Hospice professionals' experiences with patients:
A qualitative study of suicide and hastened death in Washington State

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I declare that this thesis is my own work and has not been submitted
for the award of a higher degree elsewhere

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Abstract

Several jurisdictions around the world have passed medical aid-in-dying laws that allow a physician, or, in some areas, a nurse practitioner to legally prescribe life-ending medications to individuals faced with a serious illness. There are some individuals receiving hospice services that also die by suicide without legal lethal means. Little is known, however, about deaths that are identified as suicide by professionals working with hospice patients in home settings in areas where medical aid in dying is allowed. This qualitative study undertaken in Washington State, where the Death with Dignity Act was implemented in 2009, investigates suicide and hastened death through the experiences of hospice professionals working with patients in their homes. Data were collected through in-depth, semi-structured interviews with seven nurses, seven social workers, four physicians, and three chaplains. Analysis of these data indicates participants' interpretation of suicide is often blurry, but there are some patients receiving home hospice services who take power into their own hands and die by suicide because they are not eligible for, have no knowledge of, or lack access to legalised medical aid in dying. Power is a factor shaping roles and beliefs among hospice professionals and those they serve. Participants in this study work with patients who utilise medical aid in dying despite personal or organisational challenges and conflicts. Many deaths by suicide may be interpreted as rational but a perceived taboo about suicide limits open conversations among professionals and within organisations. Culture, location, socioeconomic disparities, and organisational policy impact how patients perceive, accept, or afford legal options. Palliative care professionals need open communication with patients and each other about suicide and hastened death in homecare.

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Washington—Death with Dignity Act

Abbreviations

DWDA—Death with Dignity Act

DWD—Death with Dignity

MAiD—Medical Assistance in Dying

MeSH—Medical Subject Headings

VRFF—Voluntary Refusal of Food and Fluids

VSED—Voluntary Stopping of Eating and Drinking

Word Count: 42,155

CHAPTER ONE

Introduction

The documentary film, *How to Die in Oregon*, features individuals who have died using legal life-ending medications in Oregon, the first state to pass the Death with Dignity Act (DWDA) in the United States. The first person featured on the film, Roger, thanks the people of the state of Oregon for the "honour of doing myself in of my own volition, to solve my own problems" (Richardson, 2011). Prior to ingesting the medication, the film shows an unidentified person stirring the medication into a glass of liquid and handing the glass to Roger to drink. Within moments of drinking the liquid he lies dying, says goodbye to several people surrounding him and thanks the team for preparing the medication. The scene raises many questions including who might have been responsible for assisting Roger. Was it the initial physician who signed the prescription, the person who stirred the medication, or was the patient completely independent?   Did the patient kill himself and, if so, was this 'suicide' or a medically assisted death?

The impetus for this research came from over 20 years of experience as a hospice social worker working with several patients who later died by suicide. The deaths of patients who died by suicide using a gun or suffered severe consequences from self-induced medication overdoses were issues that did not disappear with the implementation of the Washington State Death with Dignity Act in 2009. Rather, these experiences provoked questions about professionals' experiences in a climate of changing regulations and organisational policy. Colleagues often shared with me

their personal reflections about encounters with hospice patients who intentionally hastened death, suggesting that they died by suicide, but these deaths were not reported as suicide to authorities, including the local coroner. This led me to question what experiences are considered suicide among hospice professionals, including deaths utilising the Death with Dignity Act (DWDA). The experience described in the film is only one of many that can lead to uncertainty about the definition of suicide or hastened death, particularly in a location where there is a law allowing a physician to prescribe a lethal dose of medications for a patient to self-administer. I include the term 'hastened death' because in the film, Roger's death would not legally be called a suicide or an assisted suicide. The term hastened death is broadly defined in this study as a death that is anticipated due to an advanced illness but intentionally accelerated with or without the assistance of a healthcare professional. Hastened death may include death by an individual who intentionally overdoses on medication, stops eating and drinking, or receives assistance from another to die sooner than might be anticipated. An intentionally hastened death might be seen as a suicide by some individuals and not by others and may also include deaths through medical aid in dying, where legally allowed.

1.1 Question, aim, and objectives

The research question was: What are professionals' experiences of suicide and hastened death with hospice patients in Washington State? The aim of this study is to understand hospice professionals' experiences with patients who have died by suicide or hastened death in Washington State, where medical aid in dying is permitted by law.   To achieve this aim, I have three objectives. The first is to

determine what experiences are considered to be suicide by participants who have

patients who have either died utilising the DWDA or intentionally hastened death by

other means. The term hastened death is used because some participants may

consider an experience with a patient who died using the DWDA as a suicide and

others may not because, by law, the deaths are not identified as a suicide. Using the

term 'hastened death' in the research question enables a broader understanding of

experiences that may include deaths that are not considered to be suicide.

The second objective is to determine how medical aid in dying might impact

experiences of suicide in home hospice care. This objective is included to understand

how professionals working with home hospice patients experience their patients

dying utilising the DWDA, whether the law has influenced patients' deaths by suicide,

and whether there are any differences in experiences depending on location or

where the professional is employed.

The third objective is to determine how professionals discern between patients at

risk for suicide and patients utilising medical aid in dying laws. This objective is

included to understand how suicide assessment and training is implemented in an

area where medical aid in dying is allowed.

1.2 Research design

This study seeks to capture the interpretations, experiences, and perceptions of

suicide and hastened death by enabling health professionals to provide detailed

descriptions of their experiences with patients who hastened their death or died by

suicide. When researching such a complex and sensitive area, interpretations and experiences are best captured through a qualitative research approach employing in-depth, semi-structured interviews with participants with the most knowledge of the research topic (Sandelowski, 2004). Thematic analysis influenced by a social constructionist theoretical framework was used to analyse the data. In addition, theories of power were applied post hoc as a theoretical framework because it helped to make sense of the stories and the political context in which they are shared. The thesis then examined and applied Lukes' three-dimensional view of power to the data to understand how power influences the experiences of participants (Lukes, 2005). This approach analyses terms used, and how hidden and invisible dimensions of power apply to suicide and hastened death in hospice care and is understood in relation to sociopolitical, personal, professional, and cultural influences.

