, Roman law did not punish attempted suicide or assistance in another's suicide, and Roman literature contains many references to physician aid in dying.<sup>5</sup> In his letters, Pliny the Younger discusses the intent of Titus Aristo, a man with a painful illness, to end his life if his illness could not be cured "for the sake of his wife, daughters and friends." Pliny characterizes Titus's intentions as "eminently high and praiseworthy."<sup>6</sup> In situations like this one, it is evident how euthanasia in the classical sense could overlap with suicide or assisted death. When a person deemed that their quality of life was no longer worthwhile or that their life had simply become a burden to

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<sup>4</sup> Barry Rosenfeld, *Assisted Suicide and the Right to Die: the Interface of Social Science, Public Policy, and Medical Ethics* (Washington, DC: American Psychological Association, 2004), 14.

<sup>5</sup> Rosenfeld, 15.

<sup>6</sup> Rosenfeld, 15.

others, assisted dying or suicide were options to provide an individual with a ‘good death.’

The Hippocratic school of medicine diverged from the dominant attitude that recognized physician-assisted death as a form of euthanasia, or good death. According to Rosenfeld, the Hippocratic school was responsible for a shift in the understanding of illness away from divine causes and toward physical or physiological causes. Hippocratic physicians centered their work on alleviating symptoms to improve the patient’s well-being, and assisted suicide did not fit into their framework of patient care. The Hippocratic Oath reflects the Hippocratic school’s firm stance against assisted dying. The original oath had physicians declare, “I will neither give a deadly drug to anybody, not even if asked for it, nor will I make a suggestion to this effect.”<sup>7</sup> Despite the Hippocratic stance, condemnation of suicide and assisted dying did not become widespread until Christianity came to dominate Western society.

The rise of Christianity contributed to the diminished popularity of assisted dying, the acceptability of which was already declining in second- and third-century Europe. Christian teachings against suicide and in support of the sanctity of human life transformed the practice of assisted death into “an unthinkable act,” even in the face of great suffering.<sup>8</sup> The writings of St. Thomas Aquinas, the thirteenth century theologian, represent the coalescence of a firm Christian stance against suicide, drawing on the contributions of Aristotle, St. Augustine, and Christian scriptures. St. Aquinas declares in his *Summa Theologica*, “It is altogether unlawful to kill oneself,” and, “suicide is always

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<sup>7</sup> Rosenfeld, 15-16.

<sup>8</sup> Rosenfeld, 16.

a mortal sin, as being contrary to the natural law and to charity.”<sup>9</sup> Understanding euthanasia as ‘good death,’ assisted dying—intentionally causing the death of oneself or of another—could not be considered euthanasia because it was sinful and therefore detrimental to a person’s soul. Christian society placed a ‘good death’ at odds with suicide and assisted dying.

Hippocratic teachings shaped European medical practice for centuries. Between the convictions of the Hippocratic school and Christianity, considerations of physician-assisted dying remained taboo until the nineteenth century. Through the Renaissance and the Enlightenment, some prominent philosophers, such as Sir Thomas More, Francis Bacon, and David Hume, wrote in favor of suicide and assisted dying in cases of unnecessary suffering. Despite the support for assisted dying and suicide from figures such as these, contemporary societal norms and medical practice did not reflect these philosophers’ attitudes.<sup>10</sup>

Discussions around assisted dying and euthanasia began to reappear in the medical community in the eighteenth and nineteenth centuries. Accompanying medical and scientific advancements, more accurate diagnostic and prognostic capabilities enabled physicians to better predict death. As medical knowledge grew and physicians better understood the likelihood of their patients’ survival, physicians and patients had to grapple with what to do with terminal diagnoses.<sup>11</sup> Furthermore, advances in pharmacology supplied analgesics, such as morphine, and the hypodermic syringe, which

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<sup>9</sup> St. Thomas Aquinas, “Whether One Is Allowed to Kill Oneself (Excerpts),” in *Exploring the Philosophy of Death and Dying: Classical and Contemporary Perspectives*, ed. Michael Cholbi and Travis Timmerman (New York: Routledge, 2021), p. 211.

<sup>10</sup> Rosenfeld, *Assisted Suicide*, 16-17.

<sup>11</sup> Rosenfeld, 17-18.

together resulted in the potential for quickly and painlessly ending a person's life.

Though most nineteenth century physicians were in favor of using the new drugs, the consensus was that such medications should be used to prolong life, not to invite death. Yet, there were those who saw the possibilities of these advances in relation to PAS and euthanasia. Between medical advances and changing scientific perspectives, euthanasia was becoming a topic of discussion and debate.<sup>12</sup> Assisted dying, formerly guarded by the values of Hippocratic physicians and Christian society, was no longer an untouchable subject.

Law professor Shai Lavi examines this shift in attitudes toward assisted dying in his book, *The Modern Art of Dying: A History of Euthanasia in the United States*. Lavi notes that dying, which had historically been attended to by family, community members, and religious figures, began transitioning into the realm of medicine in the nineteenth century. He writes, "Whereas in previous centuries the medical doctor would leave the bedside when it was clear that the patient was hopelessly ill, a new ethic developed in which the physician was expected to remain present at the deathbed."<sup>13</sup> Medical care for the dying, replacing the religious bent of the deathbed, became centered on providing hope and comfort for the dying patient.

Lavi describes the new, nineteenth century approach to death, in which physicians shaped the dying experiences of their patients. This approach:

...gave rise not only to euthanasia as the medical treatment of the dying patient but also to euthanasia as the medical hastening of death. Doctors believed that death should follow as soon as hope was gone. So if medicine could not create

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<sup>12</sup> Rosenfeld, 18.

<sup>13</sup> Shai J Lavi, *The Modern Art of Dying: a History of Euthanasia in the United States* (Princeton, NJ: Princeton University Press, 2009), 6.

hope, it should hasten death. The overambitious desire shared by patient and physician to profess hope at the deathbed was the origin of the medical hastening of death, a last resort to the problem of dying. The modern deathbed is simultaneously the place where all hope is lost but also the place where a final effort is made to overcome helplessness by hastening death.<sup>14</sup>

So, euthanasia, or ‘good death,’ became increasingly aligned with medically facilitated death, which was enabled by the advances in anesthetic drugs.

Advocacy for and arguments against assisted death grew in prevalence through the nineteenth century and into the twentieth. Support for euthanasia grew enough in areas of American society that in 1905 a bill to legalize euthanasia was introduced to the Ohio legislature, only for the bill to be thoroughly defeated. A similar bill was proposed and defeated again in Ohio the following year, and euthanasia fell from prominence in the US.<sup>15</sup> Meanwhile, interest in PAS and euthanasia continued to grow in Germany, but such interest was “intertwined by the growing acceptability in eugenics,” culminating in the atrocities of the Holocaust.<sup>16</sup> Assisted dying received little attention in the years after World War II, but public interest in PAS and euthanasia gained steam again beginning in the 1950s. In 1984, a court ruling in the Netherlands made it the first country to allow euthanasia, though euthanasia was not legalized there in any official capacity until 2001.<sup>17</sup> Euthanasia has remained illegal in the United States as a whole, but physician-assisted dying has been legalized in nearly one-fifth of its states since the 1990s.

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<sup>14</sup> Lavi, 60.

<sup>15</sup> Rosenfeld, *Assisted Suicide*, 20-21.

<sup>16</sup> Rosenfeld, 21.

<sup>17</sup> Rosenfeld, 21-22.

## *Physician-Assisted Suicide in the United States*

Legalization of physician-assisted dying in the United States began in Oregon in the 1990s. In 1994, a measure to legalize PAS was placed on the ballot in Oregon, and Oregonians voted in its favor. Oregon’s newly crafted PAS legislation, called the Death with Dignity Act, was initially challenged in court and did not go into effect until 1997.<sup>18</sup> For over ten years, Oregon was the only state in the US with legislation that legalized PAS. In 2008, Washington state implemented its own Death with Dignity Act, and several more states have implemented PAS legislation since then—Vermont (2013), California (2015-16), Colorado (2016), the District of Columbia (2016-17), Hawai’i (2018-19), Maine (2019), and New Jersey (2019).<sup>19</sup> As of 2020, eight states and Washington, D.C. have statutes legalizing physician-assisted suicide. In addition to these eight states and D.C., PAS is permitted, but not legalized, in Montana. Though PAS is not codified in Montana state law, a 2009 Montana State Supreme Court ruling in *Baxter v. Montana* determined that existing state laws do not prohibit PAS. Since then, a Death with Dignity Act has been proposed in Montana, as well as laws prohibiting PAS, but none of those measures have passed.<sup>20</sup>

Meanwhile, Oregon’s Death with Dignity Act (DWDA) has been in effect for over two decades. Oregon has the longest-running history of legal PAS in the US, and its DWDA has been the inspiration for other states’ statutes legalizing PAS. Because of this

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<sup>18</sup> Marjorie B. Zucker, *The Right to Die Debate: a Documentary History* (Westport, Conn: Greenwood Press, 1999), 282.

<sup>19</sup> “Death with Dignity Acts - States That Allow Assisted Death,” Death With Dignity, July 15, 2020, <https://www.deathwithdignity.org/learn/death-with-dignity-acts/>.

<sup>20</sup> “Montana,” Death With Dignity, June 29, 2020, <https://www.deathwithdignity.org/states/montana/>.

history and the robust statistical reports from the Oregon DWDA, this paper will use Oregon as its model to discuss PAS. To understand the logistics of PAS, the following section will examine the regulations and practices under the Oregon DWDA.

### *The Case in Oregon*

The Oregon DWDA has specific requirements of both patients and physicians that must be followed before a patient can receive a lethal prescription. Patients seeking a prescription under the DWDA must meet four criteria before submitting a written request: they must (1) be at least eighteen years of age, (2) be a resident of Oregon, (3) have a terminal diagnosis with a life expectancy of less than six months, and (4) be capable of making reasonable decision about their healthcare.<sup>21</sup> Additionally, the attending physician must fulfill several responsibilities that act as safeguards for the patient:

1. The physician must determine whether the patient meets the aforementioned criteria and is acting voluntarily.
2. The physician must inform the patient of their (a) diagnosis, (b) prognosis, (c) risks associated with the medication prescribed for PAS, (d) the likely lethal result of taking the prescribed medication, and (e) reasonable alternatives to PAS, such as hospice and palliative care.
3. The physician must refer the patient to another physician to confirm the diagnosis and that the patient meets the criteria and is acting voluntarily.
4. The physician must refer the patient to counseling if they may be suffering from depression or another psychological disorder.
5. The physician must ask the patient to inform next of kin of their decision (though patient is not required to do so).
6. The physician must inform the patient of their ability to rescind their request at any time.

