PHYSICIAN ASSISTED DEATH:

WHAT PREDICTS PURSUIT?

By

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ABSTRACT

Title: Physician Assisted Death: What Predicts Pursuit?

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Physician assisted death (PAD) is a legal end-of-life (EOL) option in Oregon, Washington, and Montana. Since Oregon's Death with Dignity Act (DWDA) was enacted in late 1997, a total of 1,050 Oregonians have had DWDA prescriptions written and 637 patients have died from use of the prescribed medications. However, patient motivation for pursuit of PAD is not well understood and because of this nurses and other health care providers have struggled to understand how to best provide care for those who request prescriptions under the DWDA.

This study examined the influence of commonly hypothesized factors in patient pursuit of PAD. It was a secondary analysis of data from 55 terminally ill Oregonians at the EOL who pursued PAD compared with data from 40 terminally ill Oregonians at EOL who did not pursue PAD. *t*-Tests were used to compare the two groups on measures of dismissive attachment, hopelessness, depression, pain, and desire for control. Those who pursued PAD were found to have significantly higher levels of hopelessness, depression, and dismissive attachment. Logistic regression analysis revealed that higher hopelessness, higher levels of education, and being unmarried predicted pursuit of PAD while controlling for depression, age, dismissive attachment, pain, and desire for control. The construct of hopelessness taps into expectations of the future and the impact of dismissive attachment may be related to concern about a state of dependency at the end of life that would be intolerable. These findings suggest that concern for the future may play a large role in the decision to pursue PAD. Clinicians should address current symptoms, but also inquire about expectations and fears related to the dying process that may be causing distress and tailor interventions accordingly.

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Glossary of Terms

The literature on assisted death is replete with terms that are either poorly defined or are used interchangeably. Therefore, it is important to define the different terms that have been used to describe actions taken to hasten the death of a patient.

Aid in dying (AID). In some citations, AID refers to any provision of assistance, legally sanctioned or not, to intentionally end life, including PAD, active euthanasia, advising a patient about strategies or resources for ending life, or refraining from interventions to prevent or dissuade the patient from ending life (Volker, 2001, p. 40). In this review, the term AID will be used only when referring to death hastening practices other than those that are legally sanctioned by Oregon and Washington law, which will be referred to as PAD.

Death with Dignity Act (DWDA). "An adult who is capable, is a resident of Oregon (and Washington), and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 to 127.897" (Oregon Death with Dignity Act, 1997). According to the laws regulating PAD, the patient must self-administer the death-causing agent (Werth & Holdwick, 2000). Oregon's DWDA first passed by citizen ballot initiative in 1994. Following legal injunctions, Oregon voters reaffirmed the measure in November 1997. In 2005, the US Supreme Court affirmed the legal standing of the Act. In 2009 Washington passed legislation that was patterned after Oregon's DWDA, becoming the second state in the nation to legally sanction PAD.

Desire for hastened death. A wish for death to occur more rapidly, regardless of the means by which this would occur (Breitbart et al., 2010). A desire for hastened death does not necessarily imply that action would follow this wish, however published research often confounds a patient desire for a hastened death with patient action to hasten death. In this review, a distinction will be made between desire for and pursuit of hastened death.

Euthanasia. A person (physician, nurse, or other) causes the patient's death by engaging in a specific act with the intention of causing death. Voluntary euthanasia is that which has been requested by the patient; involuntary euthanasia is administered over the patient's objection; and in nonvoluntary euthanasia, the patient has not been consulted or lacks decisional capacity to participate. While voluntary euthanasia is permitted in the Netherlands and Belgium, no type of euthanasia of any type is permitted in the United States (Lewy, 2011; Wolf, 2005). Under the DWDA, the terminally ill patient must self-administer the lethal prescription.

Hastened death. This is an umbrella term that describes an accelerated dying process (either by action or, in some instances, inaction). This term may include intentional aid in dying by health care professionals or family members, or other life-limiting acts, such as withholding or withdrawing life support, or patients' voluntary refusal of food and fluids (Werth & Holdwick 2000; Werth, 2004). This term has been used imprecisely in the published literature, for example Pearlman et al. (2005) stated, "hastened death is a lay term for physician assisted suicide" (p. 235). When used in this review, hastened death will refer to this broad concept and not serve as proxy for more specific terms such as assisted death.

Physician assisted death (PAD); physician assisted suicide (PAS). The act of providing a terminally ill person with the means (usually medication) to die. The word "suicide" (i.e., physician assisted suicide) is generally no longer used due to negative connotations. In the literature, the term PAD refers to legal acts to hasten death under the Death with Dignity Act (DWDA) but may also describe intentionally death-hastening acts by health care providers where PAD is not legal. The term is somewhat problematic, as it doesn't include other providers, notably RNs, who are often involved with life limiting decisions and actions. In this review, PAD will be used to refer specifically to those practices that are legal under Oregon and Washington law.

Suicide. The intentional taking of one's own life (Random House Webster's College Dictionary, 2001). Almost 100 people die each day by suicide in the US; it is the 11th leading cause of death for Americans (Miller, Azrael, & Barber, 2012). PAD is not classified as suicide under the DWDA (Oregon Health Authority, 2013).

Voluntary Refusal of Food and Fluids. A volitional refusal of food and fluid intake for the explicit purpose of hastening death. This is distinguished from a natural decrease in appetite and desire for fluid that can accompany some conditions at the end of life (Ganzini, Goy, et al., 2003).

Chapter One

Background and Significance

Physician assisted death (PAD) is a legally available means to hasten death at the end of life for terminally ill residents of Oregon and Washington. Since the Death with Dignity Act (DWDA), allowing PAD, was authorized by the Oregon legislature in 1997, the number of Oregonians who have pursued and ultimately received prescriptions for the purpose of hastening death has grown each year. In 1998, the first year of legally sanctioned PAD, 24 Oregonians received, and 16 used a prescription to hasten death. In the 15 years during which PAD has been legal in Oregon, a total of 1050 patients received a lethal prescription and 673 died from use of that prescription (Oregon Health Authority, 2013). In Washington, 255 have received and 241 have died by lethal prescription since the option became legally available, March 2009, through December 2011 (Washington State Department of Health, 2012). It is not known how many patients receive assistance in hastening death through covert means, but studies of both nurses and physicians consistently reveal that a clinically significant number report receiving requests from patients to hasten their death. Despite its illegality, a surprising number of both nurses and physicians admit to hastening the deaths of patients in their care (see for example, Back, Wallace, Starks, & Pearlman, 1996; Meier et al., 1998). In fact, aid in dying (AID, the term that will be used in this paper to describe acts to hasten death that are not sanctioned by law) has been estimated to account for 1-2% of patient deaths in areas where the practice is not legal (Quill and Greenlaw, 2008).

Despite the frequency with which requests for hastened death are expressed, patient motivations for PAD are not well understood. Much of what has been previously hypothesized regarding motives for PAD has assumed that important factors are transient and modifiable, such as pain, depression, and social support (Block & Billings, 1995; Foley, 1997; Meier, Emmons, Litke, Wallenstein, & Morrison, 2003). However, the research in this area has failed to clearly substantiate these factors as significant. Alternatively, the pursuit of PAD may reflect psychological, social, or existential factors (Hudson et al., 2006; Maytal & Stern, 2006) or a desire to avoid dependency that accompanies terminal illness (Oldham, Dobscha, Goy, & Ganzini, 2011). Qualitative research has suggested that individuals who request PAD are "fiercely independent" and "highly controlling" (Harvath et al 2006; Ganzini, Dobscha, Heintz, & Press, 2003). For these patients, the pursuit of PAD may represent a desire to avoid the dependency that often accompanies terminal illness. This aversion to dependency has been attributed to psychological variables, such as a high need for control or a particular style of attachment. Attachment refers to the emotional bond between individuals, initially developed during childhood. Attachment style refers to patterns of behavior related to expectations of support and care in times of need. In particular, those with a dismissive style of attachment have been described as resistant to care or inclined to retreat from care when it is offered (Levy, Ellison, Scott, & Bernecker, 2011). They tend to be distrustful of others, and situations requiring dependence or vulnerability may be aversive (Maunder & Hunter, 2009). It is possible that the needs of individuals with dismissive styles of attachment will not be met unless approached with sensitivity to the patient's need for autonomy and their likely distrust of care offered.

Establishing therapeutic relationships with patients requires understanding of psychosocial needs, including patterns and preferences of relating to others (Tan, Zimmermann, & Rodin, 2005). Provision of appropriate clinical care to terminally ill individuals who express a desire to hasten their deaths requires understanding of the complex factors and motives for pursuit of PAD. In addition to skill in assessment and medical or nursing interventions that will alleviate physical causes of distress, providers must be able to deliver interventions in a manner acceptable to the patient. They must also be able to differentiate requests for a hastened death that stem from modifiable factors that require skilled, and often increased intervention, from those where psychological factors indicate that a different approach than is common may be warranted. Therefore, a better understanding of motives behind the request for PAD is needed in order to provide sensitive care to each individual.

PAD in the United States

In the United States, interest in physician hastened death has waxed and waned over the past 100 years, with a resurgence of interest during the last 40 years. During the 1870s, physicians, legal scholars, social scientists, and the public at large engaged in debate about whether physicians should participate in a practice of using medication to end the lives of patients experiencing unremitting suffering at the end of life. The first reported legislation to permit legally sanctioned death hastening acts (specifically euthanasia) was introduced in Ohio in 1906, ultimately failing to garner enough support for passage (Emanuel, 1994). Recent unsuccessful legislative efforts to permit PAD have been put forward in California, Hawaii, Michigan, and Maine (Stutsman, 2004). The two states currently permitting legal access to PAD are Oregon and Washington, and a recent state Supreme Court ruling in Montana now prevents criminal prosecution of physicians who prescribe a lethal dose of medication to competent, terminally ill patients (Lewy, 2011; Ruble, 2010).

Requirements for PAD. In Oregon and Washington, PAD is limited to competent adults who are suffering from a terminal illness with a prognosis of less than six months of life expectancy. Such adults, who have voluntarily expressed a wish to die, may make a request for medication for the purpose of ending his or her life (Lewy, 2011). Beyond those jurisdictions however, AID is requested and practiced regardless of legality. Regional and national surveys of physicians and nurses demonstrate that patient interest and subsequent practice of AID with a health care professional is not rare.

Requests for aid in dying. A number of studies have examined the prevalence of AID. Regionally, Fried, Stein, O'Sullivan, Brock, & Novak (1993) found that 47 (18.9%) of 249 Rhode Island physicians had received requests for AID and 6 (2.5%) reported complying with the request. Doukas, Waterhouse, Gorenflo, and Seid (1995) reported that 38% of 154 Michigan oncologists received requests and 18% acknowledged performing AID. According to Lee et al. (1996), prior to enactment of the DWDA, 21% of 2761 Oregon physicians received requests and 187 (7%) acknowledged performing AID. In 2000, Willems, Daniels, van der Wal, van der Maas, and Emanuel reported that 48% of 152 Oregon family practice physicians, internists, and oncologists received requests and also reported a 7% compliance rate (at the time of this survey, the state legislature had authorized the practice of PAD, but the law had not yet been implemented). In a survey of Washington State primary care physicians and specialists most likely to provide care for those at end of life (including oncologists, cardiologists, geriatricians, and others) conducted prior to legalization of PAD, Back et al. (1996)

reported that 26% of respondents had received at least one previous request for AID (PAD or euthanasia) and 12% had received a request for AID in the past year. Physicians in that study reported providing a lethal prescription for 24% of the requests (38 of 154 patient requests).

Nationally, Emanuel, Fairclough, Daniels, and Clarridge (1996) surveyed 355 oncologists. Over 50% reported receiving a request for AID and 13.5% reported complying with the request. Meier et al. (1998) surveyed a sample of physicians in specialties most likely to receive a request for AID. Of that sample of 1902 physicians, 18.3% reported receiving a request for AID and 16% of those receiving requests reported complying with the request at least once. In 2000, Emanuel et al. surveyed 3299 oncologists. This time, an even larger percentage (56.2% or 1854 physicians) reported receiving a request for AID and almost 11% (356 physicians) reported complying with the request.

While the term “physician” assisted death has been widely used, and reflects parameters of legal practice in Oregon and Washington, it is clear that nurses involved with end of life care also receive requests for, and sometimes participate in aid in dying. While the American Nurses Association (ANA) states that participation in AID is a “violation of the *Code for Nurses with Interpretive Statements* and the ethical traditions of the profession” (ANA, 1994), research indicates that nurses have been involved in hastening the death of terminally ill patients.

Asch (1996) surveyed 852 critical care nurses in the US. He reported that 141 (17%) had received one or more requests for AID (assisted death or euthanasia) and 129 (16% for whom data were available) of those receiving a request reported engaging in behavior to hasten death. Additionally, of those engaging in behavior to hasten death, 7% did so without a request from the patient or family and 8% had done so without a request from the attending physician. Although this study has been criticized due to ambiguous questions (Dunn, 1996) and potential for confusing an instance of appropriately titrating medication and an unintended “double effect” with euthanasia (Szaflarski & Clochesy, 1996), subsequent research has confirmed some of these findings. Matzo and Emanuel (1997) reported on 441 members of the oncology nursing society living in New England states. Thirty percent of those responding (131 nurses) reported having received a request for assisted suicide and 1% (6 nurses) reported personally participating by prescribing or providing drugs to hasten death.

Oregon statistics reveal that, since the law’s inception, the majority (68.5%) of those who have received a lethal prescription under the DWDA were 65 years or older, and malignant neoplasms were the underlying illness in 80.3% of cases (Oregon Health Authority, 2013). Given the aging of the US population and the swelling of the cohort of those over age 65 nationally and in Oregon, requests for PAD and AID are likely to increase.

Changing attitudes toward PAD. The epidemiology of mortality has changed in the last 150 years. For much of human history, lifespan ranged from 20 to 40 years; now the development of public sanitation, immunization, antibiotics, and other medical technology has allowed lifespan to approach 80 years in developed countries. In previous eras, humans died relatively quickly, primarily of parasitic and infectious disease. Now degenerative diseases, especially heart disease and cancer, account for two-thirds of deaths in developed countries (Battin, 2008). Such diseases typically have long downhill trajectory with a terminal phase of dying.

While advances in medical treatment and technology have enabled longer life, prolonged life can also result in a prolonged phase of dying. Patients may now live for extended periods in a condition that they may consider to be “worse than death” (Lewy, 2011, p 4). With PAD, patients can control some features of dying, including the timing of death during the course of illness, the place and manner of death, those present, and ultimately perhaps avoid dreaded symptoms. The choice for AID is seen by some as an extension of the desire to forego aggressive treatment that prolongs quantity of life at the expense of quality of life (Cohen, Steinberg, Hails, Dobscha, & Fischel, 2000). In fact, life-limiting decisions are routinely made in 50% of deaths that occur in the ICU (Prendergast, Claessens, & Luce, 1998). Cohen (1998) notes the importance of distinguishing between a wish to die that preemptively avoids what the patient would find as an unacceptable quality of life and suicide (understood as it is in non-terminally ill patients).

Increased interest in the pursuit of PAD may also reflect changes in physician-patient relationships, with patients becoming more involved and exerting greater autonomy in care decisions than in previous eras. An additional influence may be increasing emphasis on the right of self-determination given to individuals in vulnerable groups, including those who are terminally ill. Patients, including dying patients, have rights previously usurped by paternalistic practices of medicine, including the right to refuse or discontinue treatment, stipulate that treatment is withheld under certain conditions, designate decision makers, and otherwise plan for medical and end of life care (Battin, 2008).

Intentional life-limiting decisions are becoming more common in medicine and palliative care (Cohen et al., 2000), and some authors suggest that actions to hasten death can be seen as normative and without pathology (Cohen et al., 2000; Zaubler & Sullivan, 1996). For example, Battin (2008) believes that greater interest in and acceptance of PAD/AID reflects a cultural shift toward “self-directed dying” whereby individuals now play a more central role than in previous eras in determining how and when death will occur (p. 41). In contrast however, others view pursuit of PAD/AID as reflecting psychological pathology, which, if ameliorated, would eliminate desire for AID (Zaubler & Sullivan, 1996). Still others view PAD/AID as a response to inadequate end of life care that would be mitigated by improved health care, especially symptom management, at the end of life (Foley, 1996; Jeffrey, 2009). Regarding the last two points, there is little empirical evidence to inform the discussion. Greater objective understanding of the factors that motivate patients to pursue PAD is necessary to improve palliative practice and assure that care provided accurately targets issues of patient concern.

Study Purpose and Specific Aims

The purpose of this study was to examine the factors that motivate Oregonians to pursue PAD, including the predictive value of illness related and personality related variables in the pursuit of PAD. The specific aims were:

Specific Aim #1. Examine the association between attachment style and pursuit of PAD, while controlling for demographic variables, pain, depression, hopelessness and desire for control.

Specific Aim #2 Exploratory Aim. Examine the moderator effects of dismissive attachment style on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD.

Specific Aim #3 Exploratory Aim. Examine the moderator effect of desire for control on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD.

Implications for Health Care Providers

Social change, advances in medical care and technology, coupled with an aging demographic all contribute to the current and growing interest and importance of the issues surrounding PAD. While there are disagreements as to whether assisting with death is moral or ethical, it is clear that the practice routinely occurs, whether legally sanctioned or not. Understanding patient motives for pursuit of PAD is crucial if health care providers are to respond sensitively, appropriately, and effectively to end of life concerns.

The implications for nurses are significant. From 1998 to 2012, 90% of Oregonians who used a lethal prescription to hasten death under the DWDA were enrolled in hospice care (Oregon Health Authority, 2013). Most of the care provided to patients enrolled in hospice is provided by RNs (Oregon Hospice Association, 2009) and almost 28% of all Oregon hospice nurses reported that they had cared for one or more patients who had explicitly requested a means to hasten death under the DWDA (Ganzini et al., 2002). It is clear that those pursuing a hastened death by PAD are likely to be in the care of nurses.

In that context, nurses have described difficulty and/or uncertainty regarding how to best care for patients who express an interest in PAD. In a qualitative analysis, Harvath et al. (2006) examined the experiences of hospice nurses when caring for patients who requested PAD. On one hand, nurses described the request as an opportunity to redouble efforts at symptom management. The request was also described as providing an opportunity to have important end-of-life conversations with patients, which were seen as potentially positive aspects of the request. However, nurses also described their own distress around the patient request, particularly when a patient followed the request to conclusion. In such cases, some nurses reported feeling like a “failure” insofar as they were unable to alleviate the distress presumed to be at the heart of the request. In particular, respondents expressed concerns when the individual’s desire for a hastened death was opposed by family members. Others wondered whether the proper course of action was to dissuade the patient from requesting PAD.

Nurses must be able to conceptualize different meanings and motives related to the request for PAD and provide sensitive and appropriate care in light of the meaning for each individual. Whereas some requests for PAD may indicate a need for increased intervention such as symptom assessment and treatment (whether physical, psychosocial, or spiritual), it is possible that some individuals will feel distressed if approached with offers of increased care. This research may help to increase understanding of the meanings underlying requests for PAD and thus help to guide nursing interventions.

Chapter Two

Review of Literature

Motivation for pursuit of physician assisted death (PAD) is understood to be multifactorial (Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado, & Balaguer, 2010), with a number of variables frequently hypothesized as significant. Illness related variables such as inadequate symptom management or related psychological distress, social factors, spiritual distress, and existential suffering have all been hypothesized as possible contributory variables in PAD (Foley, 1997; Meier, Myers, & Muskin, 1999; Monforte-Royo et al., 2010; Pearlman et al., 2005; Wineberg & Werth, 2003). Variables reflecting enduring behavior patterns and personal characteristics, including attachment style, (Oldham, et al., 2011; Rodin, et al., 2009), and desire for control (Ganzini, Dobscha, et al., 2003; Volker, 2001) have also been offered as influencing pursuit of PAD or desire to hasten death (DHD).

This chapter will begin with a brief discussion of the distinction between PAD and DHD. Then a description of the search strategy used for the relevant research informing this study will be provided. Next, the literature exploring the relationships between pain, depression, hopelessness, attachment style, desire for control and the pursuit of PAD will be described. Finally, the conceptual framework that will be used to frame the specific aims and hypotheses will be described.

Distinguishing Between PAD and DHD

A number of studies have explored patients' desire for hastened death (e.g., Breitbart et al. 2000; Chochinov et al., 1995; Nissim, Gagliese, & Rodin, 2009). While pursuit of PAD does by definition reflect DHD (Monteforte-Royo et al., 2010), and some authors have used the construct of desire for hastened death as a proxy for pursuit of PAD, the data from Oregon indicate that there may be notable differences between considering PAD and requesting and ultimately receiving a prescription which would allow a patient to hasten death. In a survey of family members of recently deceased Oregonians, Tolle et al. (2004) found that in a sample of 1384, participants reported that 236 decedents (17%) personally considered PAD as an option during their terminal illness; 25 (2%) requested a lethal prescription; and 1 person (< 0.10%) obtained and used the prescription. Given such large differences, it seems clear that the factors that distinguish those who pursue PAD may not be revealed by research regarding a *desire* for hastened death.

One difficulty in generalizing DHD research to those who pursue PAD has to do with a lack of clarity regarding the meaning of the term DHD (Monteforte-Royo et al. 2010; Rosenfeld, 2000b). DHD can mean many things, including a generic desire that death would come soon in the face of terminal illness, a wish to hasten death, or, as some research implies, action that would result in death sooner than would occur naturally vis-à-vis the illness. DHD research reports generally do not operationalize the dependent variable of DHD, and the manner of hastened death that might be acceptable to the respondent is rarely identified (Monforte-Royo et al., 2010; Werth, 2004).

As an example of the difference between research into desire for HD versus pursuit of PAD, consider the line of questions asked by Chochinov et al. (1995): “Do you ever wish that your illness would progress more rapidly so that your suffering could be over sooner” (p. 1186)? Affirmative responses led to follow up questions inquiring whether the respondent wished to be dead now, whether the respondent prayed for death, or whether the respondent had spoken with anyone about this wish. Obviously these questions do not reflect *pursuit* of PAD but rather inquiries about passive desire for death. The variables correlated with this dependent variable (DHD) would not necessarily generalize to those who actively pursue means to hasten death. Of note, while there were 89 participants in this study who endorsed any level of DHD (ranging from slight/fleeting to pervasive/constant) only one person made a request for PAD, highlighting that those who express a DHD typically do not pursue PAD. The study was conducted in Canada where neither PAD nor euthanasia is permitted. It is possible that the 8.5% of their study participants who were assessed as having a persistent DHD might comprise the group that would be most likely to pursue PAD if legal, as the authors asserted. But the differences between the one participant who pursued PAD and those who desired but did not pursue were not illuminated by this DHD research.

Although some authors have used DHD as a proxy for PAD, many researchers have concluded that an expression of DHD is not necessarily a declaration to act, but conveys other meaning, including an expression of current distress (Coyle & Sculco, 2004; Maytal & Stern, 2006; Meier et al., 2003), a wish to live (Coyle & Sculco, 2004) or other underlying concerns (Abrahm, 2008; Bascom & Tolle, 2002; Block & Billings, 1995; Mak & Elwyn, 2005, and others). Werth (2004) goes so far as to state that desire for hastened death is "irrelevant when examining PAD" (p. 629).