1.3 Contribution to knowledge

The results of this study may be used to inform private organisations' policies, improve professionals' communication with patients receiving hospice care, and contribute to the development of suicide assessment training for hospice professionals. In addition, this thesis contributes to the evidence on how suicide is interpreted by professionals working with patients facing a life-threatening illness.

1.4 Thesis structure

This thesis is comprised of eight chapters. This first chapter contains a brief overview of the research topic and the design. Chapter Two presents essential background information to better understand the context from a global perspective before

focusing on hospice care and medical aid in dying in the United States, and, more specifically, in Washington State, the research location.

Chapter Three is a literature review integrating qualitative and quantitative studies about professionals' experiences with suicide and hastened death in locations where medical aid in dying is allowed around the world. This review includes studies completed about professionals' experiences with patients who may have died by what is interpreted as suicide or an intentional hastened death, including experiences with medical aid in dying. The review's approach was mainly interpretive, aimed to explore the concept and language of suicide used by the authors of the studies and the experiences of the professionals in the studies. A thematic analysis was completed, the results of which supported the need for more research.

Chapter Four describes the chosen methodology, which is influenced by a social constructionist philosophy. It is followed by a description of methods used to conduct interviews and analyse the data, describe how rigour was applied, and how the research adhered to ethical standards.

Chapters Five and Six feature analysis of the findings. The findings are separated in two chapters; first, to distinguish the results identified by each professional group, and second, to identify results from across professional groups. Chapter Five recognises that there is a relationship of hospice with medical aid in dying because professionals continue to work with patients regardless of their choice to utilise

medical aid in dying, but this relationship differs by professional group. Participants had varied experiences, sense of responsibility, and power over decisions depending on their specific professional role. Chapter Six looks at the findings from across professional groups, in two parts. In the first part, issues of social justice are examined due to barriers and challenges to access medical aid in dying and how culture and environment impact these experiences. The second part of Chapter Six examines professional experiences with patients who died by suicide, and the interpretation of suicide in hospice care.

Chapter Seven discusses the key conclusions of this research, applying Lukes' theory of the three dimensions of power to the findings (Lukes, 2005). Application of Luke's theory was developed in the discussion and was not the initial theoretical focus of the research. Power is found in the relationship between the professional and the patient who hastens death or by the individual who takes power into their own hands and dies by suicide. The effect of the invisible and hidden dimensions of power on suicide and medical aid in dying in hospice care are examined. In addition, this chapter explores the uncertain, blurry boundaries of suicide in hospice that are rarely discussed or understood. Chapter Eight concludes with a summary and suggestions for future research.

CHAPTER TWO

Background

Medical aid in dying, also known as 'assisted dying', 'death with dignity', 'assisted suicide', or 'aid in dying' is allowed in seven jurisdictions of the United States, including the states of California, Colorado, Montana, Oregon, Vermont, Washington, and the District of Columbia (California Legislative Information, 2015; Colorado Revised Statute, 2016; Council of the District of Columbia, 2016; Montana Supreme Court, 2009; Oregon Legislature, 1994; Vermont General Assembly, 2013; Washington State Legislature, 2009). Medical aid in dying offers capable adults diagnosed with an advanced illness the option of requesting a prescription for a self-administered lethal dose of medications from their physician with the intent to hasten death (Death With Dignity National Center, 2017; Tucker, 2009, 2012). Individuals requesting medical aid in dying must have the ability to make and communicate healthcare decisions to their physician and consulting physician, and they may be referred to a psychologist or psychiatrist if there is concern about mental health or decision-making capacity (California Legislative Information, 2015; Colorado Revised Statute, 2016; Montana Supreme Court, 2009; Oregon Legislature, 1994; Vermont General Assembly, 2013; Washington State Legislature, 2009). Deaths in locations where medical aid in dying is authorised in the United States are not considered suicide (Death With Dignity National Center, 2017; Oregon Legislature, 1994; Washington State Legislature, 2009). The implementation of medical aid in dying laws, however, are interpreted by many—including healthcare professionals—as a form of suicide that in some cases is considered rational for a terminally ill

capable person who seeks assistance to die if life becomes unbearable (Battin, 2015a; Macleod, Wilson, & Malpas, 2012; Richards, 2017; Tierney, 2010; Vamos, 2012; Werth & Holdwick, 2000). Some studies on hastened death indicate a 'euthanasia underground' but were completed in locations where medical aid in dying was not authorised at the time of the research (Back et al., 2002; Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Emanuel, Daniels, Fairclough, & Clarridge, 1998; Magnusson, 2002; Starks et al., 2005; Stevens & Hassan, 1994; Tamayo-Velázquez, Simón-Lorda, & Cruz-Piqueras, 2012; Warren & Zinn, 2010). Despite these accounts, very little is known about professionals' experiences with hospice patients who intentionally hasten death, particularly in a state that legally permits medical aid in dying. If patients are dying by suicide other than with medical aid in dying, it is important to ask what factors are involved in these decisions to hasten death so as to improve patient care and safety and develop hospice and palliative care responses to concerns.

To understand the context for this study it is important to clarify global terms used when discussing medical aid in dying, and how hospice services are implemented in the research location. First, a brief overview of terms is provided to describe medical aid in dying in global jurisdictions and in locations allowed in the United States. Second, there is a brief explanation of hospice care in the United States and how patients access hospice as an option to understand how and where services are provided. Third, there is a description of hospice service locations in Washington State where patients are served. The chapter concludes with a description of the

issue of suicide as examined in the literature and how this applies in a home hospice context in Washington State.