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<sup>21</sup> Zucker, *The Right to Die*, 274-275.

7. The physician must confirm that the patient is making an informed decision.
8. The physician must file the appropriate documentation in the patient's medical record.
9. The physician must ensure that all of the previous steps have been followed prior to writing the prescription.<sup>22</sup>

This is just a sampling of the content of Oregon's Death with Dignity Act, but it demonstrates the intent of the act. The act is only intended for a small subset of the population, and it has measures in place to ensure that only the intended population can follow through with PAS.

In addition to the legal criteria and requirements to be met by the patient and physician, the patient must be physically capable of ingesting the lethal medication. PAS under the Oregon Death with Dignity Act is only physician-assisted to the extent that a physician assesses the patient and prescribes the lethal medication to be ingested. The patient bears the burden of initiating their own death by ingesting the medication. Assisted dying wherein another person administers lethal medication to a patient, such as by lethal injection, is considered euthanasia and is legal neither in Oregon nor in the rest of the United States.

#### *Autonomy and Death with Dignity*

Though Oregon is not the only state in the US to have legalized PAS, it was the first, and Oregon's Death with Dignity Act has become archetypal for PAS-related laws and movements in the United States. In fact, supporters of PAS in the United States often

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<sup>22</sup> "Oregon Revised Statute: Oregon's Death with Dignity Act," Oregon Health Authority, 2019, <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ors.aspx>.



refer to themselves as the “death with dignity movement.”<sup>23</sup> The language used to discuss the end of life is inextricably linked to the user’s attitudes toward life and human dignity, as demonstrated by the association between PAS and the phrase “death with dignity.”

Proponents of PAS typically view their position as one that affirms and preserves a person’s dignity and autonomy. That perspective is evident in the language of PAS-related legislation in the US—four Death with Dignity Acts; two End of Life Options Acts; the Our Care, Our Choice Act; the Patient Choice and Control at the End of Life Act.<sup>24</sup> The names of these statutes clearly point to what PAS does *for* patients rather than what it does *to* them. PAS laws and their advocates frame laws for physician-assisted dying with language of dignity, choice, and control. In addition to their emphasis on autonomy, “advocates of legalization [of PAS] buttress their case on the basis of compassion.”<sup>25</sup> Discussing the goals and benefits of PAS, the Death with Dignity National Center writes that:

Death with dignity legislation yields numerous direct and indirect benefits. For the terminally ill, the greatest comfort these laws provide is having the freedom to control their own ending. Most people who obtain medications under these laws value being able to make their own decisions, including the where and when of their death. We know this because people using the law cite loss of autonomy as their chief end-of-life concern. In addition, if you are terminally ill the option to die a peaceful death at a time and place of your choosing provides you with invaluable peace of mind, which is especially important at the end of life. In fact, so many people get reassurance from simply filling the prescription that one in three choose not to use it.<sup>26</sup>

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<sup>23</sup> Susan M Behuniak, “Death with ‘Dignity’: The Wedge That Divides the Disability Rights Movement from the Right to Die Movement,” *Politics and the Life Sciences* 30, no. 01 (2011): pp. 17-32, <https://doi.org/10.1017/s0730938400017652>.

<sup>24</sup> “Death with Dignity Acts - States That Allow Assisted Death,” Death With Dignity, July 15, 2020, <https://www.deathwithdignity.org/learn/death-with-dignity-acts/>.

<sup>25</sup> Rosenfeld, *Assisted Suicide*, 9.

<sup>26</sup> “FAQs - Physician-Hastened Death,” Death With Dignity, June 24, 2020, <https://www.deathwithdignity.org/faqs/>.

This suggests the interrelatedness of dignity, autonomy, and compassionate care as conceived of by PAS advocates. Even the illusion of control given by an unused lethal prescription is understood as a dignifying phenomenon.

The values of autonomy and self-determination are woven into the fabric of American culture and are particularly apparent in the legal system. Rosenfeld asserts that “personal autonomy, the right to make decisions for oneself and to control one’s destiny, is a central principle of American law.”<sup>27</sup> Legal arguments in favor of PAS tend to argue for the importance of choice and self-determination in the dying process and point to autonomy in death as an expression of the personal liberties guaranteed to Americans. Though autonomy and freedom of choice are central values to US law and American identity, federal courts, including the Supreme Court, have not counted PAS as a right protected by the Constitution. Supporters of PAS in New York and Washington sued the states for prohibiting PAS, claiming that such prohibitions violated the 14<sup>th</sup> Amendment’s due-process and equal-protection clauses. The US Court of Appeals for the Second Circuit did not recognize the right to die (by PAS) as a fundamental right protected by the Constitution.<sup>28</sup> The case was appealed to the US Supreme Court, which in 1997 upheld the ruling made by the Court of Appeals, and decisions around the legality of PAS have since been left to the states.<sup>29</sup>

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<sup>27</sup> Rosenfeld, *Assisted Suicide*, 9.

<sup>28</sup> Zucker, *The Right to Die*, 282.

<sup>29</sup> Zucker, xxx.

Whether or not claims based on autonomy in dying have legal merit, the concept of autonomy is ever-present in the minds of those pursuing PAS and those advocating for its legalization. As a provision of Oregon’s Death with Dignity Act, the Oregon Health Authority (OHA) must collect and publish data about the act’s implementation each year. The OHA’s annual statistical report includes the number of prescriptions given under the DWDA, the number of patients who ingest the lethal dose of medication, and demographic information on the patients. The Oregon DWDA annual report also includes the end-of-life concerns given by patients who pursue PAS. Of the 1,585 patients who have died by PAS in Oregon from 1998 to 2019, 90.2% cited “losing autonomy” as one of their end-of-life concerns. The second leading concern has been “less able to engage in activities making life enjoyable,” at 89.3%, and 74.0% expressed concern over “loss of dignity.”<sup>30</sup>

The PAS movement in the US has adopted the phrase ‘death with dignity’ to define the movement and its goals and thus has centered discussion of PAS around dignity. Patients pursuing PAS certainly cite dignity as a concern, but autonomy is the most prevalent concern of those who have died by PAS in Oregon. As noted earlier, the choice alone to obtain a lethal prescription under the DWDA provides comfort for many patients, assuaging their fears of completely losing autonomy in the dying process. In fact, one in three people who fill the prescription for their lethal dose of medication choose not to take it.<sup>31</sup> This one-third receives enough comfort from the option to die on

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<sup>30</sup> Public Health Division, Center for Health Statistics, “Oregon Death with Dignity Act: 2019 Data Summary,” Oregon Death with Dignity Act: 2019 Data Summary § (2020), 12.

<sup>31</sup> Death with Dignity, “FAQs - Physician-Hastened Death.”

their own terms that they choose not to do so. Discussing death with dignity (PAS) legislation, the DWDNC asserts that “the greatest comfort these laws provide [for the terminally ill] is having the freedom to control their own ending.”<sup>32</sup> Terminally ill patients, most of whom fear the loss of autonomy that accompanies their prognosis, regain an ounce of control over their death under legislation such as a Death with Dignity Act. From the perspective of the death with dignity movement, that degree of choice in death preserves the dignity of the dying individual. The death with dignity movement orients its language around dignity while appealing to individuals’ desire for autonomy. If a dignified death is one in which a person is able to exercise autonomy to choose how and when they die, then dignity and autonomy appear to be intrinsically linked.

Legally, measures to preserve and support autonomy can incidentally affirm an individual’s dignity. The meting out of rights that guarantee self-determination is a process that recognizes the equality and dignity of each individual receiving those rights. In the US, a person’s right to vote is an expression of that individual’s inherent value as a human being and as a citizen. Throughout history, parallels exist of suffrage being granted to social groups and the dignity and full humanity of those groups being realized by society. If granting a person the right to vote and to determine the fate of their community dignifies them, then, the death with dignity movement contests, granting a person the right to determine their own fate via PAS laws must be similarly dignifying. Though PAS has not achieved standing as a right on the federal level, some states have granted the right to PAS based on the deeply American value of autonomy as an expression of human dignity.

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<sup>32</sup> Death with Dignity, “FAQs - Physician-Hastened Death.”

The legal argument for autonomy and choice is prominent in the death with dignity movement, but patients are also concerned with autonomy so far as it relates to their physical functioning and independence. Their stated fear of “loss of autonomy” is likely related to a desire to live and die on their own terms, but it is also fear of the physical realities of their prognosis, of dying. As mentioned earlier, the three primary end-of-life concerns are loss of autonomy, loss of dignity, and loss of enjoyment. The concerns listed in the Oregon DWDA report include “burden on family, friends/caregivers” (46.7%), “losing control of bodily functions” (43.9%), and “inadequate pain control, or concern about it” (26.6%). Only 4.3% of patients listed “financial implications of treatment” as a concern.<sup>33</sup> These concerns are interconnected and are associated with the patient’s desire for physical independence.

Physical autonomy, the ability to direct and control their bodies in the minutiae of daily life, seems to be important to many of the surveyed patients. Terminal illness is an often-messy process that involves the gradual loss of control over one’s body. This is the loss of autonomy that patients interested in PAS tend to fear: the loss of control over bodily functions and mental processes. Perhaps PAS patients would rather not ‘burden’ loved ones with the messiness, grief, and inconvenience of a slow death. Or, perhaps their concern of being a burden has to do with their reluctance to relinquish their autonomy. Patients do not want to burden others with the bodily functions they *should* be able to control, the decisions they *should* be able to make.

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<sup>33</sup> Public Health Division, “Oregon Death with Dignity Act,” 12.

## *Conclusion*

Ideas of what constitutes a good death—euthanasia in its original sense—vary across times and cultures. The goodness of an individual’s death is invariably tied to how well it respects the dignity of that individual. The death with dignity movement in the US understands choice to be a major contributor to dignity in death. PAS supporters believe that giving patients choice over the time, place, and means of their death is an affirmation of autonomy and so enables them to die in a dignified manner. Patients who have pursued ‘death with dignity’ in Oregon and died by PAS have cited end-of-life concerns that tie dignity to autonomy. They fear an ‘undignified’ death in which they lose all physical autonomy.