This body of research has also been hampered by use of hypothetical scenarios to measure current or future interest in DHD/AID and correlating variables such as current functioning or symptoms with interest in DHD/AID (e.g., Breitbart, Rosenfeld, & Passik, 1996; Emanuel et al., 1996*)*. As an example, Emanuel et al. (1996) surveyed oncology patients, oncology physicians, and the public regarding whether, and under what circumstances, PAD (were it legal) would be acceptable. Participants were provided with vignettes depicting existential despair, unremitting pain, and functional incapacity and were asked to report whether PAD would be acceptable within the context of the provided scenarios. It is unclear whether or to what extent a correlation exists between envision of a novel scenario and future action. Furthermore, the link between potential future interest in PAD and current functioning or symptoms is also unkown. Hypothetical future interest is too vague to be very useful and the impact of any current symptoms as a correlate is unclear (Rosenfeld, 2000b; Rosenfeld et al., 2006). Inquiry as to what might be a likely choice under hypothetical circumstances is certainly different from research inquiry with those who are actively pursuing a course of action.

PAD and AID Research

There is a growing body of literature related to AID/PAD and other practices to hasten death at the end of life (for example, euthanasia or voluntary refusal of food or fluid), however we actually know little about those who pursue AID/PAD at the end of life. Much of the written literature regarding PAD had focused upon the moral and ethical nature of the decision and practice (for example, Jeffrey, 2009). While those are indeed important discussions, the current research is an inquiry into what motivates a terminally ill individual to pursue AID/PAD, consequently this review of literature will focus primarily on research related to pursuit of AID/PAD as opposed to moral, ethical, or legal discussions of AID/PAD or the broader DHD literature.

Search strategy. The term “suicide, assisted” was searched in Medline with the following terms mapped to that heading: death assisted, physician assisted suicide, suicide medically assisted, (and variations of those terms), yielding 4495 results. That group was refined by removing comments, editorials, lectures, legal cases, news or newspaper articles, and limiting to English language, and humans, yielding 2488 results. The search was further refined by limiting results to clinical research, resulting in 356 articles. Systematic reviews were added for a final yield of 377 articles that were reviewed by title and abstract for relevance. Those reports that specifically examined the variables contributing to pursuit of AID or PAD were retained for this review. Additional reports related to DHD were reviewed and retained if relevant to the current study.

The term “assisted suicide” was searched in PsychINFO yielding 772 articles. The search was refined by limiting to human, English language, empirical study (various types), literature or systematic review, or meta analysis, yielding 228 articles that were reviewed by abstract for relevance. Articles were retained for this literature review as noted above. The term “assist* AND suicide*” was searched in Scopus, with limits of English language, United States, yielding 527 articles reviewed by title and abstract. Articles were retained for this literature review as noted above.

Of the articles reviewed, a total of 16 reports of original empirical research, specifically addressing PAD (as opposed to AID) were found and included in this review.

Limitations of the research. AID and PAD research is hampered by the small numbers of patients who pursue AID/PAD, the frail nature of those at the end of life, as well as the difficulties and constraints related to research regarding an illegal medical practice. Furthermore, much of the PAD research in the US has been primarily conducted by one researcher (Ganzini and colleagues), thus the research may reflect certain biases in conceptualizing factors associated with PAD.

A notable issue in this body of research is that of the research informant. Due to the frail nature of those at the end of life, as well as the difficulty doing prospective research on those who might pursue AID/PAD, a retrospective research design using proxy informants has frequently been employed. In a review of clinically focused literature regarding the wish to hasten death (including studies assessing desire to hasten death as opposed to limiting the research on pursuit of hastened death), Monforte-Royo et al. (2010) identified a total of only 14 studies using patients as informants. The AID/PAD research identified and included in this review includes only five studies using patients as informants. The rest of the research relies on health care providers (physicians, nurses, social workers, and chaplains) or family members for information. Of note, the data regarding those who received PAD prescriptions gathered by the Oregon Health Authority is provided by physicians, thus information related to patient concerns is provided by these proxy informants. Using surrogates in AID/PAD research assumes that these individuals have an accurate understanding of what motivates the patients to pursue AID/PAD. The basis for that assumption is not clearly substantiated.

Additional difficulty is encountered in doing research into what is, in most areas, an illegal practice with potential negative implications for family members or licensed health care respondents. Only the research originating in Oregon, Washington, and Montana, following relevant legislation or court decision, reflects inquiry into legal practice of PAD. Volker (2004) identified risks of loss of professional licensure, legal action, and possible imprisonment for professionals who disclosed participation in AID, and identified the risk of potential legal action for family members who participated as well as impediments to this research. While authors of research into illegal AID typically identified the measures taken to insure confidentiality (see for example, Asch, 1996; Emanuel et al, 1996; Lee et al., 1996; Matzo and Emanual, 1997; Meier et al., 1998), whether respondents felt free to be forthcoming is unknown.

Response rates for much of the research included in this review are quite low, as is the case for a great deal of end of life research (Hotopf, Addington-Hall, & Ly, 2002). A possible implication of low response rate is that study samples were not representative of the population of interest. With these caveats, a review of literature relevant to pursuit of AID/PAD follows.

Variables Hypothesized to Influence Pursuit of PAD

It has long been assumed that unremitting and uncontrolled symptoms of illness at the end of life would be primary motivators for pursuit and use of PAD, and arguments for sanction of PAD have often rested upon the notion the PAD could provide relief from symptoms at the end of life. Some physicians and nurses saw a request for AID and PAD as a signal that symptoms needed greater attention, which resulted in redoubling efforts at greater patient comfort (Harvath et al., 2006; Kohlwes, Koepsell, Rhodes, & Pearlman, 2001; Schwarz, 2004).

Pain and other physical suffering. Alleviation of unremitting pain or other physical suffering has been frequently identified as a potential motive for AID, PAD and DHD (e.g., Foley, 1997; Monforte-Royo et al., 2010). Research regarding pain and other physical symptoms in pursuit of PAD indicates that pain, or fear of pain, may indeed play a role for some patients.

Pain and AID/PAD research. Seventy-five percent of 16 research studies included in this review that specifically addressed patient motives for pursuit of PAD or

AID included pain as a variable (7/9 quantitative studies and 5/7 qualitative studies). Of the seven quantitative studies measuring pain as a variable of interest, all supported pain, fear of pain, or distress due to other physical symptoms, as contributory to patient pursuit of AID or PAD. Informants in these studies included physicians (Back et al., 1996; Ganzini et al., 2000; Meier et al., 2003), hospice nurses and social workers (Ganzini et al., 2002), and hospice chaplains (Carlson, Simopolous, Goy, Jackson, & Ganzini, 2005). Family members of patients were informants in one study (Ganzini, Goy, & Dobscha, 2007) and one study relied on patients to ascribe importance to motives for pursuit of PAD (Ganzini, Goy, & Dobscha, 2009). The five qualitative studies specifically assessing patient motives for pursuit of AID/PAD revealed similar results, providing some support that pain may be a contributory factor in pursuit of AID/PAD. Informants in the qualitative research included physicians (Ganzini, Dobscha et al., 2003; Kohlwes et al., 2001), nurses (Schwarz, 2003; Volker, 2001), and patients and family members (Pearlman et al., 2005). Further description of these studies provides context and reveals nuance and limitations of the findings.

Back et al. (1996) and Meier et al. (2003) conducted mailed surveys of physicians in Washington State and nationally (respectively), and reported on physicians' perceptions of concerns for those patients who had pursued AID. Patient populations for these studies did not have legal access to PAD. Both studies revealed that approximately one-third of physicians assessed patients who had requested AID as having experienced severe pain (35% and 33%, respectively), with even higher proportions of patients experiencing "severe physical discomfort other than pain" (50% and 36% respectively) according to the physicians. It should be noted that even though pain and physical discomfort were believed to be present for 35% to 50% of patients who pursued AID, psychosocial concerns were believed to be present for greater proportions of those who pursed AID. For example, future loss of control, being a burden, being dependent, and loss of dignity were the perceived concerns of 72% to 77% of patients who had requested AID, far greater than the percentages of patients perceived to experience pain and other physical concerns (Back et al., 1996). Problematic of these studies however is that neither used standardized measures to directly assess patient pain, but rather relied on retrospective physician recall of the last one or two patients who had requested AID. Inherent in that design is risk for inaccurate recall of the patient and his or her condition. Even if the respondent's recall is assumed to be accurate, the degree to which pain/physical distress motivated pursuit of AID could well have been unknown, and description of the physicians' ability to assess that was unreported.

In a series of studies (details below), Ganzini and colleagues assessed the importance of pain and other physical symptoms as well as psychosocial concerns in the pursuit of PAD for patients who had legal access to PAD, from the perspective of physicians, nurses, chaplains, family members, and patients. Most of these studies had methodological limitations similar to those noted in Back et al. (1996) and Meier et al. (2003) above. Specifically, all but one of the Ganzini studies relied upon retrospective recall and interpretation of the patient's experience by a proxy informant. None used standardized measures to quantify the patient's pain experience, but rather asked the informants to report his or her perception of the importance of the role of pain (and a variety of other physical or psychosocial concerns) in the patient's pursuit of PAD. It is unknown how accurate the informant may have been, both in terms of the proxy's original perception of importance and his or her ability to accurately recall the patient and concern.

In 2000, Ganzini et al. reported on physicians' perceptions of patient reasons for requesting PAD, and pain (43% of patients), fatigue (41%), and dyspnea (27%) were reported as common patient concerns. Similar to results reported by Back et al. (1996) and Meier et al. (2003), psychosocial concerns including loss of independence (57% of patients), poor quality of life (55%), being ready to die (54%) and wanting to control the circumstances of death (53%) were perceived to be concerns for a greater percentage of patients than were concerns about pain and other physical concerns.

A study of hospice nurses and social workers (Ganzini et al., 2002), and a study of hospice chaplains (Carlson et al., 2005) revealed that nurses and chaplains perceived that patients' current pain / fear of future pain was an important reason for patient requests for PAD, with a median score of 4 (nurses) or 5 (chaplains) on a 1 (unimportant) to 5 (very important) scale. Once again however, a number of psychosocial concerns were perceived to be of greater importance than pain and other physical symptoms, including for example, desire to control circumstances of death, readiness for death, fear of loss of dignity, and desire to die at home. Of related interest, 84% of the nurses in that study rated the pain of patients who received prescriptions under the DWDA as about the same or less than the pain of other hospice patients, indicating that those who pursued PAD were, in general, not believed to be in greater pain than those who did not pursue PAD.

Ganzini and colleagues conducted two additional studies involving 83 family members (Ganzini et al., 2007) and 56 patients (Ganzini et al., 2009) as informants, assessing the importance of the list of concerns noted in the studies above, with some additions and changes, most notably that informants had the option to indicate separately whether current pain or fear of future pain were contributory. In each of those studies, current pain was rated as having low importance in the patient's pursuit of PAD while fear of future pain garnered some of the highest ratings of importance regarding reasons for pursuit, indicating that fear of future symptoms may be a more powerful motivator than the patient's current experience. In both of those studies psychosocial issues such as wanting to control circumstances of death, fear of future poor quality of life (QOL), and wanting to die at home, were highly rated as reasons motivating pursuit of PAD. The ability to use patients as informants regarding their reasons for pursuit of PAD overcomes the limitations of recall and uncertain validity of response. Family members would presumably have deep understanding of their loved ones pursuit of PAD, although the validity of those responses was also unknown.

While informative, these studies leave unanswered an important question: It is unknown whether those who pursue AID/PAD experience pain at greater levels, or have poorer pain control, than those at the end of life who do not pursue AID/PAD. A measure of the patient's level of pain and comparison with a group of terminally ill individuals uninterested in PAD would help to answer that question. Furthermore, the role of current pain as a concern, versus fear of future pain, has been parsed by the two most recent Ganzini studies and would benefit from further study.

The qualitative literature reveals a similar, but perhaps more nuanced view of pain and physical distress as motivators for pursuit of AID/PAD. Pearlman et al. (2005) provided a rich analysis of patient motives for pursuit of AID by interviewing patients who pursued AID and their family members. They found that issues related to the illness itself, including weakness, fatigue, pain, and loss of function were compelling factors in 68% of patients included in the study. Pain itself was deemed a motivating factor in 40% of patients involved in the study. However, this was the lowest rated factor; other physical concerns (such as feeling weak and tired) and psychosocial concerns (such as a desire for control) were all more highly rated as motivating influences in pursuit of AID. For some, the implication of pain and other physical symptoms, including inability to engage in meaningful activities, side effects of pain medications, and affronts to the patient's sense of dignity, were seen as motivating pursuit of AID.

Further evidence regarding the role of pain comes from Volker (2001) reporting on nurses who cared for patients requesting AID. The nurses described a desire for control over the dying process, including control of unremitting or intense pain, as compelling motives for patients. Also based upon retrospective recall of proxy informants (physicians) Kohlwes et al. (2001) reported that 75% of received requests for AID and 31% of honored requests were motivated by pain and suffering in a sample of physicians who cared for HIV/AIDS patients.

As was true for quantitative design studies, the qualitative studies revealed that fears about future symptoms and future quality of life and quality of dying were influential in pursuit of AID/PAD. Pearlman et al. (2005) reported that 60% of patients who had pursued AID had such concerns motivating their request. Similarly, Volker (2001) reported that patients who pursued AID were motivated by concern that aspects of the illness process might become unacceptable in the future. Ganzini, Dobscha et al., (2003) reported that motives for pursuit of PAD were more often related to future fears than current suffering.

Additional information can be gained from the Oregon Health Authority (OHA), which has been tracking end of life concerns for those who are provided a lethal prescription under the DWDA since the law's inception. As reported by physicians who provided the prescription, concern regarding, or current inadequate pain control was reported as an end of life concern for 23.5% of prescription recipients from 1998 through 2012. Issues of autonomy (a concern for 91.2% of PAD recipients), inability to engage in meaningful activities (88.8% of recipients), and dignity (82% of recipients) are much more frequently rated as EOL concerns (Oregon Health Authority, 2013).

Discussion. In summary, pain and other physical concerns have long been thought to contribute to pursuit of AID/PAD and the available evidence provides qualified support for that claim. However, the body of literature has some noteworthy limitations: the very small number of studies utilizing patients as direct informants; informant retrospective recall; lack of standardized measures of pain; and potentially confounding current pain with fear of future pain. When considered in isolation, there appears to be support for the contribution of pain to pursuit of PAD. However, when considered as one of many potential variables, pain and physical concerns appear as secondary to psychosocial concerns, noted particularly when patients are the informants. The results from Pearlman et al. (2005) indicate that the meaning of physical symptoms (including functional impairment and concomitant loss of meaning in life) may mediate the impact of physical symptoms and distress. Additionally, when fear of future pain is provided as a separate option, current pain recedes on the list of patient concerns. The current research uses standardized measures of current pain, allowing clear understanding of the impact of that variable at the time of pursuit of PAD.

Depression. Depression has been identified as a variable of interest and as a potential risk factor for AID/PAD (Ganzini & Dobscha, 2003; Monforte-Royo et al., 2010). As an ostensibly reversible condition, depression at end of life should be treated aggressively to reduce suffering and, if an influential factor, obviate the need for AID/PAD (Levene & Parker, 2011). Depression poses a potential risk factor as it may affect the patient's appraisal of his or her situation, leading to a more negative assessment than would occur absent the depression and thus influence a request for AID/PAD (Ganzini & Dobscha, 2003). If depression is severe, it may affect decisional competency (Levene & Parker, 2011; Werth, Gordon, & Johnson, 2002), although in most cases, capacity to make medical decisions is retained in the presence of clinical depression (Grisso & Appelbaum, 1995). The DWDA does not prohibit those who are assessed as depressed from obtaining PAD, however, the provider is obligated to ascertain that depression is not impairing judgment (Death with Dignity Act, 1997).

Depression is a key risk factor for suicide (attempts and completed) (Feltz-Cornelis, 2011). Whether and how the concept of action to hasten death at the end of life aligns with suicide in a non-terminally ill population has been debated. Some authors equate DHD and pursuit of AID/PAD with suicidal ideation and behavior in non-medically ill populations (Brown, Henteleff, Barakat, Rowe, 1986; Kelly & Varghese, 1996), suggesting that the same psychological processes operate in both. In a broader conceptualization, Breitbart et al. (2000) described DHD as the construct that underlies suicidal thoughts, AID/PAD, and euthanasia. Others conceptualize DHD in the context of terminal illness and place the pursuit of AID/PAD on a continuum of non-pathological decision making at the end of life that contains "do not resuscitate" orders, discontinuation of all but palliative care, cessation of life support, and terminal sedation (Cohen et al., 2000; Zaubler & Sullivan, 1996). Insofar as suicidal ideation is a clinical criterion for major depressive disorder, some find pursuit of AID/PAD as evidence of depression in and of itself, although this has been described as “circular logic” (Cohen et al., 2000, p. 198). Interestingly, it has been suggested that depression may serve as a protective factor for PAD. Apathy and fatigue are often symptoms of depression that could interfere with the relatively rigorous process that is required in order to obtain PAD (Ganzini & Dobscha, 2003, p. 929).

Assessing depression in terminally ill individuals can be difficult. Sadness, grief, and mourning are common responses to approaching death and can be difficult to differentiate from depression (Block, 2006; Block & Billings, 1995; Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005; Werth, Gordon, & Johnson, 2002; Zaubler & Sullivan, 1996) and some see depression as a normal response to terminal illness (Chochinov, Wilson, Enns, & Lander, 1994).

Accurate and appropriate clinical criteria are required for a realistic understanding of the prevalence of depression in the terminally ill. Some symptoms of depression, including fatigue, weight loss, and sleep disturbance, are common in the context of illness (Ganzini & Dobscha, 2003; Zaubler & Sullivan, 1996) and understanding the etiology of those somatic symptoms can be difficult in medically ill populations. Much of the AID/PAD research did not define what was meant by depression or the criteria used to ascertain patient status (i.e., depressed or not). Methods of assessment of depression in the studies referenced below ranged from provider recall of the patient’s clinical presentation (no formal criteria used), to use of patient questionnaire, to assessment by use of diagnostic interview.

Depression and AID/PAD research. There is a paucity of data related to patient mood states and the influence of mood on motivation for requests for AID/PAD. Only nine studies specifically addressed the contribution of depression to pursuit of AID/PAD. Of these nine, five reported on prevalence of depression in patients, either per retrospective physician recall of patient concerns (Back et al., 1996; Ganzini et al., 2000; Meier et al., 2003) or by direct patient assessment (Bharucha et al., 2003; Ganzini, Goy, & Dobscha, 2008). Five studies reported on the importance of depression on patient motivation to pursue PAD (Carlson et al., 2005; Ganzini et al., 2002, 2007, 2008, 2009). Additionally, one study reported on nurse perception of PAD recipients' depression relative to other hospice patients (Ganzini et al., 2002), and three studies (Ganzini et al., 2008; Kohlwes et al., 2001; Meier et al., 2003) reported on physician practice related to treatment of depression.

The range of prevalence of depression reported in studies included in this review is wide: 14% to 55% depending upon the study. Two studies reported high prevalence of depression: Based upon a mailed survey of Washington State physicians, Back et al. (1996) reported 55% of patients requesting AID were perceived to experience severe depression or depressed mood. Based upon a national mailed survey, Meier et al. (2003) reported that of 52% of patients requesting a lethal prescription were thought by physicians to be depressed at the time of the request. In neither of these studies was PAD a legal option for patients. In contrast, Ganzini et al. (2000) conducted a mailed survey of all Oregon physicians eligible to prescribe a lethal prescription under the DWDA.

Twenty percent of patients who requested PAD were described by physicians as having symptoms of depression. The patients in the Ganzini et al. study had PAD as a legal option. In all three of these studies, patient depression was reported by retrospective recall of the physician and none used validated measures or standardized criteria to assess depression. The major limits of these mailed surveys have been noted above, specifically, the reliability of retrospective recall of patient concerns and impact of depression on pursuit of PAD/AID was unknown.

In a series of Oregon-based studies, Ganzini and colleagues (Carlson et al., 2005; Ganzini et al., 2000, 2007, 2009) examined the importance of depression in the pursuit of PAD. Informants in these studies were hospice nurses and social workers, hospice chaplains, family members of patients requesting PAD, and patients requesting PAD. None of these studies used standardized measures of depression and all patients had legal access to PAD. Hospice nurses, social workers, and chaplains all reported that depression was not perceived to be a significant motivating factor for most of those who pursued PAD. As reported by these informants, depression or other psychiatric concerns were near the bottom of the list of items of importance in pursuit of PAD. Additionally, 77% percent of nurses believed that the patients who had received lethal prescriptions under DWDA had about the same, less, or much less depression than other hospice patients. Similarly, family members rated depression as unimportant, identifying it as one of the least important reasons for their loved one’s pursuit of PAD (Ganzini et al., 2007), and patients who had either requested or received PAD generally rated depression as unimportant in their motivation for pursuit of PAD (Ganzini et al., 2009).

Two studies included in this review used validated measures or standardized criteria to directly assess prevalence of depression in patients requesting AID or PAD (Bharucha et al., 2003; Ganzini et al., 2008). In a longitudinal study with patients and family members, Bharucha et al. concluded that depression was not a primary concern of those pursuing AID. Although they did not use a standardized measure for depression, they embedded the DSM-IV criteria for depression in their interview questions and specifically asked patients "Are you depressed?" (a question which has reported validity in identifying depression in terminally patients [Chochinov, Wilson, Enns, & Lander, 1997]). Patients (N = 35) were classified as having a probable major depressive episode (MDE), possible MDE, or depressive symptoms. None of the patients involved in the study had probable MDE while planning for and pursuing AID, three patients (9%) were assessed as having possible MDE, and five (14%) had depressive symptoms, resulting in a combined rate of 23% having some level of depressive symptoms at the time of request. This is the only longitudinal study to date to assess depression in AID, and it is possible that extended interviews allowed researchers to determine whether and when patient statements reflected depression as opposed to somatic sequela of illness, resulting in lower rates of depression than many other studies.

Ganzini et al., (2008) used standardized clinical measures of depression (the Hospital Anxiety and Depression Scale [HADS] and the Structured Clinical Interview for DSM-IV [SCID]) to directly assess depression in patients who pursued PAD. Of 58 patients who either requested or received the lethal prescription for PAD, 26% met criteria for depression by either HADS or SCID criteria. Approximately half of the depressed patients reported that depression was not an influential factor in pursuit of

PAD, however six patients (40% of those identified as depressed and 10.3% of the total sample) reported that depression either somewhat or strongly influenced their pursuit of PAD. Eighteen (31%) study participants received a lethal prescription intended for PAD, including three of those who were evaluated as depressed by criteria noted above; all three died by use of the lethal prescription. Of the three, two reported that depression was not at all important in his or her decision to pursue PAD, the third reported that depression was moderately important.

Depression has been routinely assessed and treated in response to a request for AID/PAD. Back et al. (1996) reported that physicians responded to requests for AID with antidepressant or anxiolytic medication in 65% of patient requests. In contrast, Meier et al. (1998) reported that 25% of physicians prescribed antidepressant medication in response to the request for AID. In the only study to broadly report on the impact of treatment of depression, Ganzini et al. (2000) reported that 20% of PAD requesters with perceived depression were referred for a mental health evaluation and 18% were treated with antidepressant or anxiolytic medication. Eleven percent of those patients treated for depression rescinded the request for PAD. Ganzini et al. (2008) provided case reports on three patients meeting criteria for depression who had received a prescription under DWDA. Of the three, one is known to have received subsequent treatment for depression and was assessed to be in remission according to her treating psychiatrist. Although the patient reported that depression somewhat influenced her pursuit of PAD, she died by use of lethal prescription following remission of the depression.