2.1 Overview of global terms used to describe medical aid in dying

Many terms have been used around the world to describe medical aid in dying. They include assisted suicide, physician-assisted suicide, medical assistance in dying, assisted dying, physician assisted dying, and voluntary euthanasia (Diehl-Schmid et al., 2017; Richards, 2016; Steck, Egger, Maessen, Reisch, & Zwahlen, 2013). Terms vary depending on the law, legal terms utilised in a particular jurisdiction, the researchers, or the background of the authors. For example, Tucker, an attorney and advocate, reports the term 'aid in dying' is value neutral (Tucker, 2012). Documents available from the Government of Canada cite 'medical assistance in dying', or MAiD, as the primary term used, but several other formulations are cited including 'medical aid in dying' or 'physician assisted dying' (Nicol & Tiedemann, 2016).

In the process of writing this thesis, I considered several phrases reflecting the complexities of terms used in this research. I began by using the name of the statutes in Oregon and Washington State—the Death with Dignity Act (DWDA)—because they were the only states to have adopted death with dignity laws at the time this research was initiated. I ultimately decided to use the term 'medical aid in dying', which is a term adopted by Canada and some areas of the United States (Colorado Revised Statute, 2016; Government of Canada, 2016). This term suggests that the laws are a patient-initiated process that requires approval by a physician and are

regulated by a governing authority. In these jurisdictions, the patient is not acting alone and requires the consent of a medical provider. As Salem suggests, medical aid in dying "medicalises suicide ... transforming the private act of suicide into a medical event ... an extension of medical power over life and death" (Salem, 1999, p. 30). However, the name of the law in Washington State, the Death with Dignity Act (DWDA) and the term 'Death with Dignity' (DWD) are also used since they are the most common terms participants in the study location used. Table 2.1 provides definitions of the terms used and is an example of how definitions vary depending on location:

Table 2.1. Definitions and terms

Term	Country	Definition
Voluntary Euthanasia	Belgium Canada Quebec[1] Luxembourg Netherlands	A physician or nurse practitioner[2] directly administers a substance that causes the death of the mentally competent person who has requested it
Physician Assisted Suicide (PAS)	Canada Luxembourg Netherlands	A physician or nurse practitioner prescribes a substance that the requesting mentally capable individual can self-administer to cause their own death
Assisted Suicide (AS)	Switzerland	
Medical aid in dying Aid in Dying (AiD) Assisted Dying (AD) Death with Dignity Act (DWDA) Death with Dignity (DWD) Physician-Assisted Dying (PAD)	United States	

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[1] Quebec National Assembly. (2014). *An Act respecting end-of-life care*. Québec Official Publisher Retrieved from http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2014C2A.PDF
[2] Government of Canada is currently the only country that allows a nurse practitioner to prescribe or administer lethal medications to a patient who requests it.

Medical Assistance in Dying (MAiD) Assisted dying Medical aid in dying	Europe Canada	Term used to describe both the direct administration of a lethal medication by a physician or nurse practitioner, and a prescribed substance that a mentally capable individual self-administers

As medical aid in dying laws are enacted and implemented globally, terminology appears to be shifting. For example, the Termination of Life on Request and Assisted Suicide Act in the Netherlands uses the term 'assisted suicide' to describe a lethal dose of medication that is prescribed by a physician but self-administered by an individual requesting it (Netherlands Ministry of Foreign Affairs, 2017). 'Euthanasia', the term used to describe the direct administration of medication by a physician to end life is allowed in Belgium, Canada, Columbia, Luxembourg, and the Netherlands (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016; Steck et al., 2013). The Canadian law passed in 2015, however, uses the term 'medical assistance in dying', (or the acronym 'MAiD') that suggests 'assisted suicide' as a prescribed dose of medication that is self-administered and allows 'euthanasia' as the direct administration of a lethal dose of medications by a nurse practitioner or physician (Government of Canada, 2016).

The United States is positioned alone in avoiding the term 'suicide' in the content of medical aid in dying laws or court rulings that permit 'assisted suicide'. Laws in Canada and Europe do not omit the word suicide in the legislative provisions (Dembosky, 2016; Leonard, 2015). Canada, Luxembourg, Netherlands, and Switzerland predominantly use 'assisted suicide' as a term to describe a self-

administered dose of medications prescribed by a physician (Emanuel et al., 2016; Government of Canada, 2016; Steck et al., 2013). However, assisted dying is also a term used to describe both euthanasia and assisted suicide (Lewis & Black, 2013; Voorhees, Rietjens, van der Heide, & Drickamer, 2014). Regulation and allowable practices vary globally and cannot be easily compared (Steck et al., 2013). For example, Belgium permits 'euthanasia', and Switzerland only permits 'assisted suicide' (Belgian Act on Euthanasia of May, 2002; Dierickx, Deliens, Cohen, & Chambaere, 2016; Fischer et al., 2008). Switzerland, however, does not have a specific named law, but rather an article in the penal code that suggests if certain conditions are met physicians will not be prosecuted if they are involved with deaths resulting from the self-administration of lethal medications (Gamondi, Oliver, Borasio, Preston, & Payne, 2016). Physicians in Switzerland, like areas that allow medical aid in dying in the United States, are not required to be present when the patient is ingesting the medication (Steck et al., 2013). Table 2.2 includes information about terms used in legislation around the world. Terms written in languages other than English have been translated.