The following chapter will explore the cultural and philosophical backdrop for the death with dignity movement’s association between dignity and autonomy. When such frameworks that tie dignity to autonomy are scrutinized, it becomes evident that those frameworks are insufficient to account for human dignity in all stages of life, including in the experiences of disability and dying. A wholistic picture of dignity in death requires an understanding of dignity as it applies to all people. The death with dignity movement, whether they intended to or not, has inextricably tied dignity to autonomy in the language of their movement and thus has limited the scope of human dignity.

## CHAPTER TWO

### Personhood and Human Dignity

#### *Introduction*

The stance of the death with dignity movement seems to presuppose an account of being human in which human dignity cannot be separated from the individual's capacity for choice and self-determination. Physician-assisted suicide and its supporting narrative conflate a dignified death with a person's full autonomy and freedom of choice in the dying process. This chapter will discuss philosophical anthropologies, or accounts of what it means to be human, that exist within Western culture and, through the cultural dominance of those perspectives, inform movements in favor of PAS. These accounts of being human have shaped the implicit values of the death with dignity movement, wherein an individual cannot fully claim human dignity without first having autonomy. First, the dominant cultural narrative of dignity and autonomy will be examined, as it is portrayed in the work of philosopher Charles Taylor, followed by a personalist<sup>1</sup> perspective on personhood and dignity from sociologist Christian Smith. Subsequently, this chapter will discuss models of disability and those models' implicit accounts of dignity and autonomy. Disability represents a state of personhood in which the dominant philosophical anthropologies, which largely rely on the exercise of autonomy and capacities, fall short.

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<sup>1</sup> Personalism will be defined later in the chapter.

### *Rights, Autonomy, and Dignity in Western Culture*

Canadian philosopher Charles Taylor addresses topics of identity, selfhood, and agency in modern culture through his book *Sources of the Self: The Making of the Modern Identity*. His work focuses on the amalgamation of Western ideologies into the notions of selfhood that now dominate Western culture, thus providing a useful reference for modern perspectives on autonomy and dignity. At the outset of his survey of the development of Western moral identity, Taylor discusses the rise of rights language in the Enlightenment and its impact on Western moral culture:

To talk of universal, natural, or human rights is to connect respect for human life and integrity with the notion of autonomy. It is to conceive people as active cooperators in establishing and ensuring the respect which is due them. And this expresses a central feature of the modern Western moral outlook.<sup>2</sup>

This rights language marks a shift from expressing moral norms in terms of “natural law” to expressing those norms in terms of “natural rights,” according to Taylor.<sup>3</sup> Whereas laws are externally enforced on the individual, rights are possessed by the individual. The framework of rights language for moral norms centralizes the individual person’s agency in exercising what is due to them, their natural rights.

In a moral culture of rights, emphasis lies in a person’s freedom to exert themselves in accordance with their natural rights. Taylor iterates that “autonomy has a central place in our understanding of respect.”<sup>4</sup> Society demonstrates respect for human life and dignity by allowing for and upholding the autonomy of individuals. Taylor refers

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<sup>2</sup> Charles Taylor. *Sources of the Self: the Making of the Modern Identity* (Cambridge, Mass: Harvard University Press, 1989), 12.

<sup>3</sup> Taylor, 11.

<sup>4</sup> Taylor, 12.



to “a particularly modern sense of what respect involves, which gives a salient place to freedom and self-control, places a high priority on avoiding suffering, and sees productive activity and family life as central to our wellbeing.”<sup>5</sup> It seems from Taylor’s description of the modern relationship between respect and autonomy that individuals must earn respect by exercising autonomy. Particularly of interest in this account of this modern sense of respect are the significance of freedom, self-control, and productive activity. These respectable aspects of a person’s life are linked to the individual’s capacity to exercise autonomy, to make choices, and to *do*. A person with diminished physical or mental capacities, who must rely on others for care, may not be able to participate in “productive activity and family life” and so earn respect to the same extent as a more able and autonomous person. Those with less capacity for freedom and self-control, due to disability or illness, therefore, have less social capital for gaining respect within Taylor’s scheme of personhood.

Proceeding to discuss dignity, Taylor clarifies that his use of the word ‘dignity’ is related to the respect an individual commands, or the individual’s perception of commanding respect.<sup>6</sup> According to Taylor’s notion of dignity:

Our ‘dignity,’ in the particular sense I am using it here, is our sense of ourselves as commanding (attitudinal) respect...our dignity is so much woven into our very comportment. The very way we walk, move, gesture, speak is shaped from the earliest moments by our awareness that we appear before others, that we stand in public space, and that this space is potentially one of respect or contempt, of pride or shame...Just what do we see our dignity consisting in? It can be our power, our sense of dominating public space; or our invulnerability to power; or our sense of self-sufficiency, our life having its own center; or our being like and looked to by others...<sup>7</sup>

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<sup>5</sup> Taylor, 14.

<sup>6</sup> Taylor, 15.

<sup>7</sup> Taylor, 15.

This conception of dignity, prevalent in modern culture, is founded in a system of society evaluating an individual for respect based on their physical comportment, behavior, and contribution. The individual's sense of dignity then depends on their perception of their worthiness of societal respect.

While Taylor's evaluation of persons' perceptions of dignity and respect may carry societal weight, such an understanding of dignity poses a predicament for individuals who lose capacities at the end of life. Dying individuals often lose control over their bodies and their social perception and can no longer center freedom, self-control, and productive activity in their lives. In a cultural context that so highly values autonomous capacities, the lives of dying individuals may appear, to them and to society, to be less dignified and less worthy of respect because of their loss of control. Philosophical anthropologies that center autonomy diminish the perceived dignity of the dying because of the loss of autonomy that so often precedes death.

The celebration of autonomy indicated by Taylor becomes problematic when society establishes autonomy as the basis for the good life or a life worthy of respect. In her book *How Then Should We Die?*, S. Kay Toombs examines and responds to the dominant values that inform the death with dignity movement. In a culture that places a premium on autonomy, independence, and self-determination, Toombs recognizes that "cultural attitudes contribute to the perception of loss of dignity" and can lead to the feeling that "one's value as a person is irreparably diminished"<sup>8</sup> with the loss of those culturally valuable traits.

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<sup>8</sup> S. Kay Toombs, *How Then Should We Die?: Two Opposing Responses to the Challenges of Suffering and Death* (Colloquium Press, 2018), 5-6.

Toombs specifies autonomy and independence as prominent values that impact both individual and cultural responses to end-of-life. “One of the most powerful barriers to retaining a sense of dignity in illness is the cultural perspective on autonomy—an ideal that...stresses self-reliance, personal preference, and self-determination.”<sup>9</sup> Cultural norms teach each person to expect “to be able ‘to do their own thing,’ without a sense of limits.”<sup>10</sup> These expectations create shame and a sense of loss of dignity when, as a result of illness, a person can no longer ‘do their own thing’ and act independently and must instead rely on others.

Additionally, Toombs indicates cultural preoccupations with *doing* as a contributing factor in the perceived loss of dignity that accompanies disability and illness. The “cultural emphasis on ‘doing’ as opposed to ‘being’” encourages an association between a person’s value and their productivity.<sup>11</sup> She writes, “Given this cultural attitude, a person who is unable to ‘do’ not only feels diminished by the inability to engage in projects that are deemed meaningful...but he or she also feels no longer able to contribute anything of worth to others.”<sup>12</sup> Toombs goes on to clarify that this problem of feeling diminished by being unable to ‘do’ can be resolved by affirming the value of ‘being,’ without any expectation of ‘doing.’<sup>13</sup>

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<sup>9</sup> Toombs, 5-6

<sup>10</sup> Toombs, 6.

<sup>11</sup> Toombs, 9.

<sup>12</sup> Toombs, 9.

<sup>13</sup> Toombs, 9-10.

At their core, fears surrounding the loss of dignity at the end of life are generally associated with fears of losing control.<sup>14</sup> With the primacy of “absolute autonomy, radical individualism, and the exercise of personal control,” Toombs states that, “for many people, incurable illness represents a totally unacceptable loss of individual control.”<sup>15</sup> A culture that elevates autonomy to the position of a cardinal virtue will ultimately create a population that struggles to discern dignity in the loss of control that accompanies illness, disability, and dying.

### *Emergent Personhood and Dignity*

The work of sociologist Christian Smith in his book *What is a Person?* will be explored as an alternative to the dominant Western perspective described by Taylor. Smith’s work is useful in the conversation on autonomy and dignity because of his personalist perspective, which emphasizes the irreducibility of personhood and the dignity intrinsic to all persons. The *Stanford Encyclopedia of Philosophy* describes the commitments and characteristics of personalism as such:

Though personalism comprises many different forms and emphases, certain distinctive characteristics can be discerned that generally hold for personalism as such. These include an insistence on the radical difference between persons and non-persons and on the irreducibility of the person to impersonal spiritual or material factors, an affirmation of the dignity of persons, a concern for the person’s subjectivity and self-determination, and particular emphasis on the intersubjective (relational) nature of the person.<sup>16</sup>

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<sup>14</sup> See the section *Autonomy and Death with Dignity*, beginning on page 10. Statistics from the Oregon DWDA annual report on end-of-life concerns are listed on pages 13 and 15.

<sup>15</sup> Toombs, *How Then Should We Die?*, 12.

<sup>16</sup> Thomas D. Williams and Jan Olof Bengtsson, “Personalism,” *Stanford Encyclopedia of Philosophy* (Stanford University, May 11, 2018), <https://plato.stanford.edu/entries/personalism/#DigPer>.

Personalism challenges a capacities-based account of personhood and dignity, which reduces a person's dignity and humanity to their abilities. Instead, personalism offers a perspective that attempts to include all human beings in the fullness of personhood.

In *What is a Person?*, Smith proposes a model of personhood wherein personhood is an emergent property of humans. Emergence is a process of entities coming together and interacting to produce “a new entity with its own particular characteristics,” which were not present in the new entity's constituents.<sup>17</sup> The lower-level entities that interact and give rise to emergent entities cannot fully account for the qualities of the emergent entity. Smith understands personhood as such an emergent entity that is greater than the sum of its constituent “parts.”<sup>18</sup>

In Smith's model, personhood emerges from various “causal capacities,” which are powers that “endow humans with the ability to bring about changes in material or mental phenomena, to produce or influence objects and events in the world.”<sup>19</sup> These causal capacities do not fully account for personhood, but they are necessary contributors to personhood's emergence. Smith enumerates thirty specific human causal capacities (he later clarifies that this is not an exhaustive list), some of which include the capacity for conscious awareness, volition, mental representation, language use, acting as an efficient cause, and identity formation, among many other capacities.<sup>20</sup>

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<sup>17</sup> Christian Smith, *What Is a Person?: Rethinking Humanity, Social Life, and the Moral Good from the Person Up* (Chicago, IL: University of Chicago Press, 2011), 25-26.