The state of Oregon does not collect data related to depression for those who receive prescriptions under the DWDA. It does track referrals made for a psychiatric evaluation for patients requesting a lethal prescription. During the 15 years of record keeping for Oregon, of the 673 patients who died after ingesting a lethal dose of medication prescribed under the DWDA, 42 (6.2%) were referred for psychiatric evaluation. The outcomes of the evaluations are not reported, however, all of these patients ultimately received and died by a prescription under DWDA (Oregon Health Authority, 2013). As the Oregon Health Authority (OHA) only tracks data for those who received a lethal prescription, the number of requests for PAD that were denied following psychiatric evaluation is unknown.

Discussion. To provide context for prevalence of depression in those who pursue PAD, it is useful to consider prevalence of depression for those with terminal illness. That depression rates are higher for terminally ill individuals than non-medically ill populations has been commonly reported (Rosenfeld, 2000a), although clear understanding of prevalence is elusive. In a systematic review of the literature, Hotopf et al. (2002) reported a wide range of prevalence rates found in terminally ill populations, regardless of whether the study used recognition of depression by the clinician (7% to 38% reported prevalence of depression), a single question (8% to 63% reported prevalence), a questionnaire (most often the HADS, with prevalence rates for definite depression 16% to 50%), or a diagnostically more rigorous interview (typically the SCID, with prevalence rates of 5.6% to 32% for all depressive disorders).

As the current review reveals, the reported prevalence rates of depression for PAD requesters varies widely and may be influenced by measures used, informant, and study design, with prevalence ranges from 14% to 55% in the reviewed studies. Given the similarly wide range of prevalence of depression in terminal illness and those who pursue

PAD, the question remains as to whether the prevalence of depression is greater in terminally ill patients who pursue PAD than in the general population of terminally ill patients. That is, might not similar rates of depression in terminally ill populations be expected to be found in those who pursue PAD? It is not clear that those with depression are overrepresented in the population of those who pursue PAD.

The influence of depression on pursuit of AID/PAD is even less clear than the prevalence. Since the reported prevalence rates of depression for PAD pursuers are similar to prevalence for other terminally ill individuals, what impact, and for whom, is depression a motivating factor? Although most studies of Oregonians who have pursued PAD indicate that depression was not an important factor, Ganzini et al. (2008) reported that some PAD pursuers, including some who have received and used a prescription did report depression to be influential in their decision making process.

Also unknown is whether the treatment of depression would change interest and pursuit of AID/PAD. Kohlwes et al. (2001) reported that 90% of sample physicians addressed psychiatric concerns upon receiving a request for AID and 70% reported treating depression empirically prior to coming to a decision about whether to support the patient’s request.

In an earlier study, Ganzini, Lee, Heintz, Bloom, and Fenn (1994) found that elderly psychiatric inpatients with mild to moderate depression did not change in stated preference for life-sustaining medical interventions in hypothetical situations, even if the patient experienced an improvement in their depression at follow up. For those with severe depression however, improvement in depression resulted in an increase in the number of life sustaining interventions deemed acceptable by patients. This again points toward the need to understand whether, when, and how depression may influence choices for end of life interventions including AID/PAD.

There are several limitations to the small body of research regarding depression and pursuit of PAD/AID. Beyond the general limits noted above (ie, research into an illegal practice), issues related to sampling method, response rate, and measures or methods used to assess depression further limit the generalizability of research regarding depression for those who have pursued AID/PAD.

While mailed surveys reviewed here used probability samples (Carlson et al., 2005; Ganzini et al., 2000; Ganzini et al., 2002) or random samples (Back et al., 1996; Meier et al., 1998/2003), the remaining studies used convenience samples, which may not be representative of the population of those who pursue PAD. Effects of depression on energy, interest, and motivation potentially hamper studies of depression utilizing convenience samples; depressed patients may be less likely to volunteer for research or may be excluded due their symptoms and thus may be underrepresented in patient samples (Hotopf et al. 2002). Additionally, some studies relied upon referrals from various organizations, and staff may have screened out significantly depressed patients (Ganzini et al., 2009*)*.

Low response rates also limit generalizability. Of the studies using patients or family members as informants, Bharucha et al. (2003) did not report a response rate and Ganzini et al. (2008/2009) reported a response rate of 28%. The response rates for mailed survey studies ranged from 57% to 73% (Back et al., 1996; Carlson et al., 2005; Ganzini et al., 2000; Ganzini et al., 2002; Meier et al., 1998/2003).

Perhaps most importantly, only two studies used standardized criteria to directly assess depression in patients who pursued AID/PAD. All of the other studies relied on proxy informants who were queried about the patient's mood at the time of pursuit of PAD, which was a period of time following patient contact or death. The skill level and the criteria used by informants to assess depression in these studies are unknown, leading to the uncertainty of validity and reliability of the assessments.

In summary, although depression has been noted as a clinically significant issue for those at the end of life, the current evidence does not indicate that those who pursue AID/PAD experience depression at higher rates than others at the end of life. This understanding is limited by virtue of only two studies that used standardized criteria to directly assess depression in those who pursued AID/PAD. The current study adds to understanding of those who pursue PAD by use of standardized measures to assess the level of depression and by comparing those results to data from a control group. Additionally, the current study compares the contribution of depression to pursuit of PAD among a number of other related variables hypothesized to be meaningful in pursuit of PAD.

Hopelessness. A concept closely related to depression, hopelessness has been identified as a potential factor contributing to pursuit of AID/PAD, however very few studies have specifically measured hopelessness in relation to pursuit of AID/PAD. Hopelessness is typically described as a psychiatric concern, defined as negative cognitive schema or negative future expectations (Beck, Weissman, Lester, & Trexler, 1974), although it has also been described as an existential (Chochinov et al., 2005) or spiritual (Bharucha et al., 2003; Clarke & Kissane, 2002; Rosenfeld et al., 2006) concern.

In the context of terminal illness, the construct of hopelessness can be difficult to parse, as it may be conflated with awareness of disease prognosis and assumptions made about a patient's psychological state when faced with illness that has "no hope of cure" (Rosenfeld, Gibson, Kramer, & Breitbart, 2004, p. 44). Clarke and Kissane (2002) asserted that hopelessness is at the core of demoralization, which they considered to be a central construct in the desire to die. They described hopelessness as intertwined with spiritual constructs and asserted a close relationship between hope, meaning, and purpose.

Hopelessness has been correlated with actions that hasten death in psychiatric populations (Beck, Kovacs, & Weissman 1975). While hopelessness has been identified as a core feature of depression (Beck et al., 1974; Block, 2006), it also appears to be a distinct, albeit overlapping construct (Werth et al., 2002). Hopelessness has been found to be a stronger predictor of suicidal ideation and behavior than depression (Beck, Steer, Kovacs, & Garrison, 1985; Werth et al., 2002). What is not clear is whether those findings indicate that hopelessness is an important motivating factor in patients pursuing AID/PAD.

Hopelessness and AID/PAD research. Findings in the literature generally support the hypothesis that higher levels of hopelessness are correlated with DHD (Breitbart et al., 2000; Chochinov, Wilson, Enns, & Lander, 1998; Chochinov et al., 2005; Rosenfeld et al., 2006) and interest in PAD (Ganzini et al. 1998/2002), but are mixed regarding pursuit of AID/PAD (Bharucha et al., 2003; Ganzini et al., 2008).

This review revealed two studies that specifically assessed hopelessness as a contributor to pursuit of AID/PAD. In a study of 58 patients who requested PAD or contacted an agency that offered information and assistance to those interested in PAD

(Ganzini et al., 2008), 11 (19%) patients scored at or above the cutoff score indicating clinically significant hopelessness (Beck, Brown, & Steer, 1989) on the Beck Hopelessness Scale (BHS). In contrast, 15 (26%) patients met criteria for depression. There was a trend toward participants whose request for PAD was honored to have lower hopelessness scores than those whose request was not honored. On a zero (low hopelessness) to 20 (high hopelessness) scale, those who received a lethal prescription had lower mean hopelessness scores (M =5.0 [SD = 3.00] vs M =7.5 [SD = 5.40], p = 0.80).

In a qualitative study examining the role of psychiatric factors in 35 patients who actively pursued AID/PAD (Bharucha et al., 2003), only one patient (3%) was found to have pervasive hopelessness. In that study, psychiatric symptoms, including hopelessness, were identified by clinical interview, with probes for further information as warranted. The authors concluded that hopelessness was not a motivating factor in the pursuit of AID/PAD. In the report, hopelessness and/or criteria to define the concept were not identified for the reader.

Discussion. At this time, due to the paucity of research specifically examining this factor, little is clearly known about the role of hopelessness as a motivator for pursuit of AID/PAD, although it appears to be influential. In examining this variable, the current study can help to determine whether the same factors that are salient in suicide in a non-medically ill population also pertain to those who pursue PAD, thus further explicating the phenomena.

Attachment. Qualitative research has suggested that there exist common elements of personality among those who pursue AID/PAD. Those individuals have been described as “fiercely independent” and as “highly controlling” (Ganzini, Dobscha, et al., 2003; Harvath et al., 2006). Attachment theory provides a possible explanatory model for both independence and control in the face of impending death. Attachment refers to a pattern of behavior that is triggered when safety is threatened in an effort to maintain a sense of security. Patterns of attachment behavior tend to persist through the years, appearing similar to trait-like styles of personality (Bretherton, 1985; Mikulincer & Shaver, 2009). According to the theory of attachment, individuals with certain attachment styles may exhibit behaviors that demonstrate a high need for control and/or independence.

Attachment theory. Attachment theory, originally developed and described by John Bowlby, provides a framework for understanding how and why humans develop affectional bonds with significant others. Attachment refers to the emotional bond between individuals, based upon an expectation of support in time of need (Tan et al., 2005), and attachment styles reflect patterns of relating in intimate and/or caregiving/care receiving relationships, particularly with parents, children, and romantic partners. Attachment behavior, which has also been called support seeking behavior, is that which results in closer proximity to others who are seen as stronger or wiser and thus serves the survival function of safety from predators (Mikulincer & Shaver, 2009). The behavior is believed to be the result of a biological drive with evolutionary utility that exists to increase the likelihood of survival of an immature individual without the ability to protect the self from predators. Attachment behaviors are seen easily during childhood and can persist relatively unchanged throughout the lifespan (Bowlby, 1977, 1982). While attachment refers to a pattern of behavior within relationships, as these patterns persist through the years, they become more ingrained and more similar to trait-like styles of personality (Bretherton, 1985; Mikulincer & Shaver, 2009).

Bartholomew (1990; Bartholomew & Horowitz, 1991) proposed a model of four attachment styles, depicting models of the self and other, organized along the dimensions of avoidance (discomfort with emotional intimacy and dependence on others, preference for self reliance, and low emotionality) and anxiety (a strong desire for closeness and safety, concern about the availability of the other, and worry about value to the other). The four attachment styles are labeled secure, preoccupied (or anxious), fearful, and dismissing (or avoidant), although other terms are used by different authors to describe similar constructs (see for example Maunder and Hunter, 2001; Ciechanowski, Walker, Katon, & Russo, 2002; Petersen & Koehler, 2006). Individuals are not expected to match any of the prototype attachment styles exactly, but may demonstrate more or less congruence with one or more styles. In adult populations, a secure attachment style has been reported for approximately 50% of the population (Bartholomew & Horowitz, 1991; Ciechanowski et al., 2002; Hunter & Maunder, 2001); preoccupied/anxious attachment has been reported ranging from 14%-22%; fearful attachment has been reported at approximately 20%; and dismissive attachment has been reported as 18%-23% (Bartholomew & Horowitz, 1991; Ciechanowski et al., 2002).

Secure attachment style is characterized by a positive sense of self and others. The self is seen as being worthy of love and care, and others are seen as consistent and trustworthy in ability to provide love and caring. Warm, supportive, and consistent parenting in childhood facilitates adult relationships characterized by comfort and confidence with intimacy and autonomy (Bartholomew, 1990). Individuals are comfortable with closeness and dependency, willing to rely on others for support, are confident that support will be available, able to accept and are satisfied with and trusting of support offered, and do not worry about being rejected (Collins & Feeney, 2000; Crowell & Treboux, 1995). Secure individuals are described as adaptable, trusting, and understanding (Hunter & Maunder, 2001, p. 558).

There are three types of insecure attachment reported to have substantial prevalence in the population: preoccupied/anxious, fearful, and dismissing/avoidant. Those who develop insecure attachment patterns generally report less available support and are less satisfied with support received (Bartholomew, 1990; Collins & Feeney, 2000; Rodin et al., 2007). These individuals are said to develop patterns of attachment system hyperactivation (anxious, controlling, or intrusive efforts to gain attention) or deactivation (suppression of support seeking activities) (Mikulincer & Shaver, 2009).

Preoccupied/anxious attachment is characterized by a sense of the self as unworthy of love and caring, but expectations of others as providers of love and care are generally positive. Those with preoccupied/anxious attachment experience an exaggerated desire for approval, closeness, and dependence as well as heightened concern of rejection. Children who experience inconsistent and/or insensitive parenting may develop this internal working model. Preoccupied/anxious individuals seek support and care, but the comfort gained from contact with caregivers may be transient. Their sense of their own ability to cope with threats to security is very limited, pushing them to depend upon others, perhaps desperately (Hunter & Maunder, 2001). These individuals may be described as “anxious, dependent, emotional, impulsive, and approval seeking” (Maunder & Hunter, 2001, p. 559).

Dismissing and fearful attachment are both believed to stem from early experiences with rejecting or unavailable attachment figures. Fearful attachment models are characterized by a desire for contact and intimacy, however that desire is limited by the individual's sense of the self as being unworthy, distrust of others, and fear of rejection. Fearful individuals may be hypersensitive to social approval and thus avoid situations that hold the possibility of rejection. When stressed, they seek care and support, but are ultimately dissatisfied with care offered. They may respond by ongoing requests for more support, accompanied by expression of dissatisfaction and distrust. They have been described as self-conscious, shy, doubting, and cautious (Maunder & Hunter, 2001, p. 559). Such individuals struggle with both intimacy and autonomy (Bartholomew, 1990; Bartholomew & Horowitz, 1991; Collins & Feeney, 2000).

Dismissing/avoidant individuals have developed strategies to defend against attachment needs and close relationships are seen as unimportant. They place high value on independence and self-reliance and tend to have a positive self-view, but possess negative views of others. They dread being dependent upon others (Petersen & Koehler, 2005) and may be seen as cold or competitive (Maunder & Hunter, 2001, p. 559). Dismissing individuals have developed a sense of self worth and autonomy, however they reject intimacy (Bartholomew, 1990; Collins & Feeney, 2000).

Attachment and illness related behavior. The attachment system in adulthood, as in childhood, is thought to become activated when security is threatened. Individual responses to distressing situations, such as illness, may be understood within the framework of attachment style. Attachment theory has been used to help explain multiple aspects of illness related behavior, including health seeking behavior, acceptance of care, and patient provider relationships (Ciechanowski et al., 2002; Tan et al., 2005; Thompson & Ciechanowski, 2003).

The evidence for attachment style and its relationship to illness behaviors (care seeking and treatment adherence for example) is robust. For example, in Maunder and Hunter's review of literature (2001), attachment style was found to contribute to physical illness due to altered stress response; Ciechanowski et al. (2002) found attachment style related to patients' reports of somatic symptoms, number of primary care visits and annual primary care costs; Ciechanowski, et al. (2006) found attachment style to be related to treatment adherence with diabetic patients; and Waldinger, Schulz, Barsky, and Ahern (2006) found attachment style related to levels of adult somatization. It perhaps follows logically that attachment style could impact care at the end of life.

Attachment and end of life care. The likelihood that attachment behaviors will be activated is greatest during periods of increased dependence, particularly early and late in life (Petersen & Koehler, 2006). An attachment perspective on psychological challenges and the propensity to seek and accept care at end of life may have particular salience for understanding behavior related to pursuit of AID/PAD. Terminal illness inevitably comes with decreased functioning and loss, triggering attachment schemas, and could potentially trigger a crisis related to threat to security and the need for care (Tan et al., 2005). While dying patients are generally aware of the impending loss, the fact that the loss cannot be mitigated does not undermine the role of attachment behavior to maintain security in light of the loss. End-stage cancer patients with anxious or avoidant attachment were found to report lower levels of emotional support, ultimately contributing to the patient's sense of distress at the end of life (Hunter, Davis, & Tunstall, 2006). Anxious and fearful attachment styles have also been found to be a variable in the desire for hastened death, primarily due to its contribution to depression (Rodin, et al., 2009).

Attachment and AID/PAD research. Only one study was found to specifically assess the influence of attachment on pursuit of PAD (Oldham, et al., 2011). In this study, family members were asked to rate the decedent's relationship style with a measure that categorized attachment style. Contrary to prevalence estimates in the general population, dismissing attachment style was the most frequently reported style for both PAD requesters and surprisingly for controls (56% of PAD requesters and 41% of controls). Following were: secure attachment (35% of requesters and 33% of controls), fearful attachment (6% of requesters and 14% of controls), and preoccupied/anxious attachment (4% of requesters and 11% of controls). The differences between these groups of requesters and controls approached, but did not reach, statistical significance (p = .08).

The authors concluded that requests for PAD might be understood from a framework of lifelong avoidance of dependence on others and the personality qualities of high need for autonomy, control, self-reliance, and distrust of others. These qualities are consistent with qualitatively derived descriptions of PAD requesters and of dismissing attachment style.

Discussion. There is a robust body of research regarding the impact of attachment style on medical care and outcomes of care, thus it seems logical that style of attachment might have a notable impact on end of life choices. There is little research however that describes the impact of attachment on pursuit of AID/PAD. The current study helps to describe the relationship between dismissive attachment style and pursuit of PAD.

Desire for control. Death from a terminal illness inevitably involves decreasing functional ability and increasing dependence, and for some these dependency needs are a challenge to life long values and practice (Tan et al., 2005). It has been hypothesized that controlling personality style, perfectionism, independence, and self-reliance may have an influence on pursuit of AID/PAD (Block, 2006; Block & Billings, 1995; Werth et al., 2002; Wineberg & Werth, 2003). Zaubler and Sullivan (1996) noted the importance of understanding to what extent a request for AID/PAD is consistent with life long values, such as independence and self-reliance, versus a request that reflects a condition that might be ameliorated such as depression. Cohen et al. (2000) described pursuit of AID/PAD, in some, as an expression of long standing personality traits, and reported that those who make this and similar life limiting decisions (ie, dialysis discontinuation) can be independent, perfectionist, and have high need to avoid the helplessness that comes with dependency at the end of life.

A number of studies have reported that the strong desire to control the circumstances of death seen in some patients was influential in pursuit of AID/PAD. Chochinov et al. (2006) suggested that the oft cited notion that the way individuals die is consistent with how they have lived is indeed valid, and that personality style, psychological coping mechanisms, and distress at end of life are related, although it is unknown whether the desire for control of end of life circumstances represented an enduring personality trait. If it does, then examination of this quality and its impact on coping may aid understanding of the pursuit of AID/PAD.

Desire for control and AID/PAD research. Research suggests an influence of personality traits and/or psychological coping mechanisms on pursuit of PAD. In a series of studies, Ganzini and colleagues (Carlson et al., 2005; Ganzini et al., 2000, 2002, 2007, 2009) collected data on the motivating factors for pursuit of PAD. Their studies consistently identified the desire for control over the dying process as influential for those who pursue PAD. In a survey of physicians who received requests for PAD under the DWDA (Ganzini et al, 2000) the top four conditions, values, or symptoms influencing patient pursuit of PAD were reported as: loss of independence (assessed to be a factor for 57% of patients), poor quality of life (QOL) (a factor for 55% of patients), readiness to die (a factor for 54% of patients), and desire to control the circumstances of death (a factor for 53% of patients). In a study involving hospice nurses who worked with patients who received a lethal prescription under the DWDA, 77% of nurses thought that the most important reason for requesting PAD was desire to control the circumstances of death. Additionally, 77% of nurses thought PAD recipients feared loss of control of circumstances of death more or much more than other hospice patients, and 62% thought PAD recipients feared loss of independence more or much more than other hospice patients (Ganzini et al., 2002).

Family members and patients had similar views on the importance of this trait as a motivating factor. Family members rated wanting to control the circumstances of death, fear of poor quality of life in the future, fear of loss of independence in the future, and fear of inability to care for self in the future as among the most important reasons that patients requested PAD, all garnering median scores of 5 on a 1 (low importance) to 5 (high importance) scale. When asked to identify the single most important reason for pursuit of PAD, family members identified desire to control the circumstances of death most often (Ganzini et al., 2007).

Patients who pursued PAD identified their motives and concerns (Ganzini et al., 2009): Wanting to control circumstances of death, future poor QOL, future pain, future inability to care for self, loss of independence, and wanting to die at home all garnered median scores of 5 on a 1 to 5 scale. When asked to identify the single most important reason for requesting PAD, 11 of 41 responders (27%) identified a desire to feel in control, 5 (12%) stated a desire to avoid dependence on others, 5 (12%) reported worry about future pain, and 4 (10%) identified fear of poor future QOL. All other identified reasons received 3 or fewer endorsements from patients.

Some of the richest and most vivid descriptions of the role of the desire for control in pursuit of AID/PAD can be found in qualitative literature. Volker (2001) gathered narrative accounts of patient requests for AID from oncology nurses: Desire for control of the dying process emerged as a major theme, observed from patients, family members, and from the nurses themselves. Some requests were for immediate action, seen as “a cry for help” (p. 43) in order to avoid a state seen as unacceptable. Other requests were made so as to have an alternative if pain and suffering became unbearable, such as the patient who indicated no need to hasten death “as long as she was in good shape” (p. 44). Volker speculated that the desire for control might reflect a belief that dying should be as controllable as other aspects of life.

In an Oregon-based study of physicians’ perceptions of patients requesting PAD, Ganzini, Dobscha, et al. (2003) provided rich descriptions of patients and motives for PAD. In this study, 35 physicians were interviewed and asked to describe patient personalities and motives for pursuit of PAD. Remaining in control was described as consistent with life long values. In compelling stories, two patients who were days or even hours from death were described as engaging in extraordinary efforts to muster the energy to stay alive long enough to use the lethal prescription on their own. The unusually high need for control was seen as a coping style that preceded the disease process. Contrary to the idea that requests for PAD might communicate desire for greater symptom control or the need for additional interventions, the authors reported that discussions of alternatives to PAD were generally not fruitful. Patients were described as "strong-willed", "determined", "inflexible" and "unwavering" in their desire for PAD (p. 383). A physician was quoted, "When I tried to talk them out of it or assess motivations [the patients] perceived me as obstructionist and became quite resentful" (p. 384).

Pearlman et al. (2005) conducted qualitative interviews with patients and family members involving 35 cases of pursuit of AID/PAD. In 21 of the 35 cases, pursuit of AID/PAD was seen as an expression of the patients' long-standing value of independence and desire to maintain control over future events. For example, one patient was described by a family member as "an extraordinarily independent person, who needed to be in control of her life at all times" (p. 237).