Table 2.2. Global legislative terms[3]

Country/State	Term used in legislation	Self-administered medication	Lethal injection by professional	Year implemented
Belgium	The Belgian Act on Euthanasia of May 28th 2002	No	Yes	2002
Luxembourg	Euthanasia and Assisted Suicide Law of 16th March 2009	Yes	Yes	2009
Netherlands	Termination of Life on Request and Assisted Suicide Act	Yes	Yes	2002
Switzerland	Assisted Suicide *(article in penal code)*	Yes	No	1942
Canada — All provinces	Medical Assistance in Dying Euthanasia and Assisted Suicide	Each province/territory to decide		2016
Quebec	Medical Aid to Die	No	Yes	2015
California	End of Life Option Act	Yes	No	2016
Colorado	End of Life Option Act	Yes	No	2016
D.C.	Death with Dignity Act	Yes	No	2017
Montana	Rights of the Terminally Ill Act *(court ruling)*	Yes	No	2009
Oregon	Death with Dignity	Yes	No	1997
Vermont	Patient Choice and Control at End of Life	Yes	No	2013
Washington	Death with Dignity	Yes	No	2009
Colombia	Statutory Bill on Ending Life in a Decent and Human Way and Assistance to Suicide	No	Yes	2015

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[3] Adapted from: Lewis, D., Gerson, S. M., Gamondi, C. (in press) Assisted Dying: A Global Overview. In Walshe, C., Preston, N., Johnston, B. (eds.) Palliative Care Nursing. Principles and Evidence for Practice. 3rd edit. Open University Press/McGraw-Hill Education, Maidenhead

Belgium is the only country with no minimum age limit for euthanasia, but The Netherlands allows eligible minors ages 12 to 18 to utilise euthanasia or assisted suicide (Watson, 2014). The United States and Colombia are the only countries that require the patient to have a life-threatening disease to be eligible for medical aid in dying (Emanuel et al., 2016). The omission of the term 'suicide' in the content of laws or court rulings in the United States compared to the codes or laws of other nations suggests differences in legislative processes (Emanuel et al., 2016). In addition, this variation may be reflective of cultural differences and attitudes toward suicide (Battin, 2015b).

2.2 Medication and cost of medical aid in dying

The cost for medication and medical aid in dying is included in this chapter to further demonstrate global variations. A study of costs for medical assistance in dying in Canada suggests total costs, including physician visits, medication, and pharmacist, vary from CA$268.75 to $751.85 (Trachtenberg & Manns, 2017). To be eligible for medical assistance in dying in Canada, individuals are required to be covered under the national insurance health program and there would not likely be direct costs for the patient (2002; Government of Canada, 2016; Li et al., 2017). Switzerland allows non-Swiss nationals the option of 'assisted suicide' through Right to Die associations that have costs varying from £7500 to £10,000 (Dignitas, 2017; Irwin, 2016). One study from Washington State estimated that due to the rising cost of secobarbitol, drug costs alone vary from US$500 to $5000 (Shankaran, LaFrance, & Ramsey, 2017).

The United States federal government prohibits federal funds to be used for medical aid in dying, leaving it to individual states to allocate funds for this purpose (Death with Dignity National Center, 2017; Assisted Suicide Funding Restriction Act of 1997, 1997). Patients who receive Medicaid, the state-allocated healthcare benefit for low-income residents, receive benefits for only physician visits and medications in the states of California and Oregon (West, 2017).

There is also variation in the type of medication used for medical aid in dying, particularly in the United States. There is a shortage of the medication Nembutal (pentobarbital) in the United States because of a ban enacted by the European Union to limit its use in capital punishment (Leonard, 2015). Due to the lack of availability of pentobarbital, and the increased cost of secobarbitol, different alternative medications are increasingly being used where medical aid in dying is allowed in the United States (Oregon Public Health Division, 2016; Shankaran et al., 2017; Washington State Department of Health, 2016a; West, 2017). Alternative medication—such as a phenobarbital/chloral hydrate/morphine sulfate mix or a mix of morphine sulfate, Propranolol (Inderal), Diazepam (Valium), Digoxin, and a buffer suspension—costs from US$450 to $600. (Death with Dignity National Center, 2017).

2.3 Medical aid in dying in the United States

As of May 2017, medical aid in dying has been authorised in California, Colorado, the District of Columbia (D.C.), Montana, Oregon, Vermont, and Washington. The term 'medical aid in dying' encompasses the statutes and court rulings passed in all states but is also known as Death with Dignity (DWD), or, if referring to the legislative act,

the Death with Dignity Act (DWDA) (Death With Dignity National Center, 2017). There is an anticipated increase in medical aid and dying as an option in the future as more US states propose laws (Death With Dignity National Center, 2017).

The laws of California, Colorado, District of Columbia (D.C.), Vermont, and Washington follow similar regulations as in the state of Oregon but there are some differences across states. For example, except for Colorado, the physician must wait at least 48 hours after receiving a written request from the patient before writing the prescription. California requires an attestation form to be submitted by the patient 48 hours prior to taking the medication and not all states collect data on individuals using medical aid in dying (Death With Dignity National Center, 2017).

Montana is governed by a state high-court ruling that does not prohibit a physician from writing a legal lethal prescription for their terminally ill patient and follows guidelines similar to states with medical aid in dying laws (Montana Supreme Court, 2009). In general, for an individual to be eligible for medical aid in dying in California, Colorado, D.C., Montana, Oregon, Vermont, and Washington they must:

- Be 18 years of age or older

- Be a resident of the state where they are making the request

- Have a life-threatening illness with a prognosis of 6 months or less confirmed by attending physician and consulting physician

- Make two verbal requests to attending physician a minimum of 15 days apart

- Provide a written request to attending physician

- Have mental capacity to make health-care decisions in the opinion of both attending and consulting physician

- Be referred by attending or consulting physician for psychological or psychiatric evaluation if concerned about decisional capacity

The patient may ask the physician most familiar with them for medical aid in dying medications but the physician, and all healthcare professionals, may refuse to participate for personal reasons, or if they are employed by a healthcare system that does not allow them to participate (Chin, Hedberg, Higginson, & Fleming, 1999; Dunn, Reagan, Tolle, & Foreman, 2008; Ganzini et al., 2000). There is limited evidence of how often hospice medical directors prescribe legal life-ending medications, but there is evidence that some organisations view the values of medical aid in dying as incompatible with hospice values thus preventing some hospice physicians from participating in the process (Campbell & Cox, 2010). The patient may seek out and make the request from another physician who may not be familiar with them (Chin et al., 1999). Patients may also get referrals for a physician from a medical aid in dying advocacy organisation (Compassion & Choices, 2017; End of Life Washington, 2017). Physicians may choose to be present but are not required to do so when a patient is ingesting the life-ending medications and the place of death cannot be in a public location (Dunn et al., 2008).