<sup>18</sup> Smith, 26.

<sup>19</sup> Smith, 42.

<sup>20</sup> Smith, 54.

Personhood emerges from causal capacities but does not consist of them. In “normal”<sup>21</sup> humans, personhood is an emergent property consisting of two primary components: center and purpose. The personal center “acts as the personal core or heart that integrates, coordinates, and directs those [causal] capacities in new, purposeful ways.”<sup>22</sup> While even Smith admits that the center is difficult to define or explain, it is essentially the locus of a person’s subjective experience and selfhood. The purpose of personhood “is to develop and sustain the person’s own incommunicable self in loving relationships with other personal selves and with the nonpersonal world.”<sup>23</sup> This emergent purpose directs the lower-level capacities and requires their existence for its own engagement, but purpose is altogether distinct from causal capacities. Center and purpose are interdependent in the person, each requiring the other to function and exist.

Smith’s theory of personhood focuses on human awareness and agency as key factors in both the emergence of personhood from capacities and in the very nature of personhood. Persons with mental illnesses or disabilities that affect their purposive center are marginal cases for Smith. He asserts that “radically damaged persons, to be clear, have not ceased to be persons” and that even these people still possess personal centers.<sup>24</sup> However, Smith does not explain how a person may still possess the emergent property

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<sup>21</sup> “Normal” humans are those “who are not seriously damaged physically and mentally and have not seriously deteriorated in their functional capacity.” People with disabilities or diseases that impact their functional and cognitive capacities should not be counted as normal, Smith asserts. Distinguishing between *normal* and *nonnormal* humans is essential to Smith’s discussion of personhood (Smith, 45). Smith’s use of “normal” and “nonnormal” will be discussed later in this chapter.

<sup>22</sup> Smith, 79.

<sup>23</sup> Smith, 80.

<sup>24</sup> Smith, 82.

of personhood if they are missing all of the causal capacities he listed. If a person does not have the capacities necessary to be a center of subjective experience or to have purpose, what then of their personhood? Though Smith claims personhood for all humans, his theory of emergent personhood seems to exclude people with diminished or nonexistent causal capacities from full personhood. In a footnote on “normal” persons, Smith asserts that he does not intend “to stigmatize nonnormal humans or to exclude them from the community of persons enjoying all of the rights pertaining thereto,”<sup>25</sup> yet he does not provide an adequate account of the personhood of “nonnormal” humans to save them from stigmatization and exclusion.

From his theory of emergent personhood, Smith proposes that human dignity is also an emergent property. Dignity emerges from the level of personhood, not the lower-level capacities from which personhood emerges. Human dignity does not arise from capacities such as agency or rationality, Smith argues. Rather, “dignity is a natural, irreducible, brute-fact property of personhood, not the result of exercising some capacity or other.”<sup>26</sup> Smith seems keen to ascribe dignity as an emergent property of personhood in order to include all human persons in the reality of dignity, and he revisits the notion of personhood to bolster his claims for universal human dignity.

Smith recognizes that his theory of personhood appears to create the same problem as capacity-based, non-emergent accounts of human dignity: persons without certain capacities are excluded from dignity. He reminds the reader “that personhood is proactively emergent,” meaning “that personhood adheres to each human from the start

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<sup>25</sup> Smith, 45.

<sup>26</sup> Smith, 455.

with everything needed to develop and unfold itself.”<sup>27</sup> A person can develop their capacities and grow into a fuller expression of their personhood, but they never “become ‘more’ of a person” because personhood is already a part of their being.<sup>28</sup> Personhood develops alongside a person’s capacities throughout their life, although illness and impairments may “impede a mature expression of the development of normal personhood.”<sup>29</sup> There is no human without personhood because they lack causal capacities. While variations in the expression of personhood exist between persons, Smith is insistent that every human possesses personhood and, by extension, dignity.

In Smith’s account of personhood and human dignity, he attempts to refute what he calls “capacities-based accounts.”<sup>30</sup> Such accounts of human dignity claim that “human persons possess dignity by virtue of certain specifiable dignity-conferring capacities that they have, such as rational nature or purposive agency.”<sup>31</sup> Smith recognizes that a capacities-based account of human dignity problematically does not properly account for the dignity of those whose capacities are temporarily or permanently diminished. He cites people with mental illness, disability, or Alzheimer’s; people in comas or states of unconsciousness; fetuses and infants. By making dignity an emergent property of personhood, Smith attempts to account for the inherent dignity of all persons.

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<sup>27</sup> Smith, 457.

<sup>28</sup> Smith, 458.

<sup>29</sup> Smith, 457.

<sup>30</sup> Smith, 447.

<sup>31</sup> Smith, 447.



However, Smith's theory of emergent personhood is marginally inclusive at best of what he calls "nonnormal" humans and does little to illuminate the state of personhood in these marginal cases. Smith ensures that all people can be said to have dignity, and he claims that "there are no varying degrees or partial states of the being of personhood."<sup>32</sup> Still, his account of fully actualized and flourishing personhood does not include those beyond his boundaries of "normal." Personhood as Smith depicts it involves a purposive, self-aware center, and this notion of personhood ultimately appears inextricable from the cultural values of rationality, agency, and autonomy.

In a footnote, Smith clarifies that his ideas of personhood rely on the assumption that there is a category of "normal" human persons into which most humans are grouped. Smith's use of the word normal "is not intended to stigmatize nonnormal humans or exclude them"<sup>33</sup> from community and the enjoyment of rights. Smith claims that he must distinguish between normal and nonnormal because "it is simply not possible to effectively examine the issues raised in this book without distinguishing between what is normal and what is seriously damaged and deteriorated."<sup>34</sup> While Smith specifies that he does not wish to exclude persons whom he would categorize as nonnormal, his account of personhood does not seem to allow for nonnormal persons to experience the fullness of personhood. If dignity is emergent from personhood, then marginal participation in personhood seems to imply marginal possession of dignity.

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<sup>32</sup> Smith, 458.

<sup>33</sup> Smith, 45.

<sup>34</sup> Smith, 45.

Smith's notion of emergent dignity based on personhood attempts to establish the constancy of a person's dignity, even as they lose capacities through illness, disability, or aging. Even so, Smith does not adequately address the lived reality of personhood in the liminal spaces of end-of-life and disability, where a person exists as a "nonnormal" human. His account of personhood relies on purpose and self-awareness and provides no real description of what personhood is for those who permanently lose or have never possessed the capacity to direct a purposive center. Without adequate assurance of the ubiquity of personhood, dignity as an emergent property of personhood falls short of encompassing all humans. This seems to leave dying individuals questioning their personhood along with their dignity as they lose autonomy.

#### *Autonomy and Models of Disability*

Conventional Western anthropologies tend to emphasize a person's abilities and their capacity for choice in discussions of personhood and dignity. The good, dignified life is one in which a person can exercise a maximum of choice and self-determination. For those who believe that the lives of persons with disabilities can also be good and dignified, disability ought to challenge the notion that dignity and fullness of personhood are dependent on the capacity for choice or the ability to exercise autonomy. However, Christian ethicist Hans S. Reinders notes in his book *Receiving the Gift of Friendship* that the disability rights movement and the field of disability studies has by and large fallen short of challenging the dominant veneration of autonomy. This section will use Reinders' work to examine the goals of disability studies and the way the field falls short of addressing the issue of personhood and dignity being linked to autonomy.

In *Receiving the Gift of Friendship*, Reinders explores the *telos*, or purpose, of being human, seeking an answer that allows individuals with profound intellectual disability to participate in the human *telos*. According to Reinders, though disability studies scholars do not typically engage in questions of human nature or purpose, they still rely on an account of being human to guide their work. In fact, “they are guided by a concept of human nature that understands human *telos* in terms of freedom of the self,” despite this concept’s contribution “to the source of the exclusion of people with profound intellectual disabilities in the first place.”<sup>35</sup> Though *telos* was not explicitly mentioned in the previous sections, Taylor, Smith, and the dominant models of personhood operate under the assumption that the human *telos* is autonomy and the exercise of capacities. Disability scholars work within the same framework, which assumes “freedom of the self” to be the goal of human life.

When speaking of disability studies and disability rights advocates, Reinders speaks of “social constructionism” in conjunction with these groups. The social constructionist approach to disability is the basis for the social model of disability, which claims that disability is a product of society rather than a person’s defectiveness. Social constructionism and the social model of disability recognize that disability “is constituted by a complex set of factors, including stigmatized impairments, physical environments, social arrangements, and cultural values.”<sup>36</sup> Though Reinders acknowledges that the social model is useful for addressing the oppression and marginalization of people with

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<sup>35</sup> Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: William B. Eerdmans Publishing, 2008), 52.

<sup>36</sup> Reinders, 56.

disabilities,<sup>37</sup> he points out that the social model is insufficient to address the lived experience of physical impairment experienced by many people with disabilities.<sup>38</sup>

Reinders then turns to “disability identity” as another framework from which individuals with disabilities understand disability in relation to their lives.

“Disability identity” allows individuals with disabilities to claim their disabilities and experiences as parts of themselves. Unlike social constructionism, disability identity approaches disability on an individual level where individuals are given space to identify as disabled. Reinders says, “Naming oneself ‘disabled’ as part of what one is may be an act of naming that empowers a person” and “an act of self-affirmation.”<sup>39</sup> The disability identity movement encourages individuals to name and claim their disability as part of their identity. Language is an exercise in power, and the emphasis on claiming and naming one’s identity to assert one’s personhood relies on a framework in which personhood is still dependent on autonomy and the exercise of capacities.

While Reinders admits the benefits of social constructionism and disability identity in pushing for social change and broader recognition of people with disabilities, these approaches to disability ultimately fail to challenge the hierarchies of an ableist<sup>40</sup> society. In these approaches, “the default position is occupied, either implicitly or explicitly, by the disabled person as a purposeful agent competent of self-

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<sup>37</sup> Reinders, 59.

<sup>38</sup> Reinders, 63.

<sup>39</sup> Reinders, 65.

<sup>40</sup> An ableist society consists of structures based on the views of ableism. Ableism is a “type of discrimination in which able-bodied individuals are viewed as normal and superior to those with a disability, resulting in prejudice toward the latter” (“Ableism,” Encyclopædia Britannica).

representation.”<sup>41</sup> Both the paradigm of disability identity and that of social constructionism rely on the assumption that an individual’s actualization as a person lies in their exercise of choice and will.