Discussion. Personality refers to stable and unchanging qualities that shape the ways people view and experience their world (Chochinov et al., 2006, p. 339). Sensitivity to different qualities of personality, particularly differing needs for control, will enable care providers to tailor interventions and increase the likelihood that patients at end of life will find those interventions helpful and supportive. For patients with a very high need for autonomy and control, offers of support, direct attempts to dissuade pursuit of AID/PAD, and otherwise directive care may be met with resistance and result in feelings of alienation rather than the intended comfort (Ganzini, Dobscha, et al., 2003).

While the studies above provide clinical impressions and anecdotal reports of those who pursued PAD/AID, none employed systematic measures to assess personality features or determined whether and to what extent there were common features among those who pursued action to hasten death. The current research utilized a measure of desire for control to examine differences between those who do and do not pursue PAD at the end of life. Thus the study can help to quantify this quality, which has been so vividly described qualitatively, as well as examine the differences between those who do and do not pursue PAD, something that has not been done heretofore.

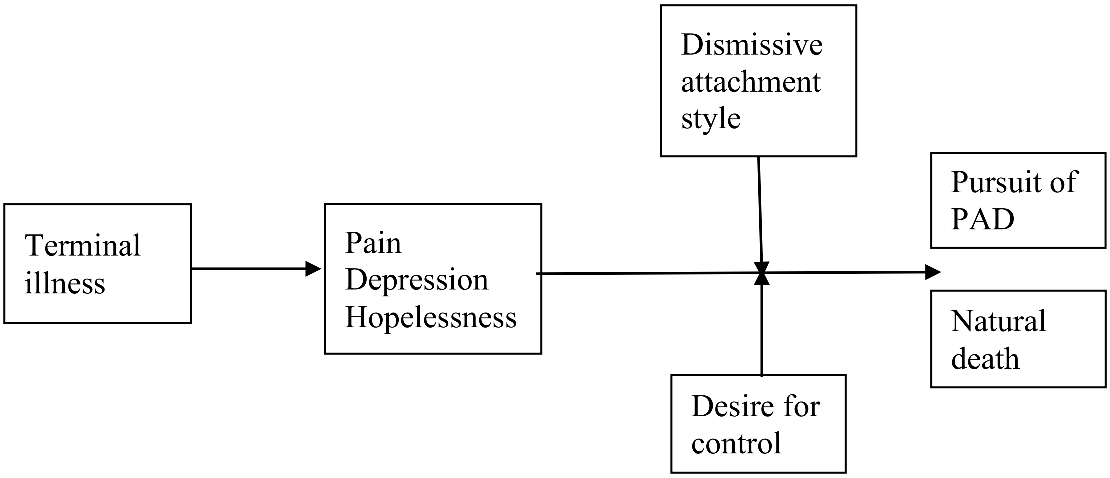
Conceptual Framework

As this review demonstrates, there are a number of variables that have been hypothesized to influence the pursuit of AID/PAD in terminally ill individuals. The majority of research to this point has focused on potentially modifiable variables, particularly physical factors such as pain and psychosocial factors such as depression. Despite that AID/PAD has long been thought of as a last resort for relief in the face of unremitting illness symptoms, the data fail to provide a compelling picture of symptom distress for those who pursue AID/PAD. Consequently, researchers are beginning to explore other variables that may help explain why some individuals, and not others, pursue AID/PAD.

The conceptual framework for this study provides a way of understanding the hypothesized variables that may explicate important motivators for pursuit of AID/PAD. Specifically, factors motivating pursuit may be understood as either related to the patient's illness or to long-standing and enduring personality related variables. If illness-related variables are instrumental in patient motivation for pursuit of AID/PAD, increased attention and high quality palliative care may attenuate those factors. In contrast, the potential for dependency that is concomitant with terminal illness may be the source of distress, and this personality-related source of distress will not be ameliorated by addressing illness related factors. It may be that these personality factors are compelling in pursuit of AID/PAD.

The conceptual model (see Figure 1) hypothesizes that illness-related symptoms (i.e., pain, depression, and perhaps hopelessness) may be associated with consideration of hastening death. Whether those thoughts translate to pursuit of AID/PAD may be influenced by personality-related variables (i.e., dismissive attachment style and/or desire for control). The current study will examine these variables for their presence and predictive value for those who pursue PAD.

Figure 1. Conceptual model hypothesizing the relationship of variables contributing to pursuit of PAD



Chapter Three

Method

The current study examined factors that motivated Oregonians at the end of life to pursue physician assisted death (PAD). A secondary analysis of data gathered by Ganzini and colleagues allowed for examination of several factors that have been previously hypothesized as important in pursuit of PAD, as well as comparison between those who pursued PAD and terminally ill individuals who did not pursue PAD. This chapter will describe the design, methods, and instruments of the current and parent studies.

Specific Aims and Hypotheses

The purpose of this study was to examine the predictive value of pain, depression, hopelessness, dismissive attachment style, and desire for control in the pursuit of PAD by terminally ill individuals as well as compare the presence and levels of those factors with a group of terminally ill individuals who were not pursuing PAD. The specific aims of this study and associated hypotheses follow.

Specific Aim #1. Examine the association between dismissive attachment style and pursuit of PAD, while controlling for demographic variables, pain, depression, hopelessness and desire for control.

- Hypothesis: dismissive attachment style will increase the likelihood of pursuit of PAD, while controlling for demographic variables, pain, depression, hopelessness, and desire for control.

Specific Aim #2. Examine the moderator effect of dismissive attachment style on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD.

- Hypothesis: Dismissive attachment style will moderate the relationship between pain, depression, hopelessness, and pursuit of PAD, while controlling for demographic variables.
    - Individuals with higher levels of pain, depression, and hopelessness are more likely to pursue PAD if they have higher levels of dismissive attachment style than individuals with lower levels of dismissive attachment style, while controlling for demographic variables.

Specific Aim #3. Examine the moderator effect of desire for control on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD.

- Hypothesis: Desire for control will moderate the relationship between pain, depression, hopelessness, and pursuit of PAD, after controlling for demographic variables.
    - Individuals with higher levels of pain, depression, and hopelessness are more likely to pursue PAD if they have higher levels of desire for control than individuals with lower levels of desire for control, after controlling for demographic variables.

Study Design

Parent study and current study. The study “Why Patients Consider Hastening Death”, funded by the Northwest Health Foundation, was approved by the Portland Veterans’ Affairs Medical Center (VAMC) and conducted by Dr. Linda Ganzini (principal investigator) during 2004-2010.

The aims of the parent study were to explore spirituality/meaning, hopelessness, and autonomy in those who pursued PAD. The parent study had, as a primary objective, intention to measure and assess the impact of attachment style on those who pursue PAD. That study gathered quantitative data on the following variables: participant desire for and pursuit of PAD, reasons for requesting PAD, current pain, hopelessness, depression, attachment style, perception of burden to others, perception of social support, functional status, religious practices, spirituality and sense of meaning, importance of control, trust in physician, and demographic variables. The current study supported the work of the parent study through analysis of the attachment data, and extended it by considering the moderating effects of attachment style on the relationship between pain, depression, and hopelessness and pursuit of PAD. Additionally, the current study examined the association of depression, pain, desire for control, and hopelessness and pursuit of PAD.

A case-control study design was utilized in the parent and current studies. Pursuit of PAD is a rare event and case-control design is an efficient method for identifying cases when incidents of cases are rare (Katz, 2006; Norman and Streiner, 2008). Alternate study designs such as cross sectional study design or prospective design would likely require very large numbers in the sample in order to yield sufficient numbers of participants pursuing PAD.

Setting and Sample

For the parent study, terminally ill patients who seriously pursued and/or requested lethal medication under the Death with Dignity Act (DWDA) were recruited for the case group, and terminally ill patients with no interest in pursuing PAD were recruited for the comparison group. The current study employed a secondary analysis to examine the contribution of variables to participants' decisions to pursue PAD. Data from a total sample of $N = 100$ (58 cases and 42 controls) were included in the original data set; due to missing data on some key variables, $N = 95$ were used in the current study.

The setting for the parent study was the state of Oregon. Participants living within Oregon were recruited from a variety of sources: Compassion and Choices of Oregon (CCO), an end-of-life advocacy organization that is a primary source of information and referral for those pursuing PAD in Oregon; several large hospices in the Portland area; ethics consultants; and palliative medicine and oncology physicians at large medical centers in the Portland area. CCO has provided information to or attended the deaths of approximately 75% of Oregonians who chose PAD (Ganzini et al., 2009) and more than 90% of those who utilize PAD were enrolled in hospice through the year 2012 (Oregon Health Authority, 2013). Most participant interviews occurred at his or her place of residence, although a small number of interviews occurred at outpatient clinics.

The referring agencies and providers sent potential participants letters approved by the VAMC institutional review board (IRB), providing information about and an invitation to participate in the study. CCO sent letters to every person who contacted the organization and who had made an explicit request to a physician, hospice employee, nurse, or caregiver for medication under the DWDA, and for whom at least one physician provided a prognosis of less than six months of life. Providers sent letters to patients who made an explicit request for PAD under DWDA. The letters instructed those interested to contact the study coordinator for more information about enrolling.

Participants for the control group were recruited from the same population as those in the case group. For case participants enrolled in hospice, comparison participants were also recruited from hospices. For case participants recruited from physicians or

CCO who were not enrolled in hospice, comparison participants were recruited from physicians' clinical practices, although no comparison participants were recruited from CCO. Case and comparison participants were matched for equal proportion in age ranges, education ranges, gender, and ethnic groups. All participants, as well as representatives from participating medical centers and hospices, gave written, informed consent to participate.

No information was provided to the investigators regarding the numbers of invitations sent nor was information provided regarding those who did not respond or participate. Thus, the response rate for the parent study is unknown.

Inclusion criteria for case and comparison participants consisted of: residence in Oregon; ability to speak and understand English; Short Portable Mental Status Questionnaire score of greater than 7 in order to exclude participants with cognitive impairment who would be unable to validly complete the study instruments; life expectancy of less than six months as determined by enrollment in hospice, physician referral, or medical record review (contingent upon patient consent) if referred by CCO; competent to participate in research as determined by the MacArthur Competence Assessment Tool (MacCAT-CR), a semi-structured interview to assess participants' understanding of the study, ability to compare alternatives to participation, and express a choice. Potential comparison participants who expressed a strong interest in PAD were excluded to prevent misclassification bias.

Data collection methods. Most participants responded to survey questions presented verbally by researchers, with responses recorded by the researchers, although a very small number of participants requested to complete the survey instruments themselves. Most participants completed the survey in one visit

Variables and Instruments

The data from the parent study that were part of the current study included: participant demographic variables (age, gender, education, ethnicity, and marital status), pain scores from the Wisconsin Brief Pain Inventory (WBPI), depression scores from the Hospital Anxiety and Depression Scale (HADS), hopelessness scores from the Beck Hopelessness Scale (BHS), importance of desire for control scores from the Burger Desirability of Control Scale (DOC), and dismissive attachment style scores from the Relationship Scale Questionnaire, Dismissive Attachment subscale (RSQ-D). The instruments, sample questions, and reliabilities for study variables are contained in Table 3.1.

Table 3.1

Instruments and Reliability

Variable and Instrument	Number of items	Format	Example of items	Cronbach's alpha
Frequency and severity of pain – Modified Wisconsin Brief Pain Inventory (WBPI) short version, pain severity subscale	4	Items rated on a 0-10 likert scale, with higher scores indicating greater pain; one item is reverse scored.	Please rate your pain, on average, in the last 2 weeks	.85-.91 (Mendoza et al., 2004)
Depression – Hospital Anxiety and Depression Scale (HADS)	14 total 7 depression 7 anxiety	Items rated on a 0-3 scale, higher scores indicate higher levels of depression and anxiety	I still enjoy the things I used to enjoy; I have lost interest in my appearance	Depression subscale: .81 - .90 Anxiety subscale: .80 - .93 (Herrmann, 1997)
Hopelessness – Beck Hopelessness Scale (BHS), modified by parent study	19 (20 in the original scale)	Items are rated as true or false; 9 items are reverse scored	I look forward to the future with hope and enthusiasm; I might as well give up because I can't make things better for myself	.87; .93 (Abbey et al., 2006; Beck et al., 1974, respectively)
Attachment – Relationship Scale Questionnaire, Dismissive attachment subscale (RSQ-D)	18 for total scale, 5 for dismissive subscale	Items are rated on a 1-5 likert scale, higher ratings indicate agreement that the item describes the participant well	I find it difficult to depend on other people; I worry about being alone.	Dismissive subscale .64 (Backstrom & Holmes, 2001; .70 Brussoni et al., 2000)
Control – Burger Desire of Control Scale (DOC), modified by parent study	15 (20 items in the original scale)	Items rated on a 1-7 likert scale, higher ratings indicate agreement that the item describes the participant well. Five items are reverse scored.	I enjoy being able to influence the actions of others; Others usually know what is best for me.	.74-.81 for the original scale (Burger, 1992)

Outcome variable. The outcome variable is dichotomous, defined as whether or not a participant made a serious inquiry regarding, and/or made a specific request for, a lethal prescription under DWDA.

Demographic variables. For the parent study, participants were asked to provide their age, race, marital status, and education in years.

Pain. Pain was measured with the severity subscale of the Modified Wisconsin Brief Pain Inventory (WBPI) short form (Daut, Cleeland, & Flanery, 1983; Mendoza et al., 2004). The WBPI short form contains two sub-scales measuring pain severity and pain interference with activity. While originally developed to measure cancer pain, the WBPI short form has been widely used and validated in non-cancer patients as well as cancer patients (see for example, Keller et al., 2004). The modified version has been validated with noncancer pain and the severity subscale had a Cronbach's alpha range from 0.85 to 0.91 (Mendoza et al., 2004). The severity subscale is a 4-item instrument to measure frequency and severity of pain on a 0-10 Likert scale. The scores were summed and the mean was calculated for a composite pain severity score (Cleeland, 2009). The WBPI is displayed in Appendix A.

Depression. Depression was assessed with the Hospital Anxiety and Depression Scale (HADS) scale (Zigmond & Snaith, 1983). The HADS is one of the most commonly used mood scales in medical and palliative care settings (Mitchell, Meader, & Symods, 2010). It is a 14-item measure with two 7-item (each) subscales for depression and anxiety. Participants rate each statement on a 0-3 scale, with some items reverse scored. Scores were summed with higher scores indicating higher depression or anxiety. Developed for a medical population, it excludes some somatic symptoms that could confound the assessment of depression and anxiety in medically ill individuals (Herrmann, 1997). In a review of psychometric properties, Cronbach's alphas were reported as .80-.93 for the anxiety subscale and .81-.90 for the depression subscale. Test-retest reliability was reported at above .80 at approximately two weeks out, decreasing with longer intervals, indicating that the instrument is sensitive to change and is measuring mood state as opposed to personality traits (Herrmann, 1997). In a meta-analysis, the total HADS score was reported to perform equally well when compared to the HADS depression subscale in terms of sensitivity and specificity for depression in cancer and palliative settings (Mitchell et al., 2010). The total HADS score was used for the current study. The HADS is displayed in Appendix B.

Hopelessness. The Beck Hopelessness Scale (BHS) (Beck et al., 1974) consists of 20 true-false items designed to measure pessimism and negativity about the future. Responses are summed to give a score of 0 to 20, with higher scores indicating greater hopelessness. A cutpoint of equal to or greater than 9 has been reported to indicate high hopelessness (Beck et al., 1989). Cronbach's alpha for the instrument was originally reported as .93 (Beck et al. 1974), and a recent study with terminally ill cancer patients yielded a Cronbach's alpha of .87 (Abbey, Rosenfeld, Pessin, & Breitbart, 2006). The parent study modified the instrument, deleting one item for a total of 19 items. The deleted item, "I can't imagine what my life would be like in ten years", has been identified as potentially problematic in a study of psychometric properties of the BHS with terminally ill individuals (Abbey et al., 2006). In that study, 71% of respondents endorsed the item, yielding an item-total correlation of .21. Due to the removal of the item, the validity of the scale is uncertain, however, asking an individual in a terminal phase of illness to imagine life 10 years hence could be perceived as quite insensitive, and thus it appears that there was a compelling rationale for removal of the item. The BHS as used and the deleted item are displayed in Appendix C.

Attachment. The way in which attachment is measured reflects its conceptualization, and there are differing opinions among attachment theorists and researchers of how it should be measured. What is the latent, underlying structure of attachment? Should attachment be measured categorically as attachment “types” (secure, preoccupied, fearful, and dismissing/avoidant) or measured along the hypothesized dimensions underlying the styles of attachment (model of self & other; avoidance/anxiety)?

Griffin & Bartholomew (1994a) proposed that attachment style might best be measured as a prototype model of the four attachment styles (secure, preoccupied, fearful, and dismissive), based upon two underlying dimensions (model of self and model of others). Individuals correspond to each of the prototypes by varying degrees based upon placement along a continuum of the two dimensions. A prototype model has the advantage of facilitating understanding of sentinel elements of the attachment style, at the same time suggests that not all of those elements need be present for one to fit reasonably well with that style. Individuals are not expected to conform exactly to any prototype, but to exhibit degrees of concordance with two or more of the prototypes, allowing for what have been termed “fuzzy” boundaries between the four attachment prototypes (Griffin & Bartholomew, 1994a). Describing attachment as prototype conveys meaningful clinical information (Griffin & Bartholomew, 1994b) and may be preferred for clinical use (Ravitz, Maunder, Hunter, Sthankiya, & Lancee, 2010).

However, the prototype approach has been criticized for its potential to imply that there exist four distinct types of attachment, and foster the practice of understanding individuals as “types”. This could have the unintended consequence of obscuring the existence and importance of the underlying structure and complexity of the latent dimensions of attachment style (Fraley & Waller, 1998). It also risks implying that all who are grouped into a prototype are equivalent on critical variables and that only differences that distinguish between groups are meaningful (Griffin & Bartholomew, 1994a; Mikulincer & Shaver, 2007). Furthermore, statistical concerns arise when individuals are categorized, insofar as important information is lost, resulting in more limited statistical analyses (Fraley & Waller, 1998).

Griffin and Bartholomew developed the Relationship Scales Questionnaire (RSQ), which provides a continuous score for each of four prototype attachment styles (1994a), to address some of the concerns noted above. On a 5-point scale, participants rate the extent to which each item describes their style in close, adult relationships. With the continuous measures along the underlying dimensions, this model addresses the concerns of simple categorization and concomitant loss of information and statistical power.

The use of attachment measures that provide continuous scores on each style of attachment has been recommended by a number of attachment researchers (Fraley & Waller, 1998; Kurdek, 2002; Mikulincer & Shaver, 2007). Use of a continuous measure of dismissive attachment has a methodological advantage over a categorical measure by virtue of being sensitive to the differences among individuals within the category and ability to capture those differences. Griffin and Bartholomew (1994a) believe that the "degree of fit" within an attachment style is an important factor to understand an individual's relationships and functioning (p 46). To allow capture of the greatest amount of information on the variable of interest, the current study used a continuous measure of dismissive attachment style for all participants as the independent variable. The benefits to this approach, both theoretical and methodological, are noted above.

In the parent study, attachment was measured with the Relationship Style Questionnaire (RSQ) (Griffin & Bartholomew, 1994a). Developed for multiple uses, the RSQ has a total of 30 available items; however, to assess the four-category model of attachment, 18 items comprise the scale (17 unique items and one item that is entered on two subscales), which has 4 subscales (one for each attachment style) (Griffin & Bartholomew, 1994a). The secure and dismissive style subscales each contains five items; the preoccupied and the fearful subscales each contain four items. Participants rate the degree to which each of statements describes their feelings about, and characteristic behavior in close relationships on a 1 (not at all like me) to 5 (very much like me) Likert scale. For the current study, the dismissive attachment subscale was used as a continuous measure of dismissive attachment style, with higher scores indicating greater concordance with dismissive style. The RSQ-D is displayed in Appendix D.

The reported Cronbach's alpha (α) reliabilities for the RSQ vary by subscale; several studies have reported low α coefficients for the secure and preoccupied subscales. The secure subscale has α values ranging from $\alpha = .32$ (Backstrom & Holmes, 2001) to $\alpha = .51$ (Brussoni, Jang, Livesley, & Macbeth, 2000). The preoccupied subscale has reported rating of $\alpha = .46$ (Backstrom & Holmes, 2001). The fearful and dismissive subscales have higher reported α reliabilities. Fearful reliability has been reported at $\alpha = .79$ (Backstrom & Holmes) and $\alpha = .76$ (Brussoni et al.) and dismissing subscale reliability at $\alpha = .64$ (Backstrom & Holmes) and $\alpha = .70$ (Brussoni et al., 2000).

Griffin and Bartholomew (1994a) explained the low reliabilities as a result of the subscales' model of two orthogonal factors (model of self and model of other). While a number of researchers have voiced support for a two-factor solution for the RSQ items (as well as other scales to measure attachment, see for example Fraley & Waller, 1998; Mikulincer & Shaver, 2007), this does not necessarily resolve the question of low reliabilities of some of the subscales. In fact, contrary to the claims of Griffin and Bartholomew (1994a), some RSQ items may indeed contribute to the low alpha reliability on the subscales. Kurdek (2002) conducted a factor analysis of the RSQ and found four items with low factor loadings, which would have a deleterious impact on α reliability. The small number of items on each subscale would also impact reliability (DeVellis, 2003).

Desire for control. Desire to be in control was measured by the Desirability of Control (DOC) Scale (Burger & Cooper, 1979). This scale measures the extent to which individuals are motivated to control events in their lives. The original scale contains 20 items rated on a 1 (does not apply to me at all) to 7 (always applies to me) Likert scale, with several items reverse scored. Scores are summed, with higher scores indicating greater desire for control. The parent study's principal investigator modified the instrument to contain 15 items, eliminating items related to driving, political participation, and business, items that may have little relevance to those in a terminal phase of illness. The full scale and deleted items are identified in Appendix E. Alpha coefficients for the original scale have been reported as .74 - .81 (Burger, 1992) with test-retest reliability as .75 (Burger & Cooper, 1979). The modified scale does not have reported reliability and validity psychometric values. Alpha reliability coefficients were assessed with the current sample data; however the validity of the modified measure cannot be evaluated.

Statistical Data and Analysis Plan

Data for the parent study were entered in SPSS, verified, and corrections made. A request was made to the parent study's principal investigator for access to the data for variables noted above. Consistent with a dichotomous outcome (i.e., pursuit or not of PAD) and case-control study design, a logistic regression analysis was employed and included moderating effects of attachment style and desire for control on the relationship between pain, depression, and hopelessness and pursuit of PAD.

As the current study was a secondary analysis, the sample size was fixed. Therefore, attention to the number of variables in the full model was a primary way of insuring adequate power. No fewer than ten cases per predictor, including interactions, are recommended to insure adequate power (Polit, 2010). The current study met this expectation with 95 participants, and no more than nine predictors expected in any model. The effect size was examined when interpreting results.