2.4 Medical aid in dying in Washington State

The DWDA in Washington State, a modified version of a law adopted in Oregon, was passed by popular vote in 2008 and implemented in March 2009 (Washington State Legislature, 2009). Figure 2.1 illustrates the numbers of individuals from 2010 to

2015 reported to have received a prescription to hasten death and numbers reported to have died from the medication utilising the DWDA. There is, though, little information indicating how many individuals begin the process of medical aid in dying but do not ultimately obtain the prescription.
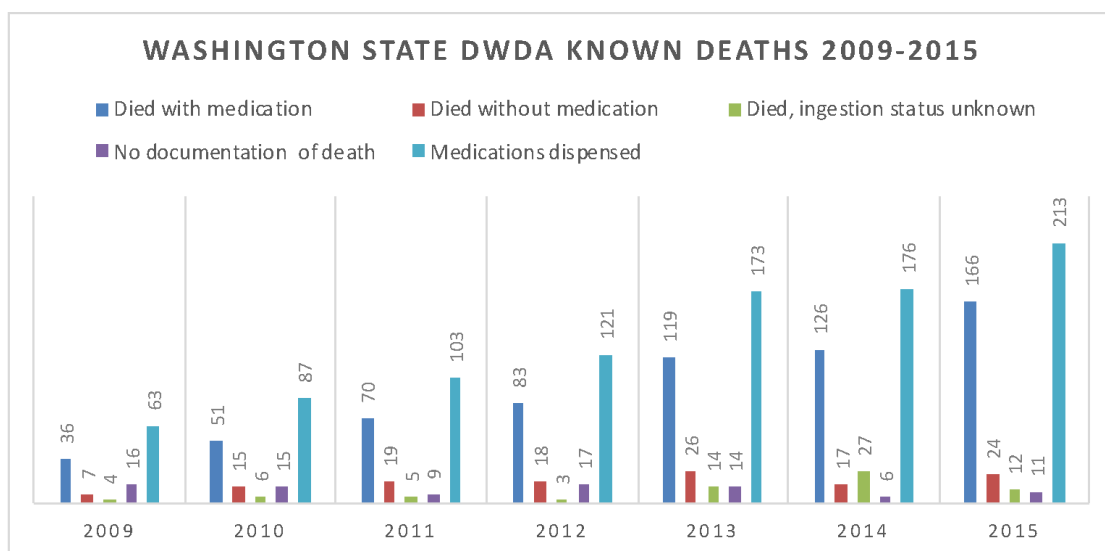
Figure 2.1. Washington State Death with Dignity participants known deaths 2009 to 2015
Adapted from:
http://www.doh.wa.gov/portals/1/Documents/Pubs/422109DeathWithDignityAct2015.pdf

Data collected by the Washington State Department of Health demonstrates that the primary reasons most patients choose life-ending medications are loss of autonomy, inability to engage in activities making life enjoyable, loss of dignity, and concerns about being a burden to family members and caregivers (Washington State Department of Health, 2016a). These data support research highlighting that the impact of loss of independence, loss of dignity, feelings of burden, depression, anxiety, physical discomfort, and spiritual distress are some of the factors that may contribute to a patient's desire to hasten death (Hendry et al., 2013; Hudson et al., 2006; Loggers et al., 2013; Pearlman et al., 2005; Starks et al., 2007; Starks et al.,

2005; Thulesius, Scott, Helgesson, & Lynoe, 2013). In addition, the Washington health data show that individuals seeking medical aid in dying are 95 to 98% white, 74% have some college education, 95% live in the western, more populated part of the state, and over 80% were receiving hospice services, suggesting that vulnerable and disenfranchised individuals are not at risk of being coerced to hasten death (Hendin & Foley 2008; Washington State Department of Health, 2016a).

2.5 Hospice care in the United States

Palliative care, which includes hospice care, offers a specialised patient-centred approach that integrates the comfort of the whole person, including physical, emotional, and spiritual symptoms (Center To Advance Palliative Care, 2017). However, these symptoms cannot always be relieved for patients facing advanced disease (Quill, Lo, & Brock, 2008; WHO, 2012). Most hospice programs in the United States are certified and follow guidelines established by the federally administered Center for Medicare and Medicaid Services to receive financial reimbursement for services provided to patients (Carlson, Schlesinger, Holford, Morrison, & Bradley, 2008). Medicare is a federal health insurance program for people over 65 years old with a work history, and for those who have been deemed to be disabled or diagnosed with end-stage renal disease (Centers for Medicare & Medicaid Services, 2017). Medicare and most other insurances, including private insurances and employee health plans, include a benefit to pay for hospice services to assist patients facing a life-threatening illness who choose to forgo curative life-prolonging measures in favour of palliative treatment to relieve symptoms (Mor & Teno, 2016). This benefit is often called the 'hospice benefit' (Centers for Medicare & Medicaid

Services, 2017). Over 85% of individuals in the United States receiving hospice services in 2014 were served by Medicare, the primary source of the hospice benefit (National Hospice and Palliative Care Organization, 2015). Private insurance, Medicaid (a joint federal and state program providing health coverage for primarily low-income individuals), self-pay, and charity care account for most of the remaining 15% of the population served by hospice (Medicaid.gov, 2017; National Hospice and Palliative Care Organization, 2015).

The National Hospice and Palliative Care Organization (NHPCO), the primary network of hospice and palliative organizations in the United States, publishes an annual report of recent facts and figures (National Hospice and Palliative Care Organization, 2015). This report, which describes the interdisciplinary team members required for hospice, indicates that the numbers of patients in the United States choosing to have hospice service is steadily increasing from 1,380,680 in 2010 to over 1,656,353 in 2014 (National Hospice and Palliative Care Organization, 2015).