Reinders can then note that, according to “the philosophy informing disability culture...having a good life is dependent on what I can choose to do with my life.”<sup>42</sup> For individuals who lack the capacity to choose due to intellectual disabilities, the philosophy of disability culture reinforces their apparent exclusion from a “good life.” Reinders asserts that “if there is to be an inclusive account of the good life, it cannot depend in any way on the centrality of the choosing self.”<sup>43</sup> If the lives of all persons are to be recognized as worth living and capable of being good, then the cultural imagination of the good, dignified life must expand to include persons who cannot exercise autonomy. The next chapter will pursue a narrative for dying well and dying with dignity that includes all people, not just the able-bodied and independent.

### *Conclusion*

The dominant narratives of personhood and dignity in Western culture lead individuals to implicitly associate dignity and autonomy. Thus, the capacities of persons for action and self-determination contribute significantly to their sense of dignity and contribute to the diminishment of that sense in cases of illness, disability, and end-of-life. Even the efforts of Smith’s personalist account of dignity and the social model of disability, which attempt to affirm the worth and dignity of all persons, fail to escape the

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<sup>41</sup> Reinders, 80.

<sup>42</sup> Reinders, 135.

<sup>43</sup> Reinders, 138.

cultural valuation of autonomy. Accounts of personhood that affirm the centrality of autonomy promote the perspective that encourages people to pursue PAS—the perspective that a life with diminished autonomy is less dignified and is not worth living. An understanding of dignity that is independent of capacities or control is necessary to respond to the concerns of dignity posed at the end of life.

This chapter explored philosophical accounts of personhood and dignity and noted the problematic assumption that full, dignified personhood is dependent on the capacity for autonomy. Such an assumption is inherent in the rhetoric of the death with dignity movement, which views vulnerability and dependence as experiences which diminish the dignity of the dying person. In response, the following chapter will offer a phenomenological response to the problem of dignity and PAS, with the goal of honoring the dignity of the dying person.

## CHAPTER THREE

### Reclaiming Dignity in Dependency

#### *Introduction*

In the previous chapters, this paper examined the “death with dignity” movement and PAS in the United States, followed by cultural accounts of personhood and dignity. This chapter will offer alternative perspectives on human dignity in the face of the loss of autonomy at the end of life. First, the stances of disability scholars Christopher Newell and S. Kay Toombs will be discussed, as they proffer attitudes toward loss of physical autonomy that oppose the dominant cultural narratives of a dignified life (and death) associated with volition and autonomy. Next, this chapter will explore the *ars moriendi*, or the art of dying, an approach to dying practiced by medieval Christians, as a response to PAS and the culturally conditioned value of autonomy. Ultimately, it will be argued that Christian community offers a model for the appropriate, dignifying response to loss of autonomy at the end of life.

#### *Alternative Perspectives on Loss of Autonomy*

Christopher Newell and S. Kay Toombs are both disability scholars who write from their lived experiences of disability. Newell and Toombs invite their readers to challenge culturally conditioned responses to end-of-life and disability that encourage rejection of the body, isolation, and pursuit of death. Incontinence will be a focus of this section, along with general loss of bodily function, as the experience of incontinence is frequently associated with shame and loss of dignity.

Christopher Newell, an Anglican priest and Australian disability rights activist, writes about the fears inherent to the loss of control over one's body, particularly in the case of incontinence. Newell shares the account of Bob Dent, the first person to die an assisted death by way of the *Rights of the Terminally Ill* legislation in the Northern Territory of Australia. The day before he died, Dent dictated to his wife a statement explaining his motivations for dying, in which he emphasizes the indignity of his loss of bowel control. Dent says, "If I were to keep a pet animal in the same condition I am in, I would be prosecuted."<sup>1</sup> Newell relates to this aspect of Dent's story and shares, "I have personally wanted to die when I have lost continence."<sup>2</sup>

Despite his personal anguish with the experience of incontinence, Newell pushes back against perspectives that would use the difficulty of incontinence as an argument in favor of PAS and euthanasia. Newell cites John Hockenberry, whose writings share his own experience with disability, in response to the "devastating topic of incontinence."<sup>3</sup> Hockenberry argues that "physical limits are a binding force in society," and "openly acknowledging limitations binds and draws people together, as an emblem and reminder of just how similar we all are."<sup>4</sup> Hockenberry's perspective challenges the perception that incontinence and other limitations that accompany disability and end-of-life are necessarily demeaning and isolating. Instead, physical limitations and loss of control offer opportunities for community in the midst of vulnerability.

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<sup>1</sup> Christopher Newell, "Disability, Bioethics, and Rejected Knowledge," *The Journal of Medicine and Philosophy* 31, no. 3 (January 2006): pp. 269-283, <https://doi.org/10.1080/03605310600712901>, 277.

<sup>2</sup> Newell, 278.

<sup>3</sup> Newell, 278.

<sup>4</sup> Newell, 278.



In response to the widely supported notion that the appropriate response to the loss of ability and independence is withdrawal and death, Newell poses this question: “Can we be more counter (Western) cultural, than to suggest that it is the isolation of the radically individual that is non-human, rather than the dependence of us humans upon one another?”<sup>5</sup> Newell proposes that the appropriate response to disability and loss of bodily function is involvement and communal support. When one’s failing body precludes independence and requires the care of others, the culturally conditioned response to isolate oneself from such support is in fact a “non-human” response. Newell’s idea of what is “non-human” directly contrasts with the accounts of personhood in the previous chapter, in which a person’s dignity or full ‘personhood’ is contingent on their capacity for autonomy. The “non-human” mode of being, according to Newell, is not deviation from the ‘norm’ of independence and ability but is isolation from—and rejection of—community. Newell’s counter-cultural stance indicates that dignity is present in the relational openness of giving and receiving care, rather than in the “radically individual” act of pursuing control through death.

Returning to the story of Bob Dent, Dent shares in his account his concerns around burdening his wife. “My own pain,” he writes, “is made worse by watching my wife suffering as she cares for me; bathing and drying me, cleaning up after my ‘accidents’ in the middle of the night, and watching my body fade away.”<sup>6</sup> Dent’s experience of incontinence paired with his inability to clean up after himself multiplies his suffering because he sees himself as a source of suffering for his wife. Perhaps in a

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<sup>5</sup> Newell, 278.

<sup>6</sup> Newell, 277.

culture less concerned with absolute autonomy, Dent's suffering could have been alleviated instead of multiplied by his reliance on his wife. Newell and Hockenberry's framework for viewing loss of bodily control allows for reliance to be an acknowledgement of dignity, rather than a denial of dignity. Hockenberry notes limitations and the need to rely on others can bind together members of a community, while Newell insists that the rejection of care and insistence on independence is a "non-human" act. S. Kay Toombs claims, "If you can demonstrate to me that my illness does not degrade my worth as a person, you affirm me in a powerful manner,"<sup>7</sup> confirming the ability of communal care to acknowledge and affirm the dignity of the person receiving care.

Toombs, in her book *How Then Should We Die?*, writes from her own experience of disability with Multiple Sclerosis and responds to the "death with dignity" movement and the growing support for PAS. Toombs examines the cultural values fueling the fear of "loss of dignity," particularly the Western emphasis on autonomy and independence and the fear of loss of control born of those values. Like Newell, Toombs discusses incontinence as a prominent example of loss of control manifest in the lives of those dealing with illness.

Toombs writes that incontinence represents "the most grievous experience of loss of dignity" for many, due to social stigma produced by the cultural emphasis on self-sufficiency and control:

Not only does one feel oneself reduced to the status of an infant (with the accompanying sense that, as an adult, one really "ought" to be able to exercise control), but there is the ever-present threat of public humiliation. This threat of

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<sup>7</sup> S. Kay Toombs, *How Then Should We Die?: Two Opposing Responses to the Challenges of Suffering and Death* (Colloquium Press, 2018), 14.

humiliation can be overwhelming in light of certain cultural attitudes that treat such disorders with contempt. So harrowing is the possibility of public disgrace that many patients withdraw from social interaction. Some decide to end their lives on the grounds that incontinence robs them of all personal dignity.<sup>8</sup>

Toombs concludes this analysis of the relationship between incontinence and perceived loss of dignity by referencing data from the 2017 Oregon DWDA annual report. That report shows that 37.1% of patients designated “losing control of bodily functions” as a reason for pursuing PAS.<sup>9</sup> Out of all patients who have pursued PAS in Oregon from 1998 to 2019, 43.9% cited “losing control of bodily functions” as an end-of-life concern.<sup>10</sup>

In response to the prevalent concerns surrounding incontinence and loss of control over bodily functions at the end of life, Toombs shares her experience with caring for her husband at the end of his life. Toombs says that her experience with MS allowed her to “understand the powerful feelings of degradation that come with loss of bodily control.”<sup>11</sup> Because of her experience and understanding, she was able to help her husband understand that the failings of his body were “purely mechanical” and not indicative of any personal failings on his part.<sup>12</sup> As this paper has already cited, Toombs says, “If you can demonstrate to me that my illness does not degrade my worth as a person, you affirm me in a powerful manner.”<sup>13</sup> From Toombs’ account, she was able to affirm her

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<sup>8</sup> Toombs, 12-13.

<sup>9</sup> Toombs, 13.

<sup>10</sup> Public Health Division, Center for Health Statistics, “Oregon Death with Dignity Act: 2019 Data Summary,” Oregon Death with Dignity Act: 2019 Data Summary § (2020), 12.

<sup>11</sup> Toombs, *How Then Should We Die?*, 13.

<sup>12</sup> Toombs, 13.

<sup>13</sup> Toombs, 14.

husband's dignity through her manner of relating to him, further supporting the notion that dignity is not affirmed by individual acts of autonomy so much as it is by communal care.

Ultimately, Toombs proposes Christian community as a model for the appropriate response to disability, suffering, and the end of life. While the aforementioned model from Newell and Hockenberry, which emphasized the necessity of communal response to disability, was not explicitly Christian, their relational focus shares in the themes of Toombs' Christian community. Drawing from her experience of communal Christian living, Toombs presents a "radically alternative perspective grounded in the counter-cultural values and practices of intentional Christian community."<sup>14</sup> Toombs outlines the ways in which intentional Christian community affirms the dignity of people in all stages of life:

In deliberately rejecting the cultural perspective on radical autonomy and self-determination, such a community affirms the centrality of covenantal relationship in our lives as Christians: relationships with God and with one another. This covenantal relationship is built upon the foundation stone of self-sacrificial love. The focus is on honoring and serving one another as the expression of the love of God. The values and practices that spring from this foundational ethic necessarily affirm human dignity in all circumstances and provide a nurturing context in which it is possible for individuals to retain personal integrity and worth in the face of pain, suffering, and the inevitable uncertainties and vulnerabilities experienced in serious illness, ageing and dying.<sup>15</sup>

The Christian life of community, according to Toombs, responds to physical ailments in a manner that nurtures the dignity of the ailing person without allowing that dignity to be called into question.