Preliminary analyses and test of assumptions. Preliminary analysis of the data was at the univariate and bivariate level. At the univariate level, the means and standard deviations of continuous predictor variables were examined to assess variability and range of values in the sample. Histograms of predictor variables assessed gaps in values and assessed for implausible or extreme values. Boxplots were used to assess outliers, none of which were more than three standard deviations from the mean, thus no transformations were necessary. Assumptions regarding the distribution of predictor variables are not required for logistic regression (Tabachnick & Fidell, 2007).

Following univariate analysis, bivariate relationships were assessed. Scatterplots were used to check for outliers in the relationship between each predictor variable and the outcome variable. Transformation of outliers was not required as no values were more than three standard deviations from the mean (Tabachnick & Fidell, 2007).

A Pearson (r) correlation matrix, evaluating the association of each predictor variable with each other, assessed multicollinearity. While variables correlated at more than $r = .85$ could have caused concerns due to multicollinearity (Katz, 2006; Tabachnick & Fidell, 2007), none were found at that level of correlation.

A point biserial correlation coefficient (r_{pb}) table was used to examine the bivariate relationship of each predictor variable with the outcome variable. Predictor variables with a significance value for the correlation of at least $p < .20$ were included in the logistic regression model. Variables with little correlation to the outcome (above $p = .21$) were eliminated from the regression model, due to the likelihood of adding little to the model and reducing the power of the analysis (Katz, 2006).

Testing assumptions following the main analysis. Logistic regression requires a linear relationship between continuous predictors and the logit transformation of the dichotomous outcome (Tabachnick & Fidell, 2007). Following the regression analysis, the Box-Tidwell statistic was used to assess linearity with the logit.

Missing data. Missing data were assessed in the preliminary analysis and examined for patterns of missingness. The strategy for dealing with missing data was dependent upon the amount of missing data, pattern of missingness, and the nature of variables from which the data were found to be missing (ie., scale item, within a case, or by variable). For variables measured by unidimensional, multi-item instruments, imputing replacement values by case mean substitution has been found to provide excellent results, rivaling the results of more complex methods of imputation such as multiple imputation when up to 30% of items were missing (Polit, 2010; Shrive, Stuart, Quan, & Ghali, 2006). This study used a much more conservative threshold for inclusion, using case mean substitution if the amount of missing data did not exceed 15%. For subjects with more than 15% of data missing on any predictor variable, listwise deletion was employed and the subject was eliminated from analysis. If subjects were missing data on demographic variables that were used in the final analysis, the subject was eliminated from analysis. A total of 12 mean substitutions were made; five subjects were dropped from the analysis due to missing data. Details of these substitutions and subject elimination are described in chapter four.

Primary analyses. *t Test.* The current study used the *t* test to examine between group differences on the primary variables of depression (HADS), hopelessness (BHS), desire for control (DOC), dismissive attachment (RSQ-D), and pain (WBPI). The scores were assessed for homogeneity of variance and the *t* test was examined for significance.

Logistic Regression. The current study employed logistic regression for data analysis. Logistic regression is an appropriate method to examine the extent to which variables contribute to the dichotomous outcome of pursuit of PAD. Logistic regression, based upon maximum likelihood estimation, models the probability of pursuit of PAD, given the variables included in the model, described in terms of an odds ratio and confidence interval.

The results of the analysis were evaluated for the entire model by the likelihood index (-2 log likelihood or -2LL) and pseudo R^2. The likelihood index represents residual error, therefore lower -2LL values indicate that the variables entered improve the fit of the model. The -2LL statistics were evaluated by the omnibus (chi-square [X^2] goodness of fit) test. When significant ($p < .05$) values were observed, the variables were considered to have significantly improved the fit of the model. Pseudo R^2 approximates a measure of overall effect size; larger values indicate a better fit of the model. The pseudo R^2 value was computed by the Nagelkerke R^2 (Tabachnick & Fidell, 2007).

Individual predictors were tested with the odds ratio (*OR*) and confidence interval (CI) for each predictor. The odds ratio represents the change in the odds of pursuit of PAD for each one-unit change in the predictor, when controlling for all other variables in the model. The confidence interval for the odds ratio was reported at the 95% level. The significance of each of the individual coefficients was evaluated by the Wald test (Katz, 2008; Tabachnick & Fidell, 2007)*,* although it is not considered to be as reliable as the confidence interval test for significance (Polit, 2010). To support the research hypothesis, the odds ratio for dismissive attachment style would be greater than 1 and the 95% confidence interval will not contain the value of 1.

Moderator analysis. A moderator analysis was conducted to help to elucidate for whom, or under what circumstances, the predictor variables were most salient. Of interest was whether and how dismissive attachment style and the desire for control moderated the relationship between pursuit of PAD and the other predictor variables. To test this interaction, continuous level variables were centered (in order to reduce multicollinearity), and a new variable was created whose value was the product of the values of two predictor variables. The new product term was entered into the multiple logistic regression analysis, along with the variables used to create the product term, and other predictor variables of interest. The product term was examined for significance and if a significant interaction were found, the nature of the interaction would have been examined by calculation simple slopes to show the effect of pain, depression, and hopelessness on PAD at different levels of the moderator. Were the research hypothesis supported, the odds ratio for the product term would have been greater than 1 and the 95% confidence interval would not contain the value of 1.

Analysis models. The analysis models for the specific aims of this study are as follows:

Specific Aim #1. *Examine the association between dismissive attachment style and pursuit of PAD, while controlling for demographic variables, pain, depression, hopelessness and desire for control.* To test this model, a logistic regression analysis was performed, with scores from the predictor variables that reached the statistical level required for inclusion in the model ($p < .20$). Those predictor variables, which included dismissive attachment (measured by the RSQ-D), depression (measured by the HADS), and hopelessness (measured by the BHS), along with demographic variables of age, marital status, and years of education, were included in the model. The results were interpreted as specified above.

Specific Aim #2. *Examine the moderator effect of dismissive attachment style on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD, assuming all met the criteria of a bivariate correlation with the outcome of* $p < .20$. To test this model, three logistic regression analyses, each including an interaction term were performed. The results were interpreted as specified above. The product term was examined for significance and had a significant interaction been found, the nature of the interaction would have been examined by calculating simple slopes to show the effect of pain, depression, and hopelessness on PAD at different levels of the moderator. Non-parallel regression lines would indicate the presence of a moderator effect.

Analysis 1:

Block 0: constant only.

Block 1: Age, education, marital status, hopelessness, centered depression, centered dismissive attachment

Block 2: Centered dismissive attachment x centered depression

Analysis 2:

Block 0: constant only.

Block 1: Age, education, marital status, depression, centered hopelessness, centered dismissive attachment

Block 2: Centered dismissive attachment x centered hopelessness

Analysis 3:

Analysis #3 was not conducted, as pain did not have a significant correlation with the outcome.

Specific Aim #3. *Examine the moderator effect of desire for control on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD*. To test this model, the plan was to conduct three logistic regression analyses, in similar fashion to specific aim #2, however, the variable desire for control did not have a significant correlation with the outcome and thus it was not retained in the logistic regression analysis. None of the proposed analyses for specific aim 3 were conducted.

Benefits and Limitations of the Secondary Analysis

General advantages of this secondary analysis include that the data were immediately available and that there was minimal cost to examine questions relevant to end of life care and nursing. Beyond issues of cost and feasibility, it is ethically important to maximize use of data obtained from frail and vulnerable individuals at the end of life.

This secondary analysis was also valuable due to the potential contribution to the end of life knowledge base that these data present: Heretofore, most information about pursuit of PAD has been gathered from proxy informants, some with more distal knowledge (health care providers) and some with more proximal knowledge (family members), yet the concordance of the reported proxy information with the patient's experience is unknown. The value of direct information from patients regarding motives for pursuit of PAD cannot be overstated, and thus, these data should be examined for information possible. Furthermore, these data allow a comparison between those who pursued PAD with a group at end of life who did not pursue PAD, a rare opportunity that should be maximally explored for the potential to understand the impact of the examined factors for those who pursue PAD.

Finally, little research regarding pursuit of PAD has involved the use of standardized measures. Use of standardized measures can provide information about the validity and reliability of the findings and can be used to build a knowledge base that can be compared across studies. Prior research regarding PAD has primarily relied upon retrospective clinical or proxy impression or upon researcher developed instruments.

Limitations with the parent data set include use of modified instruments, limiting the understanding of the validity of those scales. Additionally, the moderator analyses are sensitive to instrument reliability as the reliability of the product term is equal to the product of the reliabilities of the predictor variable and the moderator. As a secondary analysis, there is no possibility to correct any procedures in data collection if necessary. Generalizability of the results of this analysis beyond jurisdictions where PAD is a legally available option is unknown. Currently, PAD is a legally available option in Oregon, Washington, and Montana.

Potential threats to validity. *Misspecification of the model.* It is possible that not all of the relevant variables were included in the model, or that irrelevant variables were included. The case of the former would result in biased coefficients for the predictor variables, the direction of which would depend on the effect of the omitted variable on the outcome variable; the case of the latter could have the effect of increasing the standard error of parameter estimates (Menard, 2002).

Unreliability of measures. For the most part, the measures used in the parent study have acceptable Cronbach's alpha coefficients, however, the alpha coefficients for the RSQ-D is low, ranging from 0.64 to 0.70. Reliability coefficients are recommended to be above .70 to reduce the risk of a Type II error (DeVellis, 2003). The reliability of measures was assessed for the current sample and taken into consideration in understanding and interpreting the results and is further discussed in chapter five.

Selection bias. Convenience samples were used for cases and comparison group and it is possible that these self-selected groups are not representative of the population of terminally ill individuals in Oregon (both those who do and do not pursue PAD) in meaningful ways. The findings should be understood in light of the method of sample selection and may not be generalizable beyond the sample. However, the findings may be considered a part of a body of evidence regarding the motivation for those who pursue PAD. Furthermore, it is unknown whether findings obtained may be generalizable to those who pursue AID outside of jurisdictions where it is legal. Possible limitations related to the sample are further discussed in chapter five.

Protection of Human Subjects and Ethical Considerations

The ethical conduct of research involving human subjects requires adequate protection of participants from harm that might occur as a result of participation. One important aspect of this protection comes by virtue of informed, voluntary consent of those who would participate. Potential participants must be informed of, and participation must be based upon adequate understanding of, the purpose of the research, as well as potential risks, benefits, and alternatives to participation (Shadish, Cook, & Campbell, 2002). The investigators of the parent study insured informed, voluntary consent by providing potential participants with a VA-IRB approved letter, providing information about the study and instructions as to how to contact the study coordinator if interested. Competence of consent to participate was assessed by the MacArthur Competence Assessment Tool (MacCAT-CR), which provides a semi-structured interview format to assess participants' understanding of the nature of the research project, appreciation of the impact of participation on one's own situation, reasoning and decision making process, including the ability to compare alternatives, and ability to express a choice. Cut off scores were based upon recommended guidelines. Additionally, in order to exclude patients with delirium and dementia, participants who scored above 7 on the Short Portable Mental Status Questionnaire were excluded from the study. Further protection for this vulnerable group was afforded by arranging for counseling and informing the primary physician if a participant became upset during the course of an interview.

All data were de-identified for use in the current study, thus the risk of a breech of confidentiality is low. However, since the population of those who pursue PAD is relatively small, papers will be reviewed prior to submission for publication for inadvertent disclosure of potentially identifying information.

The study was submitted for approval by the Oregon Health & Sciences University – Portland Veterans Administration Medical Center institutional review board and all IRB requirements were met. No new data were gathered for this study.

Chapter Four

Results

The primary aim of this study was to examine the relationship between several predictor variables, specifically dismissive attachment style, desire for control, depression, hopelessness, and pain and with pursuit of physician assisted death (PAD) in a sample of terminally ill Oregonians. Secondary aims were to examine the possible moderating relationships between dismissive attachment style and the other predictor variables, as well as the possible moderating relationship between the desire for control and the other predictor variables, on pursuit of PAD.

Sample

The sample for this study was obtained from the study Why Patients Consider Hastening Death, led by Dr. Linda Ganzini, principal investigator. Participants in the parent study were terminally ill Oregonians who seriously pursued PAD, compared with a cohort of terminally ill Oregonians who had not pursued PAD. Participants were recruited from hospice organizations, Compassion and Choices of Oregon (CCO), physician offices and outpatient clinics. All members of the parent study's original sample ($N = 100$) were eligible if the subject had complete information on the outcome and predictor variables included in the current study.

Missing Data

Ninety-five subjects had data sufficient for inclusion in the current study ($N = 95$). Case mean substitution was used for variables measured by multi-item instruments if less than 15% of the data for instrument items was missing. Imputing replacement values by case mean substitution has been found to provide excellent results when up to 30% of items were missing (Polit, 2010; Shrive, Stuart, Quan, & Ghali, 2006). This study used a much more conservative threshold for inclusion: Subjects with more than 15% of missing data on any predictor variable were eliminated from analysis.

Eighty-eight subjects were not missing data on any variable used in this study. Seven participants were missing responses on one or two instrument items, resulting in missing data amounts from 5.26% to 10.53%. Five participants were eliminated due to missing data. Examination revealed no pattern to the missing data: three had pursued PAD; three were male; three married, one widowed, one single; ages ranged from 43 years to 90 years; education ranged from 13 to 20 years; and four were Caucasian.

There were two scales for which a mean substitution was used for included participants with missing responses: the Beck Hopelessness Scale (BHS) and the Desire for Control (DOC) scale. Nine participants were missing either one or two items on the BHS and three participants each had one missing item on the DOC scale.

Descriptive Statistics

Demographic and health characteristics of the sample are presented in Table 4.1. The average age of study participants was 63.49 (*SD* = 12.32). Participant gender was evenly divided, as 48 participants (50.5%) were female. The sample was overwhelmingly Caucasian (96.8%). Most participants were highly educated, with the mean number of years of education 15.35 (*SD* = 3.42). The most common diagnosis reported was cancer (77.7%), followed by amyotrophic lateral sclerosis (ALS) (16.0%). Of note, the group of comparator participants was largely supportive of the practice of PAD: 79% were either neutral, supportive, or strongly supportive of the practice (data not shown).

Table 4.1

Patient Demographic Characteristics (N = 95)

Patient Characteristic	*N* (%)	Mean (*SD*)	Range
Pursued PAD	55 (57.9)		
Gender			
Female	48 (50.5)		
Male	47 (49.5)		
Age		63.49 (12.32)	32 – 88
Education		15.35 (3.42)	7 – 25
Marital status			
Single	12 (12.6)		
Married / with partner	48 (50.5)		
Divorced	26 (27.4)		
Widowed	9 (9.5)		
Living situation			
Independent	91 (95.8)		
Dependent [a]	4 (4.2)		
Race			
Caucasian	92 (96.8)		
Native American	1 (1.1)		
Other	2 (2.1)		
Diagnosis [b]			
Cancer	73 (77.7)		
ALS	15 (16.0)		
Lung disease	3 (3.2)		
Cardiovascular disease	1 (1.1)		
HIV	1 (1.1)		
Hepatitis C	1 (1.1)		
Hospice enrollment			
Yes	22 (23.2)		
No	73 (76.8)		

[a] Dependent living = nursing home, foster home, retirement home.
[b] n = 94 due to missing data.

There were significant differences between those who pursued PAD and those who did not pursue in marital status, hospice enrollment, and education (see Table 4.2). Those who pursued PAD were significantly more likely to be unmarried (single, widowed, or divorced), $X^2(1, N = 95) = 5.79, p = .02$. Although less than 25% of the sample was enrolled in hospice, those enrolled in hospice were significantly more likely to have pursued PAD, $X^2(1, N = 95) = 6.72, p = .01$. Those who pursued PAD had significantly more education than those who did not pursue PAD $t(93) = -2.03, p = .05$.

Table 4.2

Group Differences for Patient Demographics (N = 95)

Patient Characteristic	Did not pursue PAD[a] *n* (%)	Pursued PAD[b] *n* (%)	Test Statistic[c]
Gender			.25
Female	19 (47.5)	29 (52.7)	
Male	21 (52.5)	26 (47.3)	
Marital status			5.79*
Married	26 (65.0)	22 (40.0)	
Not married	14 (35.0)	33 (60.0)	
Race[d]			.57
Caucasian	38 (95.0)	54 (98.2)	
Other	2 (5.0)	1 (1.8)	
Diagnosis[e]			.13
Cancer (tumor or blood)	31 (79.5)	42 (76.4)	
Other[f]	8 (20.5)	13 (23.6)	
Hospice enrollment			6.72**
Yes	4 (10.0)	18 (32.7)	
No	36 (90.0)	37 (67.3)	
Age *M* (*SD*)	60.95 (13.00)	65.34 (11.57)	$t(93) = -1.73$
Education *M* (*SD*)	14.53 (3.55)	15.95 (3.22)	$t(93) = -2.03$*

[a] $n = 40$
[b] $n = 55$
[c] X^2 test except *t*-test where indicated
[d] Fisher's exact test (2-sided)
[e] $n = 94$ due to missing data
[f] other diagnoses = ALS, cardiovascular disease, lung disease, HIV, and hepatitis C.
* $p < .05$. ** $p < .01$.

Preliminary Analyses

The data were initially examined at the univariate level, including means, standard deviations (*SD*), range, and distributions. No major concerns were identified through these univariate analyses: there were no implausible or extreme values nor were there outliers with values more than three standard deviations from the mean, thus no transformations were necessary (Tabachnick & Fidell, 2007).

Predictor variables exhibited adequate range (see Table 4.3), except for the desire for control scale (DOC) and the depression scale (HADS), where the range of scores was somewhat restricted. The observed range for DOC, 57-104 (48 points), was approximately half of the possible range of 90 points. The observed range of values for the HADS scale was two-thirds of the possible range (28 out of a possible range of 42).

*Internal consistency reliability***.** Alpha reliabilities (see Table 4.3) obtained with this sample were $\alpha = .86$ for the HADS, the BHS, and for the WBPI, which are generally considered to be very good reliabilities (DeVellis, 2003). However, alpha reliability values obtained with this sample were lower than desirable for the RSQ-D scale ($\alpha = .65$) and for the DOC scale ($\alpha = .69$). Reliability for these instruments is further discussed in chapter five.

Table 4. 3
Cronbach's Alpha Reliability, Range, Mean, Standard Deviation, and Skew

Predictor	*α*	Number of items	Scale Scoring	Observed Range	Mean	*SD*	Skew
HADS	.86	14	0 – 3	1 – 28	10.69	6.40	.79
BHS	.86	19	0 – 1	0 – 16	4.46	4.09	1.15
WBPI	.86	4	0 – 10	0 – 8.5	2.69	2.05	.59
RSQ-D	.65	5	1 – 5	1.6 – 5.0	3.55	.78	-.29
DOC	.69	15	1 – 7	57 - 104	80.56	10.00	.09

Note. For all scales, higher scores represent higher levels of the construct measured. HADS = Hospital Anxiety and Depression Scale; BHS = Beck Hopelessness Scale; WBPI = Wisconsin Brief Pain Inventory; RSQ-D = Relationship Style Questionnaire, Dismissive Attachment subscale; DOC = Desire of Control Scale.

Assumptions assessed prior to the analysis. The assumptions assessed prior to the primary analyses are as follows:

Multicollinearity. Pearson correlations between continuous predictors and the outcome were assessed for multicollinearity (see Table 4.4). The highest correlation in this group was the positive correlation between hopelessness and depression ($r = .64$), thus multicollinearity was not a problem for this sample (Katz, 2006; Tabachnick & Fidell, 2007).

Inclusion of predictors in the regression model. Predictor variables with a significance value for the correlation of at least $p < .20$ were included in the logistic regression model. Variables with no association with the outcome (above $p = .21$) were not included in the regression model, due to the likelihood of adding little to the model and reducing the power of the analysis (Katz, 2006). Based on this standard, the following variables were included in the regression model: age ($p = .09$); education ($p = .05$); marital status ($p = .02$), depression ($p = .04$); hopelessness ($p < .001$); and dismissive attachment ($p < .01$). Not included due to *p* values above .25: gender ($p = .62$); pain ($p = .48$); and desire for control ($p = .87$) (data not shown).

Table 4.4

Summary of Correlations Among Predictor and Outcome Variables (N = 95)

Variable	1	2	3	4	5	6	7	8
1. Case or Control	--							
2. Age	.18†	--						
3. Education	.21*	.05	--					
4. Marital status	.25*	.06	-.19	--				
5. Depression	.21*	-.23*	-.23*	.10	--			
6. Hopelessness	.42***	.10	-.11	.16	.64***	--		
7. Pain	.07	-.04	-.22*	.12	.38***	.18	--	
8. Dismissive Attachment	.28**	.18	-.16	.27**	.19	.38***	-.01	--
9. Control	-.02	-.04	.19	-.17	-.05	-.01	.05	.23*

Note. HADS = Hospital Anxiety and Depression Scale; BHS = Beck Hopelessness Scale; WBPI = Wisconsin Brief Pain Inventory of Control Scale; RSQ-D = Relationship Style Questionnaire, Dismissive Attachment subscale; DOC = Desirability of Control Scale.
†$p < .20$. *$p < .05$. **$p < .01$. ***$p < .001$.

Linearity of the logit assumption. The assumption of linearity of the logit was tested in the following manner. The value of the logarithm of each predictor variable included in the final model (age, education, marital status, depression score, hopelessness score, and dismissive attachment score) was calculated, resulting in new variables (for example, log age). A new variable was then created that was the product of the variable log and the variable (e.g., log age x age). These new variables were all entered into a logistic regression model with the original predictor variables. A significant value of the interaction term indicates violation of the assumption of linearity of the logit. According to Tabachnick and Fidell (2007), a reasonable standard for significance is the ratio of alpha level (.05) to the number of variables (including the log interactions) in the model. There were twelve variables in the model (age, marital status, education, depression, hopelessness, dismissive attachment, and the logarithm interactions for each variable as described above), resulting in a significance standard of .05/12 = .004. None of the variables violated this assumption (data not shown).

Bivariate relationships. The bivariate relationships among continuous and categorical predictors were assessed as follows:

Continuous predictors. Pearson correlations (r) between continuous predictor variables, for both case and control groups, were examined (see Table 4.5 and Table 4.6). Among those who did not pursue PAD, there were three significant correlations to note. Age was significantly, negatively correlated with depression ($r = -.37, p = .02$) and age had a significant, positive relationship with dismissive attachment ($r = .31, p = .05$), meaning that older adults were significantly more likely to report lower levels of depression, and significantly more likely to score higher on dismissive attachment. Those with higher levels of education were significantly more likely to score lower on dismissive attachment ($r = -.33, p = .04$).

Among those who pursued PAD, there existed significant correlations in seven pairs of continuous predictor variables. In this group, education was significantly, negatively correlated with both depression and pain. Those with more education were significantly more likely to report lower levels of depression ($r = -.37, p < .01$) and significantly more likely to report lower levels of pain ($r = -.28, p = .04$). In this group, depression was significantly, positively correlated with hopelessness and pain. Those with higher levels of depression were significantly more likely to report higher levels of hopelessness ($r = .72, p < .001$), and significantly more likely to report higher levels of pain ($r = .49, p < .001$). In addition to the significant correlations already noted, hopelessness was significantly correlated with higher levels of pain ($r = .27, p = .05$), thus those with higher hopelessness were significantly more likely to report greater pain.