Figure 2.2 illustrates an example of the process for individuals to be admitted for hospice care in the United States. The patient is seen at the centre of the family circle on the left. In general, individuals need to be diagnosed with a terminal illness with a prognosis of 6 months or less and be referred by a physician, but they must also meet other specific criteria to receive services. (National Hospice and Palliative Care Organization, 2015). These clinical criteria help to establish a patient's six-month prognosis based on their illness and are used as a guideline to assess a patient's eligibility for hospice services (Centers for Medicare & Medicaid Services, 2017; Dunn

et al., 2008). Once a patient consents to hospice services, most must "waive coverage for other treatment related to the terminal diagnosis" (Dunn et al., 2008, p. 20). 'Waiving coverage' means that the hospice is responsible for the management of the patients' comfort care related to the disease.

Hospice Interdisciplinary Team
Nurse
Social Worker
Chaplain/Spiritual Counsellor
Physician/Nurse Practitioner
Volunteer
Bath Aide
Therapists

Family

Patient

Diagnosis

Prognosis
six months or less

Palliative
Care

Referral to
Hospice

Access to
Equipment and
Comfort
Medications

Paid Caregivers

In Home

Nursing Home

Hospital

Hospice Facility
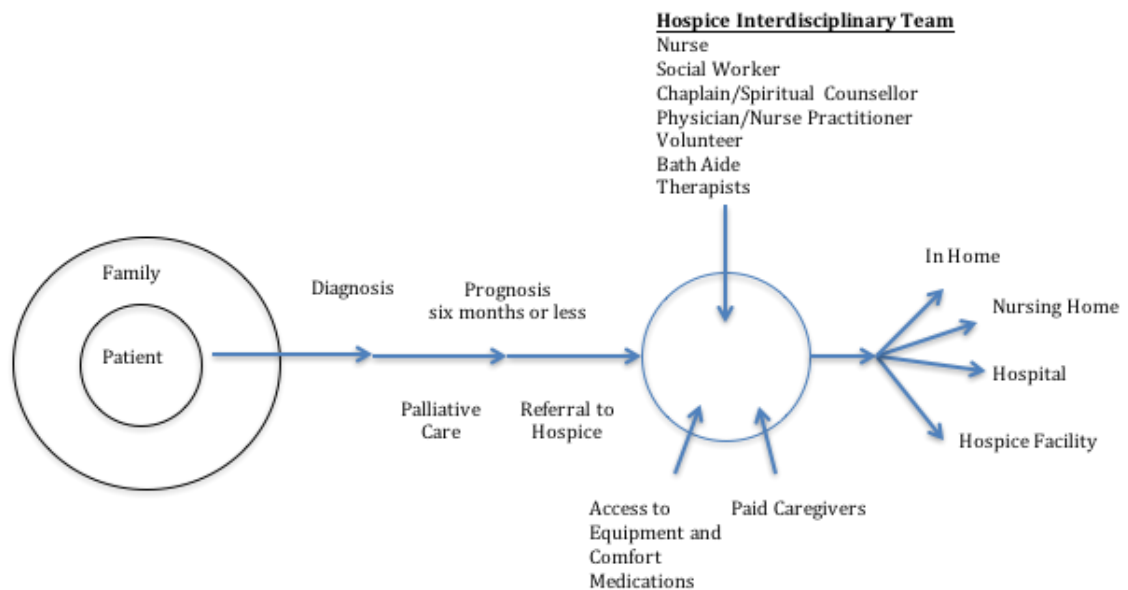
Figure 2.2. Hospice admission process

After the patient is admitted to hospice, which is mostly in the home setting (see Table 2.3), team members assess and provide support to caregivers but, in general, do not provide 24-hour care (Oliver et al., 2013). Patients who live at home might have hired caregivers, who are separate from hospice staff, if they need more care than family, friends, or community are able to provide. In addition, hospice provides equipment and medications for comfort, but do not pay for or provide medical aid in dying medications (Centers for Medicare & Medicaid Services, 2017). Federal funds, including Medicare and Medicaid, cannot be used for medical aid in dying because of a 1997 law enacted in response to the Oregon DWD law (Assisted Suicide Funding

Restriction Act of 1997, 1997; Centers for Medicare & Medicaid Services, 2017; West, 2017). As of May 2017, Oregon and California are the only states to have chosen to segregate state funding of Medicaid to pay for doctors' visits and medications for low-income eligible individuals seeking medical aid in dying (Grube & Cardenas, 2017; West, 2017).

Approximately 1 in 5 patients admitted to hospice are discharged because they are stable and determined to no longer be terminally ill (according to disease-specific Medicare criteria), or because they move or transfer to another hospice program. Patients may also choose to revoke services to pursue other treatment options, or, in rare circumstances, they are discharged for cause (Teno, Plotzke, Gozalo, & Mor, 2014). Discharge for cause, or 'live discharge' might mean that their condition has improved or stabilised, or in some cases they may be discharged improperly because of the high cost of hospitalisation (Dolin et al., 2017; Teno et al., 2014).

Most patients receiving hospice services are referred when their disease is advanced, causing the average length of stay to be a median of less than 18 days (National Hospice and Palliative Care Organization, 2015). For patients who live beyond six months, physicians or nurse practitioners are required to make what are called 'face-to-face' visits every 60 days with the roughly 10% of patients to determine if they continue to meet the criteria and six-month prognosis (Harrold, Harris, Green, Craig, & Casarett, 2013; National Hospice and Palliative Care Organization, 2015; Rothenberg, Doberman, Simon, Gryczynski, & Cordts, 2014).