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<sup>14</sup> Toombs, 93.

<sup>15</sup> Toombs, 94.

In the context of Christian community, Toombs reframes the sacrificial actions of caregivers as “love” rather than burden. Earlier in her book, while discussing attitudes surrounding autonomy and independence, Toombs points out that the cultural focus on autonomy results in “the act of ‘giving,’ of serving another” being “negatively equated with self-denial.”<sup>16</sup> It is this negative understanding of self-sacrifice that causes ill or dying patients to fear burdening their loved ones, as Bob Dent did. In Christian community, the same type of self-sacrifice through caregiving is a necessary aspect of covenantal relationships, as modeled by Jesus. She notes, “Since selfless love is the cardinal value, caregiving (care of and for another) is not considered a negative form of self-sacrifice, but, rather, it is the foundation of Christian community.”<sup>17</sup> In this perspective, caregiving is yet another aspect of love and relationship and gives dying individuals assurance even in their loss of autonomy.

Furthermore, Christian community offers a context in which reciprocity abounds, particularly in the acts of giving and receiving care. Toombs recognizes that caregiving “is a form of communion (of sharing with one another) in which *all* participants both give *and* receive.”<sup>18</sup> She says of her community, “Rather than viewing ourselves as either dependent or independent, we affirm and celebrate our mutual *interdependence*.”<sup>19</sup> Caregivers are also gifted in being able to care, receiving the love, friendship, and example of those for whom they care. The following section will explore the solidarity

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<sup>16</sup> Toombs, 6.

<sup>17</sup> Toombs, 95.

<sup>18</sup> Toombs, 96.

<sup>19</sup> Toombs, 96.

and reciprocity that is possible in care for the dying through the lens of the *ars moriendi*, or the Christian art of dying.

*Ars Moriendi: Reclaiming the Christian Art of Dying in Response to PAS*

This section will examine the tradition of *ars moriendi*, the medieval Christian art of dying well, and will consider *ars moriendi* as a model for a Christian communal response to dying in the modern day. Physician assisted suicide appears a palatable, and even preferable, option for death in a society that exalts autonomy and abhors weakness and dependence. A reimagining of *ars moriendi* can offer an alternative approach to dying that honors the dignity of dying individuals amid their infirmity.

*Ars moriendi* originated in fifteenth-century Europe and maintained popularity into the 18<sup>th</sup> century. It was a genre of Christian literature designed to guide the reader through the process of dying, “a self-help manual for the person who was dying...a set of instructions for dying well.”<sup>20</sup> Two early, seminal works of the genre include the *Tractatus artis bene moriendi*, written around 1415, and the *Ars Moriendi*, a shorter, illustrated adaptation written later in the fifteenth century.<sup>21</sup> Both of these works, along with the literary tradition that accompanied them, encourage the dying individual to turn toward God, cultivate virtue, and find peace in death.

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<sup>20</sup> Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids, MI: William B. Eerdmans Publishing Co., 2011), 81.

<sup>21</sup> Christopher P. Vogt, "Art of Dying, the (Ars Moriendi)," *Encyclopedia of Death and the Human Experience*, ed. Clifton D. Bryant and Dennis L. Peck (Sage Publications, 2009), [http://ezproxy.baylor.edu/login?url=https://search.credoreference.com/content/entry/sagedhe/art\\_of\\_dying\\_the\\_ars\\_moriendi/0?institutionId=720](http://ezproxy.baylor.edu/login?url=https://search.credoreference.com/content/entry/sagedhe/art_of_dying_the_ars_moriendi/0?institutionId=720).

The *Tractatus artis bene moriendi* was the model for the medieval *ars moriendi*, to the extent that it was translated into nearly every major European language.<sup>22</sup> The *Tractatus*, its many translations, and those works modeled after it follow a six-part structure. First is the commendation of death, which asserts that “Christians...need not and should not be sorry at the prospect of death or troubled by it.”<sup>23</sup> The second section warns the dying of the temptations that they will encounter and advises them of how to avoid or resist those temptations. The third section contains the ‘interrogations,’ or “a little catechism with questions and answers concerning faith, repentance, and the assurance of God’s pardon.”<sup>24</sup>

Following the interrogations, the fourth section instructs the dying to remember and reflect on Jesus’s death as an example of how to die well and faithfully, providing prayers for the dying individual to pray.<sup>25</sup> The fifth section provides further instruction, primarily concerned with “the responsibilities of the Christian bystander towards the dying man.”<sup>26</sup> Friends and caregivers, according to the *ars moriendi*, should be honest with the dying about their physical condition and should be equally frank regarding the dying individual’s spiritual health.<sup>27</sup> Lastly, the sixth section provides a sequence of prayers to be prayed over the dying person.<sup>28</sup>

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<sup>22</sup> David William Atkinson, *The English Ars Moriendi* (New York: Peter Lang, 1992), xi.

<sup>23</sup> Verhey, *The Christian Art of Dying*, 91.

<sup>24</sup> Verhey, 158.

<sup>25</sup> Verhey, 161-162.

<sup>26</sup> Atkinson, *The English Ars Moriendi*, xiv.

<sup>27</sup> Verhey, *The Christian Art of Dying*, 167.

<sup>28</sup> Verhey, 87.

While the *ars moriendi* encourages helpful practices of prayer, introspection, and turning to God for the dying individual, aspects of the *ars moriendi* are problematic or unhelpful for the modern reader. Christian ethicist Allen Verhey, in his book *The Christian Art of Dying: Learning from Jesus*, reclaims and reforms the medieval Christian tradition of *ars moriendi* to create a model for dying well and caring well for the dying within Christian community. In doing so, Verhey critiques the parts of the tradition that are unfounded in Christian orthodoxy and threaten to lead the dying individual astray.

Challenging aspects of the medieval *ars moriendi* include a focus on God's judgement of the dying individual, as well as Platonic soul-body dualism and Stoic influences that prompt the commendation of death. The *Tractatus* encourages one to die willingly and gladly, despite physical suffering, because one "should surely prefer to accept physical punishment from God in dying rather than experience God's everlasting vengeance beyond the grave."<sup>29</sup> Furthermore, *ars moriendi* literature "commends death as the liberation of the immortal soul from the body."<sup>30</sup> Behaviors that center on fear of punishment and denial of the body are not useful to practices of dying well that seek to honor the dignity and integrity of the person, including their body. Rather, a contemporary art of dying well can draw on the remnants of *ars moriendi* that serve to center the dignity of the dying person.

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<sup>29</sup> Vogt, "Art of Dying."

<sup>30</sup> Allen Verhey and Brett McCarty, "The Virtues for Dying Well," in *Death: Christian Reflection: A Series in Faith and Ethics*, ed. Robert Kruschwitz (Waco, TX: The Center for Christian Ethics, Baylor University, 2013), 27.



Additionally, Verhey points out the significant influence of Stoicism within the *ars moriendi*, an influence that he believes ought to be eliminated from any modern reclamation of the *ars moriendi* tradition. *Crafte and Knowledge For To Die Well*, an early *ars moriendi* manuscript, cites Christian scripture alongside Seneca, the Roman Stoic, to commend death. According to the *Crafte*, Christians should readily accept death as “nothing elles but agoyng owte off pryson and endyng of exyle, and dyscharyng off an hevy burden that ys the body” [“nothing other than the release from prison and ending of exile, the discharging of the heavy burden that is the body”].<sup>31</sup> According to this commendation of death, death offers freedom from burdensome bodies and worldly sufferings. The commendation of death, supported by Stoicism, also falls into the old heresy of dualism, which demonizes the body and the material world and promotes a sort of ‘escapism’ for the soul in death. Such a perspective is un-Christian and unfounded in the reality of the resurrection and the inherent goodness of God’s creation.

Despite its flaws, the medieval *ars moriendi* offers a starting point for dying well in a modern context. Verhey discusses the *ars moriendi* in *The Christian Art of Dying* in response to cultural approaches toward death and dying that he views as problematic. The *ars moriendi*, as Verhey utilizes it, is a counter to “medicalized” dying, an experience that dominates dying in the twentieth and twenty-first centuries and which Verhey recognizes as problematic.

A primary component of “‘medicalized death’ is that it happens in a hospital.”<sup>32</sup> In the last century, the proportion of deaths occurring in hospitals has dramatically

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<sup>31</sup> Verhey, *The Christian Art of Dying*, 89-91.

<sup>32</sup> Verhey, 13.

increased, with 90 percent of deaths happening in hospitals in 1995, up from 40 percent of deaths in 1945.<sup>33</sup> In the medicalized model of death, medicine relentlessly pursues treatment and cure of sickness to the point of denying death. “The ‘dying role’ is lost” to the patient; “only the ‘sick role’ remains” in the medicalized dying that dominates Western society.<sup>34</sup> Verhey describes the ramifications of the shift toward medicalized dying in hospitals:

In a transition as swift and imperceptible as the transfer of the dying to the hospital (and, of course, related to it), the dying were no longer treated as if they were dying; they were treated like anyone else who was recovering from major surgery or a serious disease. You do not go to the hospital, after all, to die. You go there to get better. You are expected to admit that you are sick, but you are also expected to share the hospital’s goal, to avoid death. So suddenly, no one was “dying” anymore. They were just “sick.” That spelled the end of “the dying role” with its rituals and community.<sup>35</sup>

The end of the dying role accompanied an insistent pursuit of cure and mastery of disease as the goal of medicine. To accept that a patient is dying would be to admit that medicine had failed, so patients are permanently consigned to the sick role until death takes them.

Physician assisted suicide, like the medicalized dying described by Verhey, denies the dying role. While medicalized dying does so in a systemic manner, born of the curative goals of medicine, PAS allows individuals to opt for death rather than take on the dying role. In a similar parallel with PAS, medicalized dying also seems to be characterized by one more grasp at control by the dying or their caregivers. PAS like medicalized dying, gives individuals the opportunity to subvert the experience of dying.

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<sup>33</sup> Verhey, 13.