Finally dismissive attachment style was significantly correlated with hopelessness and desire for control. Those who reported higher levels of dismissive attachment were significantly more likely to report higher levels of hopelessness ($r = .37, p < .01$). Those with higher dismissive attachment were also significantly more likely to report higher desire for control ($r = .29, p = .04$).

Categorical predictors. Bivariate associations of the categorical predictor variables, marital status and gender, were assessed by chi-square tests. Whether one was married or unmarried was significantly correlated with pursuit of PAD. Those who were not married (single, widowed, divorced) were significantly more likely to pursue PAD than those who were married (or with a partner) $X^2(1, N = 95) = 5.79, p = .02$.

The total sample was evenly matched for gender; there was not a significant correlation between gender and pursuit of PAD for the total group, $X^2(1, N = 95) = .25, p = .62$. However, of those who pursued PAD, women were significantly more likely to be unmarried than men $X^2(1, N = 55) = 9.53, p < .01$. In the group that did not pursue PAD, there was not a significant difference between men and women in regard to marital status $X^2(1, N = 40) = .05, p = .82$.

Table 4.5

Summary of Correlations for Age, Education, HADS, BHS, WBPI, RSQ-D, and DOC for Those Who Did Not Pursue PAD (n = 40)

Predictor	1	2	3	4	5	6	7
1. Age	--						
2. Education	-.07	--					
3. HADS	-.37*	-.15	--				
4. BHS	.06	-.16	.30	--			
5. WBPI	-.09	-.19	.19	-.04	--		
6. RSQ-D	.31*	-.33*	.03	.19	-.18	--	
7. DOC	.15	.19	-.26	-.18	.07	.19	--

Note. HADS = Hospital Anxiety and Depression Scale; BHS = Beck Hopelessness Scale; WBPI = Wisconsin Brief Pain Inventory; RSQ-D = Relationship Style Questionnaire, Dismissive Attachment subscale; DOC = Desire of Control Scale.
$*p < .05$

Table 4.6

Summary of Correlations for Age, Education, HADS, BHS, WBPI, RSQ-D, and DOC for those who Pursued PAD (N = 55)

Predictor	1	2	3	4	5	6	7
1. Age	--						
2. Education	.09	--					
3. HADS	-.23	-.37**	--				
4. BHS	.01	-.25	.72***	--			
5. WBPI	-.02	-.28*	.49***	.27*	--		
6. RSQ-D	-.01	-.14	.21	.37**	.10	--	
7. DOC	-.22	.20	.09	.09	.03	.29*	--

Note. HADS = Hospital Anxiety and Depression Scale; BHS = Beck Hopelessness Scale; WBPI = Wisconsin Brief Pain Inventory; RSQ-D = Relationship Style Questionnaire, Dismissive Attachment subscale; DOC = Desire of Control Scale.
**p* < .05. ***p* < .01. ****p* < .001

Primary Analyses

Between group differences. Of the five predictor variables used in this analysis, three demonstrated significant mean differences between those who pursued and those who did not pursue PAD (see Table 4.7). Note that all of the scales used in this study were designed such that higher scores indicated higher levels of the variable being measured. The largest mean difference was in the hopelessness scale (BHS), which rated hopelessness on a 0 – 19 scale. Those who pursued PAD had, on average, higher hopelessness scores ($M = 5.90$, $SD = 4.41$) than those who did not pursue PAD ($M = 2.47$, $SD = 2.54$), $t(88.87) = -4.78$, $p < .001$. Similarly, those who pursued PAD also had significantly higher depression scores as measured by the HADS on a 0-42 scale (*M* = 11.85, *SD* = 7.00) than those who did not pursue PAD (*M* = 9.10, *SD* = 5.13), *t*(92.99) = -2.21, *p* = .03. Finally, those who pursued PAD scored significantly higher on the measure of dismissive attachment style (RSQ-D). On a 1-5 scale, those who pursued PAD had a higher average score (*M* = 3.73, *SD* = .73) versus those who did not pursue PAD (*M* = 3.30, *SD* = .79), *t*(93) = -2.75, *p* = .007.

Two scale measures did not yield significant group differences. Those who pursued PAD rated pain at a mean score of 2.82 on a 0 – 10 scale (*SD* = 1.98) and those who did not pursue PAD rated their pain at a mean score of 2.51 (*SD* = 2.16), *t*(93) = -.71, *p* = .48. Results that were contrary to hypothesized expectations were those for desire for control. Those who pursued PAD and those who did not pursue PAD did not differ significantly in their desire for control as measured by the DOC on a 15 – 105 scale. For those who pursued PAD, the mean value for desire for control was 80.41 (*SD* = 9.07) and for those who did not pursue PAD, the mean score on desire for control was 80.77 (*SD* = 11.25), *t*(72.83) = .16, *p* = .87.

Table 4.7

Predictor Mean Differences by Group Membership

Predictor	Did Not Pursue PAD[a] *M (SD)*	Pursued PAD[b] *M (SD)*	*t*	*df*	*p*
HADS[c]	9.10 (5.13)	11.85 (7.00)	-2.21	92.99	.03
BHS[c]	2.47 (2.54)	5.90 (4.41)	-4.78	88.87	< .001
WBPI	2.51 (2.16)	2.82 (1.98)	-.71	93	.48
RSQ-D	3.30 (.79)	3.73 (.73)	-2.75	93	.007
DOC[c]	80.77 (11.25)	80.41 (9.07)	.16	72.83	.87

Note. For all scales, higher scores represent higher levels of the construct measured. HADS = Hospital Anxiety and Depression Scale; BHS = Beck Hopelessness Scale; WBPI = Wisconsin Brief Pain Inventory; RSQ-D = Relationship Style Questionnaire, Dismissive Attachment subscale; DOC = Desire of Control Scale.

[a] n = 40.

[b] n = 55.

[c] Equal variances not assumed.

Results for specific aims. The analyses and results for the specific aims follow.

Specific aim 1. Examine the association between dismissive attachment style and pursuit of PAD, controlling for demographic variables (age, education, and marital status), depression, and hopelessness.

Standard logistic regression was used to determine whether the psychological and relational variables (depression, hopelessness, dismissive attachment style) included in the model significantly predicted pursuit of PAD, while controlling for demographic variables of age, education, and marital status.

The model was evaluated by examination of omnibus X^2 test of model coefficients, tests of significance for each predictor, odds ratios for significant predictors, and effect size for the model. Based upon the theoretical model, previous literature, and the bivariate correlations from this study sample, the following variables were included in the logistic regression equation: age, marital status, education, depression, hopelessness, and dismissive attachment style. While desire for control and pain were hypothesized to contribute to pursuit of PAD, the bivariate correlations for these predictors with the outcome were not significant and thus these variables were not included in the logistic regression analysis.

All variables were entered into the model simultaneously. The group of variables, tested against a constant only model by the omnibus X^2 test, was significant, $X^2(6, N = 95) = 36.51$, $p < .001$, indicating an improvement in model fit over the constant only model. An additional test of model significance, the Hosmer and Lemeshow X^2, was non-significant, also indicating improvement in model fit over the constant only model ($X^2 = 4.46$ (*df* 8), $p = .81$). The Cox and Snell R^2 and the Nagelkerke R^2, providing some indication of effect size, ranged from .32 to.43, (respectively). The -2 log likelihood reduced from 107.45 to 86.70, indicating reduction of residual error from block 0 to block 1.

The regression coefficients, Wald statistics, odds ratios, and confidence intervals for the final model are displayed in Table 4.8. In the final model, education, marital status, and hopelessness predicted pursuit of PAD while controlling for the other variables in the model. Higher levels of education were significantly related to pursuit of PAD: For every one year increase in education, the likelihood of pursuit of PAD increased by a factor of 1.32, controlling for all other variables in the model ($p < .01$, CI [95%] 1.10-1.57). Thus, each year additional year of education resulted in a 32% increase in likelihood of pursuit of PAD. Similarly, higher levels of hopelessness were significantly related to pursuit of PAD. For every one point increase in hopelessness, the likelihood of pursuit of PAD increased by a factor of 1.31, while controlling for all other variables in the model (*p* < .01, CI [95%] 1.07-1.63). In other words, each one-point increase in hopelessness resulted in a 31% increase in the odds of pursuing PAD. Finally, marital status was a predictor of pursuit of PAD. The odds of pursuing PAD decreased by a factor of 0.33 for those who were married compared to those who were not married (*p* = .01, CI [95%] 0.11-0.96). Those who were married were 67% less likely to pursue PAD than their unmarried counterparts.

Table 4.8

Individual Predictors for Logistic Regression Analysis of Pursuit of PAD

				95% Confidence Interval for Odds Ratio	
Variables	*B*	Wald test	Odds Ratio	Lower	Upper
Age	.02	.89	1.02	.98	1.07
Education	.27	9.42**	1.32	1.10	1.57
Marital Status	-1.11	4.14*	.33	.11	.96
Depression	.03	.22	1.03	.92	1.15
Hopelessness	.28	6.53**	1.32	1.07	1.63
Dismissive Attachment	.53	1.90	1.71	.80	3.65
Constant	-7.92	8.38**	.00		

Depression = Hospital Anxiety and Depression Scale; Hopelessness = Beck Hopelessness Scale; Dismissive Attachment = Relationship Style Questionnaire, Dismissive Attachment subscale.
**p* < .05. ***p* < .01.

Specific aim 2 and specific aim 3. Specific aims 2 and 3 called for examining possible interactions among variables impacting relationships examined in this analysis. Specific aim 2 was to examine the moderator effect of dismissive attachment style on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD. Specific aim 3 was to examine the moderator effect of desire for control on the relationship between (each) pain, depression, and hopelessness and pursuit of PAD. However, due to the absence of a significant bivariate relationship of pain or desire for control with the outcome, both of those variables were dropped from the analysis. Therefore, the moderating effects of dismissive attachment style on depression and hopelessness were examined. To do so, separate hierarchical logistic regressions were conducted for each moderation relationship hypothesized. The predictors included in the interactions were centered and the product term of the centered variables was entered into the model. Centering variables is recommended in order to reduce collinearity since uncentered predictors will be highly correlated with the product terms of those variables (Aiken & West, 1991). Tables containing the results of the analyses are contained in Appendix F.

Two separate hierarchical logistic regression analyses were performed in similar fashion: The predictor variables, including the demographic variables, predictor variables, and centered moderating and centered predictor variables, were entered in block 1. The product term of the centered variables was entered in block 2. The regression analysis was examined for a significant improvement in fit from block 1 to block 2. The following pairs of centered moderator and predictor variables were entered in logistic regression analyses (along with the demographic and other predictor variables as noted above):

dismissive attachment and depression; dismissive attachment and hopelessness. None of the analyses resulted in a significant improvement in fit from block 1 to block 2, indicating that none of the hypothesized moderating relationships was significant.

Summary

This study examined the between group differences and the predictive value of disease related (depression, hopelessness), personality related (dismissive attachment style), and demographic (age, marital status, education) variables for the pursuit of PAD. The main findings were that those who pursued PAD experienced higher levels of dismissive attachment, higher hopelessness, higher levels of depression, were more likely to be unmarried, and had higher levels of education than the comparator group. Furthermore, a greater sense of hopelessness, being unmarried, and higher levels of education were significant predictors of pursuit of PAD, while controlling for other variables in the model.

Chapter Five

Discussion

Major Findings

This secondary analysis provided an opportunity to examine potentially motivating factors for a sample of terminally ill Oregonians who pursued physician assisted death (PAD) under the Oregon Death with Dignity Act (DWDA), compared to a sample of terminally ill Oregonians who did not pursue PAD. Factors hypothesized to contribute to pursuit of PAD (i.e., dismissive attachment style, desire for control, hopelessness, depression, and pain) were examined for between group differences as well as ability to predict those who pursued PAD. Additionally, this study sought to examine whether there existed interactions among the hypothesized factors that helped to explain motivation for pursuit of PAD.

The findings revealed that significant differences existed between the two groups on a number of variables. Those who pursued PAD experienced significantly higher levels of dismissive attachment, hopelessness, depression, were significantly more likely to be unmarried, and had significantly higher levels of education than the comparator group. Also noteworthy were the ways that the two groups did not differ: neither pain nor desire for control were significantly different between the groups. Of the variables assessed, hopelessness, education, and marital status predicted pursuit of PAD while controlling for all other variables in the model.

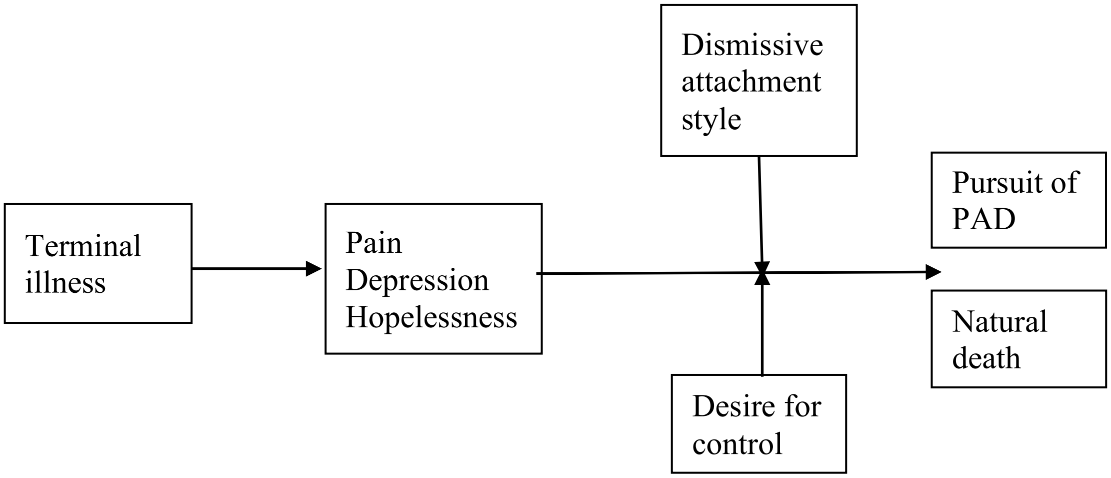
Although empirical data are mixed, pursuit of PAD has often been explained in terms of uncontrolled symptoms such as pain or depression. When viewed through a qualitative lens however, the literature consistently paints a picture of vivid personality attributes of those who pursue PAD, with transient symptoms appearing to be less important. This study revealed that there existed significant differences in both state (transient) and trait (enduring) qualities between those who pursued and those who did not pursue PAD.

The discussion of these results will begin with a brief review of the conceptual model that guided this inquiry and description of specific aims, followed by a discussion of the major findings of the analysis. Clinical and research implications will then be discussed, along with strengths and limitations of the study.

Conceptual Model

The conceptual model posits that many terminally ill patients experience symptoms related to the disease process, such as pain, depression, and/or hopelessness at the end of life, and for some, these factors may be influential in the decision to pursue PAD. However, most terminally ill individuals do not pursue PAD at the end of life, even when legally available. Personality qualities or traits, such as dismissive style of attachment and or a high desire for control over the dying process, may be influential for a significant portion of the patients who actually pursue PAD. The results from this study provided support for much of this model. And although pain and desire for control did not differ between the case and control groups in this study, fear of future pain has been reported in the literature (Ganzini et al., 2007, 2009), as has the desire to control circumstances of death (Ganzini et al., 2003, 2007, 2009; Loggers et al., 2013). The conceptual model is depicted in Figure 2.

Figure 2. Conceptual model hypothesizing the relationship of variables contributing to pursuit of PAD



Discussion of Results

Dismissive style of attachment. One aim of this study was to examine the degree to which pursuers of PAD differed from the comparator group in terms of dismissive style of attachment. The results showed that those who pursued PAD had on average, significantly higher scores on the Relationship Style Questionnaire – Dismissive Attachment (RSQ-D) subscale than those who did not pursue PAD, indicating greater concordance with dismissive attachment. The *t* test of the between group difference in RSQ-D scores was significant ($p = .007$), with those who pursued PAD significantly higher in dismissive attachment than those who did not pursue PAD. The significance of this did not persist in the regression analysis: dismissive attachment did not predict pursuit of PAD while controlling for the demographic and psychosocial variables in the model. However, the lack of significance in the logistic regression model may be accounted for by the significant, bivariate correlation between dismissive attachment and hopelessness for those who pursued PAD ($r = .37$, $p = .005$), as well as the significant, positive correlation between marital status (unmarried) and dismissive attachment ($r = .27$, $p = .007$), as well as by the sample size. A larger sample may well have yielded significant findings in the logistic regression analysis.

These findings are important because attachment style and attachment related behaviors are associated with engagement in health care system and with health outcomes (Lo et al., 2009). Style of attachment refers to an internal model of the self and significant others focused largely on safety and expectations of the availability, reliability, and desirability of others for care and support at times of vulnerability. Threats to security concomitant with illness will activate attachment schemas and behavior that are consistent with long standing attachment styles (Petersen & Koehler, 2005; Tan et al., 2005).

Those with dismissive styles of attachment develop internal models calling for intense self-reliance, autonomy, and independence, often at the expense of intimacy. Individuals with dismissive attachment tend to perceive social support as less available and less reliable, and are less likely to engage supportive relationships (Bartholomew, 1990; Collins & Feeney, 2000; Rodin et al., 2007). When confronted with threats to security, they may recoil at the idea of relying on others for care, and an option that allows avoidance of dependency, such as PAD, might be appealing. Thus PAD may be a way for individuals to maintain an ultimate sense of control and autonomy within an end of life process that allows very little opportunity for either. The individuals in the current study were pursuing access to PAD in advance of severe physical or psychological symptoms; thus what may have been most unbearable was the anticipated dependency that may come with illness rather than the physical symptom themselves. These findings indicate that pursuit of PAD, at least for some, reflects behavior that is consistent with personal values, such as autonomy and self-reliance.

Hopelessness. The role of hopelessness in mental and physical health is well documented and robust. Hopelessness, independent of depression, is one of the strongest predictors of suicide in a physically healthy population (Beck et al., 1985; Werth et al., 2002) and has been associated with a variety of negative health outcomes, including markers of endothelial dysfunction (Do, Dowd, Ranjit, House, & Kaplan, 2010), cardiac events in percutaneous coronary intervention patients (Pedersen et al., 2007), and myocardial infarction and cancer (Everson et al., 1996), among others. Clearly, hopelessness has a strong and pervasive influence on health.

In this sample there was a significant difference in level of hopelessness between those who pursued and those who did not pursue PAD as measured by the Beck Hopelessness Scale (BHS). The t test of the difference in mean BHS scores was significant, with those who pursued PAD reporting significantly higher levels of hopelessness than those who did not pursue PAD ($p < .001$). The significance of hopelessness persisted in the regression analysis: higher hopelessness significantly predicted the likelihood of pursuit of PAD while controlling for other predictors in the model. Of interest, the BHS is a 19-item (as used in this study) true-false instrument. The difference in mean scores ($M = 5.90$, $SD = 4.41$ for those who pursued, and $M = 2.47$, $SD = 2.54$ for the comparator group) showed that endorsement of just 2 to 4 additional items was predictive of those who pursued PAD. It should be noted however, that the mean for both groups, pursuers and non-pursuers, was below the commonly used cut-off score of 9 to determine high hopelessness (Beck et al., 1989) indicating that most in the study did not meet the level of high hopelessness. This leads to a question of how hopelessness may be different for those at end of life than for the medically healthy populations for which the BHS was developed. This study extends the work of the parent study by examining the contribution of hopelessness to pursuit of PAD while holding other factors constant. This study demonstrated that hopelessness significantly contributes to pursuit of PAD while controlling for depression, a concept with which hopelessness is closely linked.

This finding is consistent with previous research by Ganzini et al. (2002), who found that hopelessness, measured a median of 11 months before death, predicted interest in PAD in a sample of terminally ill ALS patients. In contrast Bharucha et al., (2003) examined hopelessness in those who pursued PAD and did not find it to be an important factor for respondents. The differences between the findings reported by Ganzini and Bharucha may be related to the instrument and method used to measure hopelessness: Ganzini et al. used the BHS scale and Bharucha et al. used a clinical interview to assess hopelessness. As will be discussed below, it may be that for those at the end of life, the BHS does not measure hopelessness as it is commonly understood. The Bharucha et al. study was a longitudinal, qualitative study, which may have provided the investigators with a richer, deeper and more nuanced understanding of hopelessness as it applied to those participants. Enabled by in depth interviews, Bharucha et al. may have been able to understand the latent constructs of hopelessness differently than the common understanding of the BHS.

This study’s finding clearly demonstrated a difference in hopelessness between those who pursued and those who did not pursue PAD. However caution should be exercised in interpreting the meaning of this finding vis-à-vis the sample to which it applies. There are myriad definitions of hopelessness in the medical, nursing, and psychological literature, and it has been speculated that there are differences in the meaning of hopelessness for those with terminal illness at the end of life compared to other populations (Abbey et al., 2006; Nissim et al., 2010; Rosenfeld et al., 2004; Rosenfeld et al., 2011). Hopelessness has been generally defined as the absence of hope, a negative cognitive schema, negative expectancies regarding the future, and/or as an existential or spiritual experience (Beck et al., 1974; Bharucha et al., 2003; Chochinov et al., 2005; Clarke & Kissane, 2002). In the context of terminal illness, hopelessness may reflect, at least in part, an understanding of the reality of a terminal prognosis rather than hopelessness as it is generally defined for other populations.

Previous factor analyses may help to explicate possible underlying constructs that the BHS measures. When used with a depressed, physically healthy sample, Beck et al. (1974) found three factors named “feelings about the future”, “loss of motivation”, and “future expectations”. Beck and colleagues described hopelessness as a system of negative cognitive schemas and negative expectancies of the future, which are elements of psychopathological conditions. Alternatively, with a sample having advanced cancer, Nissim et al. (2010) found a two-factor model, including “negative expectations” and “loss of motivation” to best fit the data. Nissim and colleagues described the dimension labeled negative expectations as reflecting a “circumscribed, pessimistic assessment of the future, rather than a dysfunctional cognitive schema, in the context of a poor medical prognosis"; the dimension labeled loss of motivation was thought to describe "helplessness, meaninglessness, and loss of control" (p. 260).

The distinction between realism and hopelessness is not always clear for those at the end of life. Given a terminal prognosis, a sense of hopelessness may be seen as understandable or even expected and the lack of hopelessness may be seen as unrealistic optimism (Rosenfeld et al., 2011). There is research to support the concept that hopelessness might reflect a realistic view of the future versus psychopathological negative expectations. In a recent study using a sample of physically healthy, psychiatric inpatients and non-psychiatric, community based individuals, Pompili et al. (2011) found that higher BHS hopelessness scores were correlated with lower scores on a measure of unconscious self-deception. Unconscious self-deception was defined as a psychological defense, in which an individual holds contradictory beliefs, one of which is shielded from consciousness by "motivated unawareness" of information that would be felt as threatening (p. 25). Self-deception was thus described as a coping strategy for stressful life events (p. 28). If this applies to those at end of life, it may be that higher hopelessness scores reflect that PAD pursuers employ methods other than unconscious self-deception to manage and cope with the knowledge and stress of a terminal prognosis.