2.6 Location of hospice services in Washington State

Hospice in the United States is primarily provided in the patient's home setting but family, informal unpaid, or paid carers commonly aid patients requiring 24-hour care. Hospice team members are then available to consult to address pain and symptom management, counsel, and support the patient and carers (Oliver et al., 2013; Ong, Brennsteiner, Chow, & Hebert, 2016). There are variations in location of hospice services nationwide compared to Washington State. Centers for Medicare and Medicaid Services (2017) report that in 2015 the site of service for hospice nationwide is nearly 52% in a home setting. In contrast, data collected from Washington State indicates that in 2015, 56.8% received care in a home setting. Differences in site of services nationwide compared to Washington State is described in **Error! Reference source not found.** below:

Table 2.3 Site of Services

Site of Hospice Services	Washington State 2015 **34 Medicare Certified Programs**	United States 2015
Private residence	56.8%	51.9%
Nursing home (skilled care)	2.8%	6.4%
Assisted living	20.5%	11.1%
Residential facility (unskilled care)	8%	14.9%
Hospice inpatient	7.9%	8.8%
Acute care hospital	2.6%	5.3%

Adapted from Centers for Medicare & Medicaid Services (2017) Hospice Provider Data 2015

2.7 Suicide, hastened death, and medical aid in dying in home hospice

Few studies have examined the impact of how medical aid in dying laws have affected hospice professionals' experiences with patients hastening death, and

whether this impact has shaped communication and assessment of patients at risk of suicide. Studies examining suicide as an important topic with hospice patients in the United States have been carried out, though not specifically in locations where medical aid in dying was allowed, including two unidentified south-eastern states, California, and a nationwide survey of social workers (Arnold, 2004; Fairman, Montross Thomas, Whitmore, Meier, & Irwin, 2014; Washington et al., 2016). Schoonman, et al, explored attitudes of the public in The Netherlands regarding non-physician assisted suicide with patients who did not qualify for legalised euthanasia. They found that in certain cases most people were supportive, but they could not find research about experiences with hospice or palliative care patients in jurisdictions where medical aid in dying is allowed and who may have hastened death through other means (Schoonman, van Thiel, & van Delden, 2014). The limited depth of understanding of the organisational and societal impact on experiences of clinicians in the United States, either before or since the passing of legislation is reported in various qualitative studies (Back et al., 2002; Bharucha et al., 2003; Blondeau, Dumont, Roy, & Martineau, 2009; Dobscha, Heintz, Press, & Ganzini, 2004; Harvath, Miller, Ganzini, Smith, & Clark, 2005; Nissim, Gagliese, & Rodin, 2009; Pearlman et al., 2005; Starks et al., 2007; Starks et al., 2005).

Suicide risk is often associated with a person's "history of self-harm; a diagnosed mental health problem; personality disorder; addiction problems and gender" (Robson, Scrutton, Wilkinson, & MacLeod, 2010, p. 1250). However, patients with advanced disease may consider ending their own lives due to physical suffering, paralysis, or emotional pain, including hopelessness that may be treated with

pharmacological and/or non-pharmacological methods (Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado, & Balaguer, 2011). There is limited understanding about how professionals, including physicians, nurses, and social workers conduct conversations with patients about desire for hastened death and discern the difference with suicidal intent, particularly in the home setting (Kelly, Burnett, Badger, et al., 2003; Kelly, Burnett, Pelusi, et al., 2003; Monforte-Royo et al., 2011; Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado, Mahtani-Chugani, & Balaguer, 2012; Robson et al., 2010).

There are several cross-sectional studies, surveys, and qualitative research exploring hospice clinicians' attitudes and experiences of working with patients who considered hastening death (Arnold, 2004; Arnold, Artin, Person, & Griffith, 2004; Back et al., 2002; Carlson, Simopolous, Goy, Jackson, & Ganzini, 2005; Dobscha et al., 2004; Fenn & Ganzini, 1999a; Ganzini, E. R. Goy, et al., 2003; Ganzini et al., 2002; Ganzini, Nelson, Lee, et al., 2001; Kohlwes, Koepsell, Rhodes, & Pearlman, 2001). A comprehensive investigation of the research is examined in the next chapter. Significant gaps in knowledge remain about the influence that external factors such as use of terminology and organisational, cultural, and professional ethical issues within the patient/healer relationship have on professionals' experiences and communication about patients' concerns. Such concerns require the hospice professional to identify and discern the difference between a patient's risk for suicide due to depression or mental illness associated with impaired decision-making capacity, and those patients with decision-making capacity who might want to hasten death or are seeking medical aid in dying.

Campbell and Black (2014), in their study examining the policies of Washington State hospice organisations, suggest important organisational differences regarding language, values, and approach to dilemmas around issues of hastened death. They argue that hospice philosophy is geared to support an individual's desire for autonomy, yet the policies of some organisations providing hospice services have missions in opposition to medical aid in dying that pose restrictions on staff. Campbell and Black use the term 'physician assisted death' and say that it "presents a defining question that requires reflection and discussion on the meanings and purposes of ... hospice values" (p. 151). However, they do not discuss how staff interpret and carry out the policy in their work with patients. Understanding how policy is applied or affects professional clinical practice with hospice patients may help to make sense of the 'defining question' alluded to by Campbell and Black. A belief may be that there is limited or no relationship between medical aid in dying and hospice care if restrictions are imposed on staff when the organisational policy is in opposition to participation with the DWDA. This leads one to question how professionals are working with patients who utilise the DWDA in different organisations and if there is a difference depending on the policy of the professionals' employer.