<sup>34</sup> Verhey, 4.

<sup>35</sup> Verhey, 14.

Theologian Christopher Vogt discusses the suffering and shattering of identity that can result when a person learns that they are dying. Terminally ill patients may suddenly “find themselves no longer fitting their former definition of ‘dignified human life.’”<sup>36</sup> In this reality, where dying individuals no longer understand their lives as dignified and fear the vulnerability, suffering, and loss of control ahead, PAS may appear to them the most humane and dignifying option.

With the reality of suffering that attends the end of life, Christians and their faith communities have a duty to provide care and support to the dying. Moreover, the teachings and example of Jesus in his life and death equip Christians to care for the dying beyond what can be offered to them through PAS or medicalized dying. The example of Jesus, particularly expressed through the tradition and practices of *ars moriendi*, can teach Christian communities to die well and to care well for the dying. The Christian art of dying well, exemplified by Jesus, offers an approach to dying that recognizes vulnerability, suffering, and dependence as parts of the human experience that are shared by Jesus and by the dying individual’s community.

*A Contemporary Ars Moriendi: Affirming Vulnerability within Community*

This section will examine how the *ars moriendi* can be a model for contemporary Christians to learn to die well as a community. The teachings of the *ars moriendi* tradition provide the church with a starting point for considering what dying (and living) faithfully can look like. Individuals, alongside their communities, can cultivate virtues and practices that will enable them to die well, with the life and death of Jesus as a guide.

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<sup>36</sup> Christopher P. Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well* (Lanham, MD: Rowman & Littlefield Publishers, Inc., 2004).

Verhey begins his modern remake of the *ars moriendi* with a commendation of life, in direct contrast to the tradition's commendation of death. Any Christian approach to death must first recognize that life is a good gift from God and death "remains a cause of sorrow and grief."<sup>37</sup> The hope that Christians have is not in an escape from a broken world through death. Rather, Christian hope springs from the resurrection of Christ and the promise of redemption and resurrection on a cosmic scale. This perspective affirms the goodness of life and the created order, and it is essential for establishing a Christian approach to dying that does not denigrate the body or welcome death.

Sections of the *ars moriendi* focus on inculcating certain virtues throughout the dying process in response to the temptations faced by the dying. Those temptations—loss of faith, despair, impatience, pride, and avarice—are countered by the virtues of faithfulness, hope, patient love, humility, and serenity. Allen Verhey and Brett McCarty, in "The Virtues for Dying Well," "appropriate the virtues for dying well given by the *Ars Moriendi* literature," and Verhey does the same, albeit more effusively, in *The Christian Art of Dying*. This paper will do the same, appropriating the virtues of *ars moriendi* to propose an alternative means of dying well and 'with dignity' in response to the death with dignity movement. To do so will require a look at each virtue upheld by the *ars moriendi* and the counter-cultural response to dying and loss of ability inherent in each virtue.

According to *ars moriendi* literature, the most fundamental temptation of the dying is to lose faith. *Crafte and Knowledge For to Die Well* says, "The ffyrst

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<sup>37</sup> Verhey, *The Christian Art of Dying*, 201.

[temptation] is off the ffeythe,”<sup>38</sup> and the first illustration of the block book *Ars Moriendi* is of the dying man, Moriens, being tempted to lose his faith. One demon tells Moriens, “Hell is prepared for you;” another says, “Do as the pagans do,” encouraging Moriens to deny his faith, and yet another demon suggests that Moriens should kill himself.<sup>39</sup> The *Crafte* quotes Augustine to emphasize the primacy of faith, saying, “ffeyth is foundment off all goodness and begynnyng of mannes helthe.”<sup>40</sup> In Verhey’s more contemporary language, “faith is the foundation of all virtue and the source of a person’s well-being.”<sup>41</sup> The temptation to lose faith does not necessarily precede the other temptations for the dying person, but the *ars moriendi* addresses this temptation first because of the centrality of faith to the Christian art of dying, including the practice of other virtues.

A driving factor of the temptation of loss of faith, as McCarty and Verhey point out, is loneliness and suffering in the midst of dying. This represents a space in which a community can embrace and support the dying individual in their difficulty. While weathering the storms of doubt is ultimately an individual experience, it need not be done alone. Not only does Jesus’s faith serve as a model for the faith of the dying, but it also models the relationality and trust to which members of Christian community are called. In dying, individuals can cultivate faithfulness toward God while both they and their communities cultivate faithfulness toward one another. The model for faith through suffering is found in the person of Jesus. McCarty and Verhey write, “In the agony and

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<sup>38</sup> David William Atkinson, ed., “Crafte and Knowledge For to Dye Well,” in *The English Ars Moriendi* (New York: Peter Lang, 1992), p. 3.

<sup>39</sup> Verhey, *The Christian Art of Dying*, 111.

<sup>40</sup> “Crafte and Knowledge,” 3.

<sup>41</sup> Verhey, *The Christian Art of Dying*, 113.

loneliness of dying, faith in God can seem to be a difficult, if not impossible, prospect. During these darkest moments, *ars moriendi* is right to turn our gaze toward the faith of Jesus, who displayed his trust in God and God's cause even unto death."<sup>42</sup>

The second temptation of the dying person described in the *ars moriendi* is to despair, or loss of hope. *Crafte* describes this temptation as such: "ffor whan a seeke man ys sore tormented and vexed with sorowe and seekeness of hys body, than the deuyll ys most besy to superadde sorowe to sorowe with all the weyes that he may"<sup>43</sup> ["for when a sick man is tormented and vexed with sorrow and sickness of his body, then the devil is busiest to add sorrow to sorrow with all the ways that he may"]. The illustration of the temptation to despair in *Ars Moriendi* shows demons accusing Moriens of the sins of adultery, perjury, avarice, and murder.<sup>44</sup>

Both *Crafte* and *Ars Moriendi* focus on the despair wrought by loss of hope in God's forgiveness and doubt of one's own righteousness. While contemporary Christians may experience similar doubts that tempt them to despair, Verhey suggests many people encounter despair as they are dying because of the threat death poses: "not just an end to one's existence, but the unraveling of meaning, the severing of relationships, the shattering of hopes."<sup>45</sup> Individuals encounter the potentially earth-shattering realization that they may lose their autonomy and enter a state of vulnerability and dependence.

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<sup>42</sup> Verhey and McCarty, "Virtues for Dying Well," 28.

<sup>43</sup> "Crafte and Knowledge," 5.

<sup>44</sup> Verhey, *The Christian Art of Dying*, 117.

<sup>45</sup> Verhey, 261.

The virtue of hope is the response to the temptation to despair.<sup>46</sup> The end of life confronts the dying with the threat of loss—of relationships, physical abilities, independence, meaning as it was once construed. However, Christians have hope that death is not the end of their being. Their hope is in the God of creation, resurrection, and redemption and can assure them that existence, meaning, and love do not end in death. An important caveat to that hope, which Verhey points out, is that “the scope of Christian hope is nothing less than cosmic.”<sup>47</sup> Christians should not let hope “shrink to the egocentric hope that a solitary individual may experience the bliss of heaven.”<sup>48</sup> The hope of the Christian is in the good future of redemption for the cosmos, not just for the singular dying person. Christian community offers space for the cultivation of this virtue by reminding the dying of their ultimate hope in the midst of despair. Intentional Christian communities in their presence with, ministry to, and love for the dying person model God’s eternal presence, ministry, and love, fueling the hope of the dying that they need not despair in death.

The third temptation for the dying person, impatience, is also identified as temptation against charity. *Crafte* describes the temptation of impatience as that “whych ys ageuyn charyte by the which we be boundyn to loue God aboue all thynges”<sup>49</sup> [which is against charity by which we are bound to love God above all things]. The depiction of Moriens in *Ars Moriendi* shows him lashing out violently at those caring for him, acting

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<sup>46</sup> Verhey and McCarty, “Virtues for Dying Well,” 28.

<sup>47</sup> Verhey, *The Christian Art of Dying*, 265.

<sup>48</sup> Verhey, 265.

<sup>49</sup> “Crafte and Knowledge,” 6.

impatiently and rudely out of his suffering instead of demonstrating love toward his caretakers.<sup>50</sup> The temptation to be impatient is also a temptation against charity, or against love, and impatience with the suffering of dying can prompt them to act in violation of their love of God and love of others.

Because impatience can also be unloving, two virtues, love and patience, oppose the temptation of impatience. Loving patience is especially salient from the lens of a culture that values autonomy as a cardinal virtue. Impatience results, as McCarty and Verhey note, in suicide for some who cannot bear patiently the suffering and dependence of dying.<sup>51</sup> Rather unhelpfully, “the *ars moriendi* literature focuses on how to overcome, or at least ignore, temporal and bodily suffering through an escapist love of God.”<sup>52</sup> McCarty and Verhey propose instead that “by loving God and all else as it relates to God, we learn to properly love our bodies, our lives, and the innumerable relationships that define who we are.”<sup>53</sup> This proper love of the very body, life, and relationships gifted by God encourages patience through suffering. Furthermore, by recognizing relationships as gift, the dying person may more patiently bear the dependence and loss of autonomy that accompanies dying. Then the experiences of being a burden and of humiliation that can accompany dependency may be ameliorated. Bearing one another’s burdens is characteristic of a loving community that mirrors the love and care given by God.

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<sup>50</sup> Verhey, *The Christian Art of Dying*, 121-122.

<sup>51</sup> Verhey and McCarty, “Virtues for Dying Well,” 29.

<sup>52</sup> Verhey and McCarty, 29.

<sup>53</sup> Verhey and McCarty, 29.



The fourth temptation of dying is pride. For one who has overcome the other temptations of loss of faith, despair, and impatience, pride may come in a self-congratulatory form for ‘defeating’ the other temptations and doing well in one’s pursuit of a good death.<sup>54</sup> The historical *ars moriendi* is primarily concerned with “spyrytual pryde,” with which “the deuell tempteth and vexeth most relygyous & deuoute & perfyte men” upon seeing that they have not succumbed to the other temptations.<sup>55</sup> In *Ars Moriendi*, the demons try to tempt Moriens into self-righteousness, praising him for remaining firm in the virtues and telling him, “Exalt yourself,” while one demon offers him a crown.<sup>56</sup> In attending to the spiritual exercises of dying with virtue, the dying individual can easily lapse into pride in their own righteousness and abilities.