It is possible that pursuers of PAD in the current study found particular resonance with facets of the scale Nissim et al. (2010) described as a circumscribed, pessimistic assessment of the future. This may reflect a "steely-eyed realism" (L. Ganzini, personal communication, January 21, 2013), that is, a willingness to view the likely reality of their illness and prognosis without great psychological investment in unlikely outcomes (i.e., long term survival). The personal qualities of patients who pursued PAD, as described by physicians, seem inconsistent with factors indicating lack of motivation, but very consistent with a lack of self-deception, as identified above. Those qualities, described as “independent”, “clear, adamant, and unwavering”, and reflecting a desire to “control the dying process” (Ganzini, Dobscha et al., 2003) seem at odds with factors conceptualized as loss of motivation. Psychological adjustment to illness has been found to be mediated by coping strategies, with passive strategies associated with greater hopelessness (Schnoll, Harlow, Stolbach, & Brandt, 1998). PAD is not a passive approach to the end of life, thus adding to the question of the meaning of high hopelessness scores for those who pursue PAD.

The results of the current study provide useful information to extend our understanding of the concept of hopelessness for those who pursue PAD. It is an important concept for health care providers insofar as addressing and ameliorating causes of suffering at the end of life is a goal of care. However, while the nature of hopelessness in this population is not clear, at minimum it can be understood that hopelessness is a multidimensional construct, with context-specific meaning. Further exploration of these data vis-à-vis the discussion above is warranted.

Depression. Depression is of considerable interest and concern in relation to those all of those at the end of life, not only those who pursue of PAD. There is a strong correlation between depression and suicidal thoughts and behavior in physically well individuals (Feltz-Cornelis, 2011), thus similar associations have been suspected (Brown et al., 1986; Kelly & Varghese, 1996) regarding those with terminal illness who pursue actions to hasten death. As a treatable condition, it is very important to understand the role of depression in pursuit of PAD. Previous research in Oregon with a variety of professional care providers consistently indicated that depression was neither a primary concern nor a motivating factor for patients who pursued PAD (Carlson et al., 2005; Ganzini et al., 2000, 2002) and family members and patients echoed those findings (Ganzini et al., 2007, 2009).

In the current study however, those who pursued PAD had depression scores that were, on average, significantly higher than those who did not pursue PAD. And although the average depression score for pursuers did not reach a commonly identified HADS screening cut-off of 15 indicating probable depression (Mitchell et al., 2010), 27% (15/55) of pursuers compared to 18% (7/40) of non-pursuers had scores over 15. The HADS is best used as a screening measure (Mitchell et al., 2010; Zigmond & Snaith, 1983) and as such prioritizes sensitivity over specificity, thus prevalence of depression tends to be overestimated (Hotopf et al., 2002). It is therefore possible that not all of those who scored above the cut-off level experienced clinical depression. Despite the potential for false positive scores, the results provide support for the concern that depressive symptoms may be a factor for at least some of those who pursue PAD. Whether or not depression is the cause of pursuit of PAD, these data provide evidence that those who pursue PAD experience, on average, higher levels of symptoms of depression than those who do not pursue PAD.

In the regression analysis, depression did not retain significance as a predictor of pursuit of PAD. There was a strong bivariate correlation with hopelessness that accounted for depression variance in the logistic regression model and limited the impact of depression on pursuit of PAD.

These data may be contrasted with previously published data regarding depression and pursuit of PAD (noted above), with the caveat that this study and the parent study are the only ones to use a standardized measure to assess depression. In this sample it can be seen that depression, whether or not deemed important or contributory by the patient, was higher for those who pursued PAD than those who did not. Previously published findings from the parent study on this sample of pursuers included both patient assessment of whether depression was contributory to pursuit of PAD and response to treatment (if known). In that report of 58 individuals who pursued PAD, 15 met the study's case criteria for depression. Six of the 15 felt that depression somewhat or strongly influenced their pursuit of PAD. Three participants who received the lethal prescription under DWDA met case criteria for depression at the time of receipt and went on to die by use of the prescription medication. One of the three successfully treated for depression, and went on to use the lethal prescription as a means of death. The treatment of depression for the other two is unknown (Ganzini et al., 2009).

Desire for control. The findings for desire for control were not significant and as such were surprising for the lack of relevance for this sample. The between group difference for desire for control (DOC) scores for those who pursued PAD versus the comparator group of those who did not pursue PAD was non-significant. Because of the non-significant bivariate correlation with the outcome, DOC was not included in the logistic regression model nor was the moderation analysis for specific aim 3 conducted.

Previously published results from this sample of PAD pursuers quite clearly demonstrated the interest of those participants in controlling the circumstances of death. When given the opportunity to respond to the question of motivation, this group of participants who pursued PAD rated desire for control of the dying process as one of the top three reasons for pursuit, along with concern for future poor quality of life and fear of future pain. Additionally, of those who reported a single most important reason for pursuing PAD, the most commonly reported answer, by 15% of those who responded, was “to feel in control” (Ganzini et al., 2009, p. 491).

The body of literature related to those who pursued PAD has been consistent regarding the importance of controlling the circumstances of death as a very important motive (for example, Ganzini et al., 2000, 2002, 2007; Volker, 2001). The data from the state of Oregon is consistent with data from PAD research noted above. Loss of autonomy has been the top end of life concern reported by the population of those who received and utilized a prescription to hasten death under the DWDA, identified by 91.2% of the population (Oregon Health Authority, 2013), thus the lack of significance for desire for control in the current study is surprising.

The data from the current study suggest that either both pursuers and non-pursuers have the same level of desire for control at the end of life, or the DOC instrument does not measure the latent construct relevant to control for those who pursued PAD. The DOC scale was developed to measure a general desire for control, described as a personality trait (Burger, 1992), assumed to be evident in a wide variety of interpersonal relationships and settings. The instrument is purported to broadly measure an individual’s motivation to exercise control over events and situations. Smith, Wallston, Wallston, Forsberg, and King (1984) found however that the DOC scale did not differentiate between those expressing differing desires for control enhancing health care options when provided with a hypothetical illness scenario. It may be that this instrument does not reliably differentiate desire for control of medical procedures, processes, and care.

Factor analysis of the DOC revealed five factors: general desire for control; decisiveness; preparation-prevention control; avoidance of dependence; and leadership (Burger, 1992). Others (Thomas, Buboltz, Teague, & Seeman, 2011) found a three-factor model for the instrument (leadership, decision avoidance, and destiny control). These factors would appear to reflect personality qualities often used in qualitative studies to describe those who have pursued PAD: "strong-willed… patriarchal", "independent and controlling", "active", "autonomous", valuing "self-determination" (Ganzini, Dobscha et al., 2003, p. 383). These qualities appear to be concordant with the notion of long-standing personality traits that could be measured by the factors noted by Burger or by Thomas et al. above, adding to the surprise that those who pursued PAD did not score differently than non-pursuers.

It should also be noted that the parent study modified the DOC scale by omitting five items (identified in Appendix E). The validity of the 15-item scale had not been previously measured and it is possible that the revisions resulted in the changes in the instrument that rendered it less sensitive to the construct it was intended to measure.

The current findings are useful as the DOC is one of the most widely used instruments for measuring the construct (Thomas et al., 2011), and the discrepancy between pursuer's statements regarding the importance of control (Ganzini et al., 2009) and lack of significance between the two groups should lead to further inquiry regarding the construct of control at end of life and the ability of the DOC to measure the construct.

Pain. Although pain has been previously reported as a reason for pursuit of PAD (Back et al., 1996; Meier et al., 2003) the data from the current study presents compelling evidence that current pain was not an issue or motivator for pursuit of PAD. There was no significant difference in pain scores between those who pursued and those who did not pursue PAD and the mean scores for both groups were quite low (less than 3 on a 0-10 scale, with higher scores reflecting higher levels of pain), indicating that pain was being well controlled for all patients in the study. In bivariate analysis, significant Pearson correlations revealed that those with higher education levels reported lower levels of pain, indicating perhaps that education provides patients with skills for self-advocacy, resulting in even greater levels of symptom control.

These results are in contrast to previous research where pain was identified as a motivating factor (Foley, 1997; Monforte-Royo et al., 2010). The difference in results may be in large part due to differences in study design. This study was the first to use a standardized, validated measure to assess pain for those pursuing PAD and the first to contrast pain levels with a comparable group of terminally ill patients. Previous research using health care and/or palliative care professionals as proxy informants, relying on recall of patient concerns, indicated that pain or other physical distress was an important factor in the request for aid in dying (AID) or PAD, although physical distress was generally considered to be less important than other psychosocial concerns (Back et al., 1996; Ganzini et al., 2000; Pearlman et al., 2005).

However, the current findings are consistent with previous research involving patients and family members in Oregon. When those respondents had the option to distinguish concerns about current pain from fear of future pain, current pain was not identified as a concern. These findings also support the findings from previous research from hospice nurses who felt that the pain of patients who pursued PAD was equal to, or less than, the pain of other hospice patients (Ganzini et al., 2002). However, this study did not assess whether, and to what extent, fear of future pain may have been a motivating factor. Fear of future pain has been identified as a concern of those who have pursued PAD (Ganzini et al., 2007, 2009).

The findings from the current study contribute to the body of literature related to motivation to pursue PAD. By use of a standardized measure of pain and a comparator group, it is clear that, for this sample, current pain was not a factor at the time of pursuit. What is not clear from this study is whether fear of future pain is a significant predictor and/or whether a sample that scored higher on measures of pain might produce different results.

Marital Status. In this study, marital status was a robust finding in regard to pursuit of PAD. At the bivariate level, being unmarried (single, widowed, or divorced) was significantly, positively associated with pursuit of PAD. Being unmarried was also significantly associated with gender in this sample; women were significantly more likely to be unmarried than were men. While male pursuers of PAD were equally likely to be married or unmarried, female pursuers were significantly more likely to be unmarried. Although gender did not have a strong enough bivariate correlation to be included in the regression model, marital status was included and remained a significant predictor while controlling for all other variables in the model: being unmarried predicted pursuit of PAD. The sample in the current study was evenly split between those who were married (50.5%) and unmarried (49.5%). This is similar to the population of those who received a lethal prescription under the ODDA of whom 45.5% were married and 54.6% were unmarried (Oregon Health Authority, 2013). Analysis also revealed that there was a significant relationship between dismissive attachment and marital status: those who were unmarried had significantly higher mean scores on the RSQ-D.

The relationship between marital status and mortality is well documented: mortality rates (all-cause and cause-specific) are higher for unmarried than married individuals. Research indicates that married individuals are more likely to have illness diagnosed at earlier stages, have better overall health, and are likely to have better mental health (Kravdal & Syse, 2011). There are a number of proposed explanations for the protective effects of marriage, including the benefit of social and emotional support, economic support, the likelihood of healthier individuals getting and staying married, and the absence of stress due to divorce or marriage dissolution (Rendall, Weden, Favreault, & Waldron, 2011). These protective effects extend to elderly populations (Manzoli, Villari, Pirone, & Boccia, 2007) and are consistent with the results from the current study.

Furthermore, the impact of family support (spousal or other) may be relevant to the decision to pursue PAD. Although the research related to factors influencing end of life decisions is limited (Cicirelli, MacLean, & Cox, 2000), there is research that add context to the current findings. Cicirelli (1997) found no impact of marital status on the acceptability of a range of end of life decisions that included ending life (including the specific example of PAD), maintaining treatment, or letting others decide. On the other hand, Russ, Shim, and Kaufman (2007) reported on the role of family support (although not specifically marital) on the decision to discontinue dialysis. They suggested that patients with family involvement were less likely to discontinue treatment, even in the face of very poor quality of life, in order to “protect the family from grief” (p. 2242) and that family members sometimes pressured the patient to continue treatment.

The relationship between gender, marital status, and pursuit of PAD is interesting and complex. What is it about being married that would make it less likely for women, but not men, to pursue PAD versus their unmarried counterparts? Are men less likely to support a female spouse in pursuit of PAD, or are women less likely to leave a husband? These questions remain unanswered by the current research but are important for future research.

Education. In this study there was a significant difference in educational level between those who pursued PAD and those who did not pursue. PAD pursuers were, on average, more highly educated than those who did not pursue PAD. This finding is not surprising as the data reported under the DWDA is concordant with this finding: 71% of those who obtained and used a lethal prescription had at least some college (Oregon Health Authority, 2013). This finding is also consistent with other research related to end of life decision making. For example, Decker and Reed (2005) found education to be a relevant factor for elders’ end of life decision-making process: those with higher education less likely to voice support for aggressive treatment or to prolong life.

Interestingly, for those who pursued PAD, education had a significant inverse, bivariate relationship with depression ($r = -.37, p < .01$), and an inverse bivariate relationship with hopelessness that approached significance ($r = -.25, p = .06$). Especially in light of the inverse bivariate relationship with hopelessness, it is perhaps surprising that education remained a significant predictor in the regression model, while controlling for all other variables in the model. For every one-year increase in education, the likelihood of pursuit of PAD increased by a factor of 1.37, resulting in a substantial increase in the odds of pursuit of PAD between, for example a high school graduate and a college graduate. A possible explanation for this may be that those who are more highly educated are better able to advocate for their desires, and better able to find and engage the professionals necessary to pursue PAD.

Implications

Implications for clinical practice. Discussion of PAD often turns to moral and ethical considerations of the practice and impact on the patient, family, and care providers. This research was not undertaken to argue either for or against the practice, but rather to help explicate factors that may contribute to, or be relevant for those who pursue PAD.

There has been a steady increase in utilization of PAD as an end of life option in Oregon, and other jurisdictions have joined in legal sanction of the practice. How should health care providers understand a request for PAD? Does it reflect the presence of physical or emotional distress that can and should be ameliorated by increased interventions? To the extent that any of the factors that motivate pursuit of PAD reflect sources of suffering that can be alleviated, it is the mission of palliative care providers to do so. To the extent that any relevant factors reflect long standing personal values or traits, care providers must be sensitive and respectful in order to provide care that is palatable to the patient. The following are discussions of implications for clinical practice for providers working with patients who pursue PAD.

Regardless of questions about the structure of the underlying construct of hopelessness for those pursuing PAD, a sense of hopelessness was demonstrated to be a concern for those who pursued PAD. Hopelessness is complex and multifactorial, and as such may provide multiple pathways or opportunities for provision of meaningful care. Clinicians should also recognize that some encountering the end of life may respond with clear-eyed realism, without any expectation or hope for cure, and such a posture may be consistent with long standing personal values and qualities. Clinicians should be aware of the possibilities that the meaning of hopelessness may have for those at the end of life and communication with those patients should be sensitive to the needs and values of the individual. Providers may find it difficult to be forthcoming and transparent in discussion of prognosis and options (Khan et al., 2010), but frank discussion may be highly valued by those whose approach to end of life is “clear, adamant, and unwavering” (Ganzini, Dobscha et al., 2003, p. 385). In the event that hopelessness does reflect a sense of demoralization, therapies are being developed and tested to target those symptoms. Meaning-Centered Group Psychotherapy and the individual therapies, Managing Cancer and Living Meaningfully and Dignity Therapy, have shown promising results (Khan et al., 2010). It will take effort and intention to distinguish between distress and personality, between state and trait, but such a determination is necessary for respectful end of life care.

While questions remain as to the extent of the impact of attachment style, there is evidence that at least for some, pursuit of PAD reflects distress related to affronts to long held values or personality traits, as opposed to distress related to more transient symptoms or states. When encountering these individuals, care providers must appreciate and respect the tendency for some to insist on autonomy and hold offered interventions or offers of assistance at arm’s length. Of course, assessment for symptom management (in all biopsychosocial domains) must be ongoing and appropriate interventions offered, but providers should also realize that for some, the dependency involved in the end of life decline is the source of distress and further offers of support might be met with resistance. Such patients should be understood as having a high need for autonomy and self-reliance, and support of those needs may be more highly valued by the patient than measures that could ostensibly provide other physical or psychological comfort. For some, the process of dying and dependency is so abhorrent that death is seen as “the only escape from dying” (Sullivan, 2003, p. 396).

Poor quality of life is strongly associated with depression (Hotopf et al., 2002). As a potentially treatable condition, unrecognized or untreated depression has significant consequences for those at the end of life. Even though pursuers of PAD have consistently indicated that depression is not the reason for pursuit, these results show that those who pursued PAD had higher levels of depression than those who did not pursue. Health care providers must recognize the possibility of untreated depression and actively engage patients in treatment for that condition to the extent possible and tolerated by the patient. Ly, Chidgey, and Addington-Hall (2002) reported that depression is substantially under recognized and under treated at the end of life. Khan et al. (2010) reported that prior to routine screening, only 40% of depressed individuals with metastatic cancer were being referred for treatment, and elderly patients were referred at much lower rates than younger patients. For those patients, aggressive measures should be taken to assess and treat depression in order to provide for the best quality of life, and death, as possible. Commonly used antidepressants may take several weeks to be efficacious, making clear the need for early screening and treatment in those with terminal illness, however, initiation of antidepressant often occurs in the last two weeks of life (Lloyd-Williams, Friedman, & Rudd, 1999). This too calls for the need for novel treatment interventions, perhaps such as stimulant medications, which have immediate results. While research indicates that care providers aggressively assess for and treat depression when a request for PAD is expressed (Kohlwes et al., 2001), more should be done early in the end of life trajectory to try to prevent any possible impact of depression. At the same time, clinicians should realize that treatment of depression, while offering improved quality of life, might not ameliorate the patient's desire for and pursuit of PAD.

Implications for research. There is a relative dearth of information about psychosocial issues at end of life – dismaying in light of the aging population and advances in medical technology that result in end of life experiences with a long, predictable trajectory. Advances in medical care have resulted in a robust understanding of how best to care for the physical being at the end of life, however interventions for psychosocial needs do not have the same degree of understanding. While the literature is replete with identification of psychosocial concerns, there is little systematic evaluation of treatments to address those concerns. Constructs such as hopelessness at the end of life, treatment of depression in the face of terminal illness, the roles of spirituality and dignity, are at nascent stages of understanding and utility in end of life care.

The construct of hopelessness is clearly important to understanding the issues relevant to those at the end of life and those who pursue PAD. Recently, Rosenfeld et al. (2011) developed an instrument to assess hopelessness in terminally ill patients. Research with such an instrument might provide better understanding of the meaning of hopelessness for those at the end of life and given the importance of the finding in the current research, better understanding of the construct is a priority.

While attachment style is generally thought to be relatively stable through adulthood, external circumstances, life context, and concomitant impact on psyche are understood to impact an individual's resonance with styles of attachment at the time of assessment (Mikulincer & Shaver, 2007). According to Busko (2010), measurement of psychological attributes is impacted by state and trait components, therefore the results of such measurement reflect a combination of the attributes of the person and the specific situation within which the assessment is made. The impact of clearly impending death in the context of terminal illness could impact both one's sense of self and relationships with others. Attachment, including attachment-seeking behavior and stability of attachment style for older adults and at the end of life has received little study (Bradley & Cafferty, 2001), supporting the value of further investigation in this area.

Despite difficulties encountered with the reliability of the RSQ-D, there was a significant between group difference on this measure, leading to speculation that a more reliable instrument would have yielded more robust results that would have held in the regression analysis. Recently Lo et al. (2009) developed a modified, brief (16 item) version of the Experiences in Close Relationships scale (ECR) to assess attachment style. Thus far it has demonstrated good reliability and validity and could be used in further research with those at the end of life. The qualitative literature has been so robust in describing the personality qualities of those who pursue PAD, and the results of the current study lend support to attachment style as a salient factor, that following this line inquiry is important in understanding the motives, strengths, and challenges of those who pursue.

Strengths

There are several notable strengths to this study. Foremost is the opportunity to understand pursuit of PAD from directly from those who have engaged in actions to enact this option, in contrast to research with those who express a desire to hasten death without legal access or action related to pursuit (ostensibly hypothetical interest). Heretofore, most information about pursuit of PAD has been gathered from proxy informants, some with more distal knowledge (health care providers) and some with more proximal knowledge (family members), yet the concordance of the reported proxy information with the patient's experience is unknown. There is great value in direct information from patients regarding motives for pursuit of PAD.

Furthermore, understanding of the factors motivating pursuit is greatly enhanced by the ability to contrast the findings with a sample of individuals at the end of life who did not pursue such action. Thus results on all of the measures used here are made even more meaningful by the contrast between the groups of pursuers and non-pursuers. Additionally, using a secondary analysis design allowed for efficient and full use of the contribution of those at the end of life. It is ethically important to maximize the contribution to science from those who had limited time and energy and who generously contributed to the pursuit of knowledge in this field.

An additional strength of the study is the use of standardized instruments for all predictor variables, providing confidence in the validity of the findings. Previous research has been hampered by the method of assessing psychosocial concerns, frequently done by retrospective clinician recall, without explanation of the criteria used to qualify the patient as having the condition of interest. Use of standardized, commonly used instruments adds greatly to the body of research regarding PAD as well as end of life research. This method provides opportunities for further comparison to past research with groups who have been evaluated by these measures as well as for potential future comparisons. These measures also allowed for use in regression analyses to build prediction models and test interactions, something that has been rarely done regarding those who pursued PAD.

The use of the HADS allowed for identification of symptoms of depression without the confounding effect of physical symptoms that occurs with many depression screening measures. Since terminal illness, by definition, has significant impact on physical health and functioning, separating these symptoms from psychological symptoms is extremely valuable.

Another strength of this study is the opportunity to contrast the data herein with data from the population of those who used a lethal prescription under the DWDA. The state of Oregon has been collecting and disseminating data about those who received and used a lethal prescription under the DWDA since its inception in 1997. Because of this, it was possible to compare the sample for the current study to the population of PAD users on some variables, particularly the demographic variables to aid understanding of any sampling bias.

Limitations

Sampling bias. A potential limitation of this study is whether and to what extent the sample is representative of the population of those who pursued PAD to receipt of the lethal prescription in Oregon. Only a subset of those who inquire about PAD go on to pursue the option (Loggers et al., 2013). The sample of cases in the current study were individuals who made a serious inquiry regarding PAD; the Oregon data refers to those who followed interest in PAD to the end result of receipt and/or use of the lethal prescription provided. The parent study does not have complete data regarding receipt and use of a lethal prescription for those who were in the case group. Data are missing for 16 (29.1%) of the 55 case group participants who pursued PAD. With that said, the sample in the current study was comparable to the Oregon DWDA population on gender (current study 50.5% female; DWDA 48.4% female), race (current study 96.8% Caucasian; DWDA 97.6% Caucasian), marital status (current study 50.5% married; DWDA 45.4% married) and diagnosis (current study 76.9% cancer; DWDA 80.3% cancer). However, as a convenience sample, it is possible that the participants did not represent the population for those at the end of life in Oregon (both pursuers of PAD and those who do not pursue) on some important variables. Depression may be underrepresented as referral sources may have screened out individuals thought too depressed to participate, or depressed individuals may not have volunteered to participate. The same may be true for those with high levels of pain or high levels of hopelessness.

The timing of recruitment of participants into the study may have introduced selection bias as a limitation of the study. The sample was recruited over an extended time period (2004-2010), with many in the control group recruited late in the study compared to those recruited early. Understanding and acceptance of PAD over that period of time could have had an impact on the sample. As well, advances in medical technology may have resulted in significantly different end of life experiences for those recruited late in the study.