In a culture so defined by its focus on individual ability and autonomy, pride is inevitable, particularly in the vulnerable space of end-of-life. Pride “is not just the pretense of self-righteousness; it is also any pretense to self-sufficiency.”<sup>57</sup> When they fall into pride, dying individuals can fool themselves into believing that they do not need to, or perhaps should not, rely on others, including God. Verhey indicates the relationship between pride and the overvaluation of autonomy in contemporary Western culture:

The temptation of pride is a common one in our culture, given its emphasis on autonomy and independence. Like my mother’s son, our culture is not particularly good at acknowledging neediness—or at gratitude. The temptation of pride comes long before the deathbed, of course, but when we are dying, the habit of pride makes dying well difficult. Pride can keep us from receiving care graciously. It can make those in need of care ashamed of “being a burden” and resentful of

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<sup>54</sup> Verhey and McCarty, 30.

<sup>55</sup> “Crafte and Knowledge,” 7.

<sup>56</sup> Verhey, *The Christian Art of Dying*, 125.

<sup>57</sup> Verhey, 286.

those compassionate caregivers whose very care reminds us of just how needy we are.<sup>58</sup>

Pride causes people to fear and resent their reliance on others for care rather than receive care with gratitude. It causes people to cling to their autonomy and self-sufficiency to the point of choosing death over dying, as in the case of PAS. This point is not intended to shame people who pursue PAS for their sin of pride. Rather, it should prompt the reader to consider how pride may shape an individual's experience of dying.

Pride is difficult to face, and “any effort to resist it through one's own efforts can feed into the very problem one is attempting to overcome, lending credence to the illusion of self-reliance.”<sup>59</sup> The dying person cultivates humility not by their own efforts but by the grace of God through the humility of Jesus. “In humble faithfulness Christ was willing to endure humiliation and even allowed others to care for him in the midst of it.”<sup>60</sup> The humility of Christ is both an example and a comfort to dying individuals who depend on others to feed them, bathe them, and handle the results of their incontinence. Just as God through Jesus bore the vulnerability of incarnation and the humiliation of the crucifixion, so can dying persons accept the ‘indignities’ of dying with graciousness and humility. Humility in dying entails graciously and gratefully accepting one's dependence, for all persons are dependents of God and of others. “Both living well and dying well require help from others” and “take community,” according to Verhey.<sup>61</sup> Pride can

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<sup>58</sup> Verhey, 286.

<sup>59</sup> Verhey and McCarty, “Virtues for Dying Well,” 30.

<sup>60</sup> Verhey and McCarty, 30.

<sup>61</sup> Verhey, *The Christian Art of Dying*, 286.

prevent the dying from receiving care as a gift, deceiving them with the lie that they were ever fully independent.

Lastly, *ars moriendi* literature names avarice as a temptation faced by the dying. The literature portrays avarice as a clinging to worldly things. In *Crafte*, avarice is an “overmoche occupacion & busyness owtewarde aboute temporall thynges as her wyfes, her children, her carnall ffrendes, and wordely rychesses, and other thynges that they haue loued inordynatly byffore.”<sup>62</sup> This paper has already mentioned the problematic nature of the dualism present in the *ars moriendi*, which denigrates bodies and “worldly” things. Verhey critiques this dualism, but he maintains that the *ars moriendi* is right to condemn avaricious clinging—whether it be to possessions, loved ones, or life—when clinging to those things becomes idolatrous.<sup>63</sup> Still, “temporall thynges” are God-given and good. “Dying well,” says Verhey, “requires that I do not cling to them anxiously as if I could expect them to save me from my mortality...but it also requires that I do not discard them as distractions.”<sup>64</sup> Ascetic denial of love is not a virtue of dying well.

Avarice is balanced by the virtue of “letting go, of serenity, and of generosity,” for want of an entirely adequate term.<sup>65</sup> McCarty and Verhey describe this temptation as “an anxious, tightfisted grasping, a desperate and idolatrous clinging to life above all else.”<sup>66</sup> Verhey also describes avarice as “the anxiety that prompts us to hoard the little

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<sup>62</sup> “Crafte and Knowledge,” 8. Avarice is a preoccupation and busyness outward about temporal things, such as their wives, their children, their carnal friends, and worldly riches, and other things that they have loved inordinately before.

<sup>63</sup> Verhey, *The Christian Art of Dying*, 154.

<sup>64</sup> Verhey, 154.

<sup>65</sup> Verhey and McCarty, “Virtues for Dying Well,” 30.

<sup>66</sup> Verhey and McCarty, 30.

resources we think we have against our vulnerability to suffering and death.”<sup>67</sup> For some people, those “little resources” may be relationships, experiences, or possessions from which they derive meaning. Others may cling to medical technology to preserve and prolong their biological life at any cost. Dying individuals who opt for PAS may cling to their autonomy as the last barrier between them and the ‘indignity’ of dependence. In opposition to the temptation to cling anxiously to life, Jesus demonstrates the virtue of serenity, or letting go, on the cross. He is free from anxiety and a worried clinging to life because of his confidence in God’s grace and goodness. His prayer, “Father, into your hands I commend my spirit,” is an expression of letting go made possible by his faith, hope, and patient love. The appropriate response to avoid avarice in dying is to trust in God’s grace and commend oneself and loved ones “into the hands of a God who can be trusted.”<sup>68</sup>

The virtues advocated by the *ars moriendi* were exemplified in the life and death of Jesus. He exhibited faithfulness in his dying, trusting in God though he suffered and felt grief, praying, “Father, into your hands I commend my spirit.”<sup>69</sup> The dying and resurrection of Jesus creates the paradigm for Christian hope; Jesus did not hope to die, but “he hoped for the good future of God” and “recognized that there were goods more compelling than his own survival.”<sup>70</sup> In his faithfulness to God and his hope in God’s

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<sup>67</sup> Verhey, *The Christian Art of Dying*, 289.

<sup>68</sup> Verhey and McCarty, “Virtues for Dying Well,” 30-31

<sup>69</sup> Verhey, *The Christian Art of Dying*, 259-260.

<sup>70</sup> Verhey, 269.

good future, Jesus exhibits patience as he dies. Verhey describes the patience of God that is exhibited in Jesus:

God is not short-tempered; he is slow to anger, eager to forgive. It is not apathy or indifference...God's patience is God's refusal to give up on God's children; it is God's refusal to give up on the desire to bless them (even the Ninevites, Jon. 4:2); it is God's decision to accept suffering rather than to surrender love...Such patience is surely on display when Jesus is on the way to the cross and when he hangs there.<sup>71</sup>

Jesus does not lash out in anger at those who torment him, nor at the disciples who failed him. Instead, he loves patiently and unrelentingly, even as he suffers.

Jesus's humility as he died is perhaps the most instructive virtue of his death, particularly considering PAS and the human urge to avoid vulnerability. He submits himself fully to God's plan, with no arrogance or contempt for the vulnerability and weakness thrust upon him. Beyond acting humbly, Jesus was humiliated. His experience of humiliation does not commend humiliation as good, just as his dying does not commend death. However, the humiliation of Jesus offers comfort to the dying who have been, or fear being, humiliated by their failing bodies. Verhey points out that one does not need to be exceedingly proud to find incontinence humiliating. Even those who accept a posture of acknowledging their dependence may find their experience of dying to be humiliating at times.<sup>72</sup> In those moments, the crucifixion of Jesus reminds the dying that "Jesus died in solidarity with the humiliated."<sup>73</sup> In fact, he was deliberately humiliated by his executioners and the spectators to his death. The Jesus that God raises

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<sup>71</sup> Verhey, 282.

<sup>72</sup> Verhey, 286.

<sup>73</sup> Verhey, 287.

and exalts is the same Jesus that was brutalized and humiliated, and that is the promise and the comfort of the solidarity of Jesus with the suffering and the humiliated.

The last virtue of the *ars moriendi*, serenity or letting go, is demonstrated by Jesus in his freedom from anxiety and trust in God as he is dying, as was mentioned in the previous discussion of avarice. However, the example of Jesus also demonstrates that serenity allows space for lament and does not deny grief. “His freedom from anxiety,” Verhey says, “was not a matter of indifference to life or to his family and friends,” “was not freedom from sadness in the face of death,” and “did not mute the voice of the sufferer.”<sup>74</sup> Jesus, in fact, demonstrates his serenity through lamentation. Lamentation cries out from a place of suffering, loneliness, bewilderment, and all the painful realities of the world. However, the act of crying out demonstrates trust and hope in God, the divine listener. Jesus cries out, “My God, my God, why have you forsaken me?” (Psalm 22) and alternately prays, “Into your hands I commend my spirit” (Psalm 31), both lines from psalms of lament.<sup>75</sup> Jesus honestly confronts his great sorrow and despair, yet he does so in a posture of letting go and trusting in God.

The virtues of the *ars moriendi* and the example of Jesus harmonize readily with the intentional Christian community described by Kay Toombs. That community presented by Toombs offers a backdrop of sacrificial love, mutual care, and affirmation of dignity. Such a backdrop allows the transformative practice of *ars moriendi* to take place, for the cultivation of those virtues of faithfulness, hope, patient love, humility, and serenity occurs most readily in a communal context. Importantly, the Christian

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<sup>74</sup> Verhey, 290.

<sup>75</sup> Verhey, 228-229 and 290.

community that practices the virtues of the *ars moriendi* does not deny the grief, pain, and suffering that accompany dying and debility. Jesus suffered, he was humiliated, he lamented, and he died. Rather, the community reflects between its members examples of care and solidarity that do not shy away from the messiness, fear, and vulnerability. That community follows the example of Jesus as it practices how to live together, care for the dying, and die well.

### *Conclusion*

The phenomena of physician assisted suicide and euthanasia represent the harmful impact that absolute individualism and an overvaluation of autonomy have on dying in Western society. Rather than accepting the vulnerability, dependence, and limitations that accompany the dying process, many dying individuals fearfully cling to their autonomy, to the point of intentionally expediting death, as control slips through their fingers.

The heavy emphases on autonomy and freedom within Western culture have led many to believe that their dignity is dependent on their capacity for action and self-determination. Intentional Christian community, paired with a mindful approach to dying inspired by the *ars moriendi*, offers an alternative attitude towards dying. This attitude allows for vulnerability, dependence, and loss of physical abilities to occur without denigrating the dignity of the dying individual. If covenantal community and interdependence were valued by the dominant culture in the same way that autonomy is, PAS and euthanasia would seem to be less viable options. Instead of choosing an expedited death to avoid the indignity of suffering and dependency, dying individuals could rest assured in knowing that their communities would support them and affirm their dignity through the end of life.

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