An additional difference in this sample versus the population of PAD users from Oregon is in regard to hospice enrollment. Through the 15 years of legal access to PAD, 90% of those who used a lethal prescription under the DWDA were enrolled in hospice at the time of death (Oregon Health Authority, 2013). The percent of PAD pursuers enrolled in hospice was 33% at the time data were collected for the current study. It is possible therefore, that this sample was markedly different from the population. An alternative hypothesis for the difference is that the PAD pursuers in this study would eventually enroll in hospice, but at the time of data collection did not desire that level or type of intervention. If this is true, it implies that those in the study may have been relatively early in the end of life trajectory. Symptoms such as pain, depression, and hopelessness, measured at the time of the study, could have increased through the dying process. This would also indicate that those who pursue PAD do so early in the process, prior to the experience of intolerable symptoms, should they occur.

An additional potential limitation lies in uncertainty as to whether the sample of controls was indeed representative of those who do not pursue PAD. The participants for the comparator group recruited for the study were remarkably supportive of PAD, perhaps more than might have been expected in the general population. Only 21% of the comparator group was opposed to PAD, and in fact, one participant was dropped from the control group due to her eventual desire to pursue PAD. The high level of support was hypothesized to be due, at least in part, to the name of the study “Why Patients Consider

Hastening Death", which may have served to screen out those who were opposed to the practice of PAD (L. Ganzini, personal communication, January 21, 2013).

Limitations of the instruments. RSQ-D. The lack of significance of dismissive attachment in the logistic regression model may be due in part to the low reliability of the RSQ-D for this sample (α = .65). Low reliabilities are a concern as alpha reliability is considered to reflect the proportion of obtained score variance attributable to the true score of the underlying latent variable, and is directly and inversely related to error variance (DeVellis, 2003). Low reliabilities reduce the power of tests to detect significant relationships, increasing the likelihood of a Type-II error (Ponterotto & Charter, 2009; Ponterotto & Ruckdeschel, 2007). Measures with low reliability generally lead to underestimated effect size; that is, the obtained effect size will likely be lower than that of the population to which it is hypothesized to pertain (Baugh, 2002). It may be worth noting that the alpha reliability for this sample is consistent with published literature (e.g., Backstrom & Holmes, 2001; Brussoni et al., 2000), speaking to consistent issues regarding the reliability of the measure as opposed to sample specific issues. The RSQ-D reliability was likely impacted by the small number of items on the scale (five).

The validity of the modified instruments may have impacted the results. The BHS and DOC were each modified for use in the parent study, but the validity of the modified instruments had not been assessed. As noted above, the lack of significant findings for the DOC measure may reflect that the instrument does not measure the aspects of desire for control of the dying process that has been so widely reported for those who have pursued PAD, including in this sample (Ganzini et al., 2009).

Summary

The current study examined disease related variables and personality related variables for relevance and contribution to pursuit of PAD in a sample of terminally ill Oregonians. A case-control design was used, allowing comparison with a group of terminally ill Oregonians who did not pursue PAD. The study showed the following significant differences between the two groups: Those who pursued PAD were, on average, more depressed, experienced greater hopelessness, were more likely to resonate with a dismissive attachment style, had more education, and were more likely to be unmarried than their comparator counterparts. Also revealed in the study was that levels of pain and desire for control did not significantly differ between the two groups.

In the logistic regression model, hopelessness, having more education, and being unmarried reliably predicted pursuit of PAD, controlling for depression, age, and dismissive attachment. Beyond demographic variables (education and marital status), hopelessness was the only variable to predict pursuit of PAD.

By use of standardized instruments to measure variables and the use of a comparator group, this study provided an opportunity to understand the factors that motivate individuals to pursue PAD and allows understanding in the context of the body of end of life research. With that said, the current study leads to further questions and opportunities for research about those who pursue PAD. It is unclear that the latent construct of hopelessness for medically healthy individuals, as measured by the BHS, is the same as for those at the end of life. Factor analysis of data from the current study could provide additional understanding of the construct. Additionally, the results related to dismissive attachment style show a difference between pursuers of PAD and those who did not pursue. Further inquiry with an instrument with greater reliability or larger sample size may yield more definitive results. Questions unanswered by this study include the availability of social support beyond marital status and the role of spirituality, if any, in pursuit of PAD.

This research can be used to support those who pursue PAD as it provides understanding as to the motives at the time of inquiry and pursuit. Consistent with other research in this area, these results indicate that clinicians may provide important support by not only addressing current symptoms, but also by paying particular attention to concerns related to the future, such as fear of future symptoms or fear of dependency that may become intolerable.

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Appendix A

Wisconsin Brief Pain Inventory (WBPI) – Modified

1. Please rate your *pain* *<u>at its worst</u>* in the last <u>two weeks</u> by circling the <u>one</u> number that best describes it. (A rating of 10 would indicate pain so severe as to prohibit all activity; the worst you can imagine.)

No pain 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine.

2. Please rate your *pain* *<u>on the average</u>* in the last <u>two weeks</u> by circling the <u>one</u> number that best describes it. (A rating of 10 would indicate pain so severe as to prohibit all activity; the worst you can imagine.)

No pain 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine.

3. Please rate how much *pain you have* *<u>right now</u>* by circling the <u>one</u> number that best describes it. (A rating of 10 would indicate pain so severe as to prohibit all activity; the worst you can imagine.)

No pain 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine.

4. Please rate how much *relief* pain treatments or medications have provided <u>on average</u> in the last <u>two weeks</u> by circling the <u>one</u> percentage that best describes it. (*If no pain relief medications are needed,* please circle 100%.)

No relief 1 2 3 4 5 6 7 8 9 10 Complete relief (R).

Appendix B

Hospital Anxiety and Depression Scale (HADS)

Choose one response from the four given for each statement. Give an immediate response and do not think too long about your answers.

1. I feel tense or wound up:

   Most of the time – 3

   A lot of the time – 2

   From time to time, occasionally – 1

   Not at all – 0

2. I still enjoy the things I used to enjoy:

   Definitely as much – 0

   Not quite so much – 1

   Only a little – 2

   Hardly at all – 3

3. I get a sort of frightened feeling as if something awful is about to happen:

   Very definitely and quite badly – 3

   Yes, but not too badly – 2

   A little, but it doesn't worry me – 1

   Not at all – 0

4. I can laugh and see the funny side of things:

   As much as I always could – 0

   Not quite so much now – 1

   Definitely not so much now – 2

Not at all – 3

5. Worrying thoughts go through my mind:

A great deal of the time – 3

A lot of the time – 2

From time to time, but not too often – 1

Only occasionally – 0

6. I feel cheerful:

Not at all – 3

Not often – 2

Sometimes – 1

Most of the time – 0

7. I can sit at ease and feel relaxed:

Definitely – 0

Usually – 1

Not often – 2

Not at all – 3

8. I feel as if I am slowed down:

Nearly all the time – 3

Very often – 2

Sometimes – 1

Not at all – 0

9. I get a sort of frightened feeling like “butterflies” in the stomach:

Not at all – 0

Occasionally – 1

Quite often – 2

Very often – 3

10. I have lost interest in my appearance:

Definitely – 3

I don't take as much care as I should – 2

I may not take quite as much care – 1

I take just as much care as ever – 0

11. I feel restless and as if I have to be on the move:

Very much indeed – 3

Quite a lot – 2

Not very much – 1

Not at all – 0

12. I look forward with enjoyment to things:

As much as I ever did – 0

Rather less than I used to – 1

Definitely less than I used to – 2

Hardly at all – 3

13. I get sudden feelings of panic:

Very often indeed – 3

Quite often – 2

Not very often – 1

Not at all – 0

14. I can enjoy a good book or radio or TV program

Often – 0

Sometimes – 1

Not often – 2

Very seldom – 3

Appendix C

Beck Hopelessness Scale (BHS)

The following items are answered on a true-false scale.

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

19. There’s no use in really trying to get something I want because I probably won’t get it.

The following item (designated by the number in the original scale), is included on the original version of the Beck Hopelessness Scale, but was eliminated from the BHS scale used in the parent study.

Item #4. I can’t imagine what my life would be like in 10 years.

Appendix D

Relationship Style Questionnaire – Dismissive Attachment subscale (RSQ-D)

Rate how well these phrases describe you on a scale where 1 = “not at all like me” and 5 = “very like me”.

1. It is very important to me to feel independent.

2. I am comfortable without close emotional relationships.

3. It is important for me to feel self sufficient.

4. I prefer not to have other people depend on me.

5. I prefer not to depend on others.

Appendix E

Desirability of Control Scale (DOC)

Instructions: Below you will find a series of statements. Please read each statement carefully and respond to it by expressing the extent to which you believe the statement applies to you. For all items, a response from 1 to 7 is required. Use the number that best reflects your belief when the scale is defined as follows.

1 – Does not apply to me at all.

2 – Usually does not apply to me.

3 – Most often, does not apply

4 – I am unsure whether or not the statement applies to me/applies to me about half the time

5 – Applies more often than not.

6 – Usually applies to me.

7 – Always applies to me.

1. I prefer a job where I have a lot of control over what I do and when I do it.
2. I try to avoid situations where someone else tells me what to do.
3. I would prefer to be a leader than a follower.
4. I enjoy being able to influence the actions of others.
5. Others usually know what is best for me.
6. I enjoy making my own decisions.
7. I enjoy having control over my own destiny.

8. I would rather someone else take over the leadership role when I'm involved in a group project.
9. I consider myself to be generally more capable of handling situations than others are.
10. When I see a problem, I prefer to do something about it rather than sit by and let it continue.
11. When it comes to orders, I would rather give them than receive them.
12. I wish I could push many of life's daily decisions off on someone else
13. I prefer to avoid situations where someone else has to tell me what it is I should be doing.
14. There are many situations in which I would prefer only one choice rather than having to make a decision.
15. I like to wait and see if someone else is going to solve a problem so that I don't have to be bothered with it.

The following items (designated by the number in the original scale), are included on the original version of the Desirability of Control Scale, but were eliminated from the DOC scale used in the parent study.

Item #2. I enjoy political participation because I want to have as much say in running government as possible.

#6. I am careful to check everything on an automobile before I leave on a long trip.

#12. I'd rather run my own business and make my own mistakes than listen to someone else's orders.

#13. I like to get a good idea of what a job is all about before I begin.

#17. When driving, I try to avoid putting myself in a situation where I could be hurt by someone else's mistake.

Appendix F

Moderator Analyses

Table F1

Logistic Regression Predicting Pursuit of PAD Including Interaction Of Dismissive Attachment and Depression

Predictor	*B*	Wald test	Odds Ratio	95% Confidence Interval for Odds Ratio	
				Lower	Upper
Step 1					
Age	.02	.89	1.02	.98	1.07
Education	.27	9.42**	1.32	1.10	1.57
Marital Status	-1.11	4.14*	.33	.11	.96
Hopelessness	.28	6.53**	1.32	1.07	1.63
Depression – centered	.03	.22	1.03	.92	1.15
Dismissive attachment – centered	.53	1.90	1.71	.80	3.65
Step 2					
Depression Centered X Dismissive Attachment	.01	.04	1.01	.88	1.17

Depression = Hospital Anxiety and Depression Scale; Hopelessness = Beck Hopelessness Scale; Dismissive Attachment = Relationship Style Questionnaire, Dismissive Attachment subscale.

*$p < .05$. **$p < .01$.

Table F2

Logistic Regression Predicting Pursuit of PAD Including Interaction Of Dismissive Attachment and Hopelessness

Predictor	*B*	Wald test	Odds Ratio	95% Confidence Interval for Odds Ratio Lower	Upper
Step 1					
Age	.02	.89	1.02	.98	1.07
Education	.27	9.42**	1.32	1.10	1.57
Marital Status	-1.11	4.14*	.33	.11	.96
Depression	.03	.22	1.03	.92	1.15
Hopelessness – centered	.28	6.53**	1.32	1.07	1.63
Dismissive attachment – centered	.53	1.90	1.71	.80	3.65
Step 2					
Hopelessness Centered X Dismissive Attachment	-.05	.21	.95	.76	1.19

Depression = Hospital Anxiety and Depression Scale; Hopelessness = Beck Hopelessness Scale; Dismissive Attachment = Relationship Style Questionnaire, Dismissive Attachment subscale.
**p* < .05. ***p* < .01.

Appendix G

Consent Documents

OHSU
Oregon Health & Science University
Consent & Authorization Form

eIRB#: 2780

Protocol Approval Date: 7/3/2007

OREGON HEALTH & SCIENCE UNIVERSITY
Consent & Authorization Form

TITLE: Why Patients Consider Hastening Death— Survey

PRINCIPAL INVESTIGATOR: Linda Ganzini, MD, MPH (503) 220-8262 ext. 156492

CO-INVESTIGATORS:
Elizabeth Goy, PhD (503) 220-8262 ext 157470
Steven Dobscha, MD (503) 220-8262 ext. 156444

SPONSOR: Northwest Health Foundation

This form contains important information about the study in which you are being invited to participate. Please read the form carefully, ask questions of the investigators or others who are obtaining your consent to participate in the study, and take time to think about your participation. You may want to discuss the study with your family or friends before agreeing to be in the study.

What is the purpose of this study?

This study involves research. You have been invited to participate in this research study because you have expressed an interest in pursuing options to hasten your death. The purpose of this research study is to understand why some individuals with advanced disease wish to hasten death.

We will enroll about 120 patients in this study, including 20 subjects from OHSU.

What is required to participate in this study?

To qualify for this study, you must meet the following criteria:

1. Be able to speak English.
2. Not have dementia or confusion.
3. Have a shortened life expectancy.
4. Have an interest in pursuing hastened death.

What can I expect as a study participant?

You will be asked questions about your interest in hastened death, mood, hope for the future, religious and spiritual views, worries about burdening others, physical symptoms, relationships with other people, social support, and interest in control. The interview may occur at your home or at the Portland VA Medical Center. A portion of this survey will be audiotaped.

This survey will take about 60 minutes to complete. Your participation in this study will last for one or two visits. If you are not able to complete the entire survey in one visit, we will arrange for a second visit.

If you have any questions regarding this study now or in the future, contact Dr. Linda Ganzini (503) 220-8262 ext. 156492 or Dr. Elizabeth Goy (503) 220-8262 ext. 157470.

What effect will this study have on my care?

Your participation in this research study is voluntary. The authorization to use your protected health information is also voluntary. You may refuse to sign this informed consent form and authorization. However, in order to participate in this study you must sign the informed consent form and authorization.

Being in this study will not affect any care that you might receive at OHSU.

How will my privacy be protected?

We will protect your privacy in the following ways:

1. Your name or other protected information will not be used. Instead, we will identify you by a code number.
2. Only Dr. Ganzini, Dr. Dobscha, Dr. Goy and study staff will be able to access your information.

Once information is received, we will limit record access to study personnel and store files in a locked cabinet.

The specific health information we will collect from you will be limited to: name, date of birth, social security number, address, and phone number. The survey will gather some health information including a measure of physical functioning, diagnosis of depression, cognitive status, and pain rating. From your medical record, we will gather information about your outcome. The purposes of our use and disclosure of this health information are described in the Purpose section of this Consent & Authorization Form.

The persons who are authorized to use and/or disclose your health information are all of the investigators who are listed on page one of this Research Consent Form and the OHSU Institutional Review Board.

The persons who are authorized to receive this information are Northwest Health Foundation and the Portland VA Medical Center Institutional Review Board as required for their research oversight and public health reporting in connection with this research study.

This authorization will expire and we will no longer keep protected health information that we collect from you in this study after study results are published.

What are the possible risks of participating in this study?

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality. The risks of participating are that it may inconvenience you or tire you out. Some of these questions may seem personal or embarrassing and may upset you. You may refuse to answer any of the questions that you do not wish to answer. If you become so upset by the questions that you appear to need counseling, you will be referred to an appropriate counselor.

What are the possible benefits of participating in the study?

You will not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

Will it cost anything to participate?

There are no costs to you for participating in this research study.

You will be reimbursed $50.00 cash for your participation at the completion of the survey. If you chose to withdraw from the study, you will still receive $50.00. If you choose to come to the Portland VA Medical Center for the interview, we will reimburse your mileage at $0.36 per mile.

What if I am harmed or injured in this study?

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact **Dr. Linda Ganzini at (503) 220-8262 ext. 156492.**

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

What are my rights as a participant?

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU.

To revoke this authorization, you must write to:

Linda Ganzini, MD, MPH
Portland VA Medical Center, R&D - 66

P.O. Box 1034
Portland, OR 97207
(503) 220-8262 ext. 156492

If the researchers publish the results of this research, they will do so in a way that does not identify you unless you allow this in writing.

You may be removed from the study if the investigator stops the study.

New findings developed during the course of the Research Study, which may affect your willingness to continue participation, will be explained and your consent for continued participation will be required.

To participate in this study, you must read and sign this consent and authorization form. If you withdraw your authorization for us to use and disclose your information as described above, you will be withdrawn from the study.

We will give you a copy of this consent form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

OREGON HEALTH & SCIENCE UNIVERSITY

INSTITUTIONAL REVIEW BOARD

PHONE NUMBER (503) 494-7887

CONSENT/AUTHORIZATION FORM APPROVAL DATE

Jul. 3, 2007

Do not sign this form after the

Expiration date of: 7/2/2008

____ ______________ __________

Signature of Subject *Date* *Time*

____

Signature of Investigator or Investigator Representative

Oregon Health & Science University
Consent & Authorization Form

eIRB#: 2780

Protocol Approval Date: 05/20/2010

OREGON HEALTH & SCIENCE UNIVERSITY
Consent & Authorization Form

TITLE: Why Patients Consider Hastening Death— Survey for Controls.

PRINCIPAL INVESTIGATOR:	Linda Ganzini, MD, MPH (503) 220-8262 ext. 56492
CO-INVESTIGATORS:	Elizabeth Goy, PhD (503) 220-8262 ext. 57470 Steven Dobscha, MD (503) 220-8262 ext. 56490
STAFF MEMBERS:	Robert Socherman, PhD (503) 220-8262 ext. 54522 Tawni Kenworthy-Heinige, BS (503) 494-3277 Molly Delorit, BA (503) 220-8262 ext. 57747

SUPPORTED BY: This research study is supported by Veterans Affairs Health Services Research and Development Research Enhancement Award Program resources.

This form contains important information about the study in which you are being invited to participate. Please read the form carefully, ask questions of the investigators or others who are obtaining your consent to participate in the study, and take time to think about your participation. You may want to discuss the study with your family or friends before agreeing to be in the study.

What is the purpose of this study?

This study involves research. You have been invited to participate in this research study because you have **not** expressed any interest in pursuing options to hasten your death. The purpose of this research study is to understand why some individuals with advanced disease wish to hasten death. You are being included for comparison purposes.

We will enroll about 120 patients in this study, including 40 control subjects from OHSU.

What is required to participate in this study?

To qualify for this study, you must meet the following criteria:

5. Be able to speak English.
6. Not have dementia or confusion.
7. Have a shortened life expectancy.
8. Have no interest in pursuing hastened death.

What can I expect as a study participant?

You will be asked questions about your thoughts on hastened death, mood, hope for the future, religious and spiritual views, worries about burdening others, physical symptoms, relationships with other people, social support, and interest in control. The interview may occur at your home, at OHSU, or at the Portland VA Medical Center.

This survey will take about 60 minutes to complete. Your participation in this study will last for one or two visits. If you are not able to complete the entire survey in one visit, we will arrange for a second visit.

If you have any questions regarding this study now or in the future, contact Dr. Linda Ganzini (503) 220-8262 ext. 56492 or Dr. Elizabeth Goy (503) 220-8262 ext. 57470.

What effect will this study have on my care?

Your participation in this research study is voluntary. The authorization to use your protected health information is also voluntary. You may refuse to sign this informed consent form and authorization. However, in order to participate in this study you must sign the informed consent form and authorization.

Being in this study will not affect any care that you might receive at OHSU.

How will my privacy be protected?

We will protect your privacy in the following ways:

3. Your name or other protected information will not be used. Instead, we will identify you by a code number.
4. Only Dr. Ganzini, Dr. Dobscha, Dr. Goy and study staff will be able to access your information.

Once information is received, we will limit record access to study personnel and store files in a locked cabinet.

The specific health information we will collect from you will be limited to: name, date of birth, social security number, address, and phone number. The survey will gather some health information including a measure of physical functioning, diagnosis of depression, cognitive status, and pain rating. From your medical record, we will gather information about your outcome. The purposes of our use and disclosure of this health information are described in the Purpose section of this Consent & Authorization Form.

The persons who are authorized to use and/or disclose your health information are all of the investigators who are listed on page one of this Research Consent Form, the OHSU Institutional Review Board, and the Knight Cancer Institute.

The persons who are authorized to receive this information are the Northwest Health Foundation, the Portland VA Medical Center Institutional Review Board, and other authorized VA personnel and federal agencies, such as the Office for Human Research Protections (OHRP) and the Government Accounting Office (GAO), in order to meet VA and other federal or local regulations.

We will keep protected health information that we collect from you in this study indefinitely.

The information about you that is used or disclosed in this study may be re-disclosed and no longer protected under federal law.

If the information to be used or disclosed contains any of the types of records or information listed just below, additional laws relating to use and disclosures of the information may apply. You understand and agree that this information will be used and disclosed only if you place your **INITIALS** in the applicable space next to the type of information.

NA___ Acquired immunodeficiency syndrome (AIDS) or human immunodeficiency virus (HIV) infection information
NA___ Drug/alcohol diagnosis, treatment, or referral information
________ Mental or behavioral health or psychiatric care
NA___ Genetic testing information

Under Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

What are the possible risks of participating in this study?

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality. The risks of participating are that it may inconvenience you or tire you out. Some of these questions may seem personal or embarrassing and may upset you. You may refuse to answer any of the questions that you do not wish to answer. If you become so upset by the questions that you appear to need counseling, you will be referred to an appropriate counselor.

What are the possible benefits of participating in the study?

You will not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

Will it cost anything to participate?

There are no costs to you for participating in this research study.

You will be reimbursed $50.00 for your participation. If you chose to withdraw from the study, you will still receive $50.00. If you travel 100 miles or more to be interviewed at OHSU or the Portland VA Medical Center, you will be reimbursed $0.50 cents per mile for travel costs. You will be paid by check; the check will be mailed to you after the study visit.

The check will be issued by the Portland VA Medical Center. In order to process the payment request, your name and address will be provided to the VA employees who manage reimbursement.

What if I am harmed or injured in this study?

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Dr. Linda Ganzini at (503) 220-8262 ext. 56492.

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

What are my rights as a participant?

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU.

To revoke this authorization, you must write to:

Linda Ganzini, MD, MPH
Portland VA Medical Center, R&D – 66
P.O. Box 1034
Portland, OR 97207
(503) 220-8262 ext. 56492

If the researchers publish the results of this research, they will do so in a way that does not identify you unless you allow this in writing.

You may be removed from the study if the investigator stops the study.

New findings developed during the course of the Research Study, which may affect your willingness to continue participation, will be explained and your consent for continued participation will be required.

To participate in this study, you must read and sign this consent and authorization form. If you withdraw your authorization for us to use and disclose your information as described above, you will be withdrawn from the study.

We will give you a copy of this consent form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

OREGON HEALTH & SCIENCE UNIVERSITY

INSTITUTIONAL REVIEW BOARD

PHONE NUMBER (503) 494-7887

CONSENT/AUTHORIZATION FORM APPROVAL DATE

May 20, 2010

Do not sign this form after the

Expiration date of: 05/19/2011

Signature of Subject	*Date*	*Time*

Signature of Investigator or Investigator Representative

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent	*Date*	*Time*