Although this research is focused in Washington State, how policy affects practice pertains to other areas where medical aid in dying is allowed, particularly where there is debate about the need for euthanasia and assisted suicide to be distinct from palliative care (Materstvedt, 2013). A white paper from the European Association of Palliative Care (EAPC) on euthanasia and physician-assisted suicide

suggests that because the focus of palliative care is not to hasten death, it is not "compatible" with medical assistance in dying (Radbruch, L. et al, 2016). Other professional palliative care organisational statements such as the International Association for Hospice & Palliative Care (IAHPC) and the Australian and New Zealand Society of Palliative Medicine (ANZSPM), indicate that all forms of assistance in dying including euthanasia, physician assisted suicide, and assisted suicide are in opposition to the palliative care goal not to hasten death (Materstvedt & Bosshard, 2015). The American Association of Hospice and Palliative Medicine (AAHPM) position statement emphasises that physicians working where Physician Assisted Dying (PAD) is allowed should not have to participate nor should they be prohibited from working with patients requesting assistance (AAHPM, 2016). Organisational policies and statements from professional medical organisations, however, do not necessarily indicate what is actually occurring in practice.

Overall, there are a few cultural differences in the population of Washington State that are unique, and some results of this research may be context specific. For example, Washington State had an overall higher rate of suicide at 14.7 per 100,000, than the national average of 13.2 deaths per 100,000 in 2013 (Washington State Department of Health, 2016b). Suicide rates appear to be increasing, however, as Center for Disease Control data from 2016 reports that the Pacific Northwest region including Washington, Oregon, and Idaho had suicide rates of 17.8 per 100,000 (American Association of Suicidology, 2017). Some reasons for this higher suicide rate are suggested to be due to lack of access to healthcare, rural and social isolation, and access to firearms (US Department of Health and Human Services, Health

Resources and Services Administration, 2015). The suicide rate rises to 25 per 100,000 in rural counties of Washington (Washington State Department of Health, 2016b). For comparison, California has a suicide rate of 10.8 overall, but the rate increases to 19 per 100,000 in rural counties (United Health Foundation, 2015). Across the United States, evidence indicates there is increased suicide in rural areas compared to urban locations, and firearms are a major cause of these deaths (Miller, Azrael, & Barber, 2012). Since deaths from DWD medications are not considered suicide, they are not included in the any of the United States suicide reports. Suicide rates, rural population, and access to care resources are some of the differences that may be more context specific but relevant in other areas.

The research question in this study was: What are professionals' experiences with suicide and hastened death with hospice patients in Washington State? It is the aim of this study to examine these issues about suicide and hastened death that includes medical aid in dying from the experiences of the professionals working with patients in Washington State. Understanding how power is related to the results of the study may help to make sense of the extent to which individuals do or do not have power in their lives and deaths and provide information to overcome barriers impacting patient safety and quality of life. The objectives of this study are to determine what experiences of patient deaths are considered to be suicide, how medical aid in dying might impact experiences of suicide in home hospice care and understand how professionals discern between patients at risk of suicide from those utilising the DWDA.

Palliative care requires that the clinician listens to patient concerns, and that they work collaboratively with the patient and interdisciplinary team members to provide relief from suffering. Yet hospice professionals' ability to respond to what is important to the patient may depend on several factors including personal, organisational, and cultural issues, particularly in the home setting, which may differ from a clinical environment. A professional's ability to provide assessment may be limited depending on their clinical training, where they work, use of terminology, experience, and personal and cultural views. The knowledge gained from this research will help to inform private organisations' policies to address concerns about hastened death and the impact of medical aid in dying laws on professional experiences with patients dying by suicide

CHAPTER THREE

Literature review: Professionals' experiences of suicide and hastened death with hospice patients where medical aid in dying is allowed

The purpose of this literature review was to provide a comprehensive understanding of professionals' experiences with hospice patients who die by suicide or hasten their death in areas where medical aid in dying is legally allowed. To date, no published review could be found that identified studies concerning both unassisted and assisted suicide among hospice or palliative care patients where there is legal medical aid in dying.

This review follows what Dixon-Woods, et al (2005) suggest largely as an interpretive approach to include both qualitative and quantitative evidence to gain a comprehensive understanding of the literature examining professionals' experiences of suicide in a hospice or palliative care context. The aim of an interpretive approach is conceptual development summarising the findings rather than specifically an integration of clearly defined data (Dixon-Woods et al., 2005). The guiding epistemology of this research is inductive, seeking to explore experiences identified as suicide and language used when describing experiences about assisted suicide, euthanasia, or hastened death used by the authors of the studies.

3.1 Method

This review is approached systematically and in a rigorous manner containing six essential elements identified by Popay et al, (2006): identifying the review focus,

specifying the review questions, identifying studies to include, data extraction and quality appraisal, synthesis, and dissemination. The analysis is primarily an inductive approach, meaning there is not a "complete set of a priori themes" but reflects the "main ideas and conclusions across the studies" (Popay et al., 2006 p 18). Thematic analysis is used because of the flexibility integrating diverse forms of evidence to gain a comprehensive understanding of the topic in a single review (Boland et al., 2014; Hawker, Payne, Kerr, Hardey, & Powell, 2002; Popay et al., 2006).

The results follow Popay et al's (2006) recommended guidelines for a narrative synthesis: preliminary analysis, exploration of relationships, and assessing the robustness of the synthesis (Popay et al., 2006). Popay et al (2006) suggests narrative synthesis is a way of telling the story of research evidence that is also flexible when combining studies from diverse methodologies.

3.2 Review focus

In this chapter, the term 'medical aid in dying' will include both euthanasia, where a medical professional administers a lethal dose of medication to an individual who requests it, and physician assisted suicide or assisted suicide, where an individual self-administers a prescribed lethal dose of medication.

As previously discussed in the introduction, medical aid in dying is a general name applying to various laws or court rulings currently in effect in several countries around the world including Belgium, Canada, Columbia, Luxembourg, Netherlands, Switzerland, and areas of the United States, including California, Colorado, Montana,

Oregon, Vermont, Washington, and the District of Columbia (D.C). A list of terms used in literature is included in Appendix 1.

Many patients requesting to utilise medical aid in dying are enrolled in hospice or palliative care programmes and professionals working with them are affiliated with health care institutions (Campbell & Black, 2014; Campbell & Cox, 2012; Hesselink et al., 2010). The scope of literature reviews that gather evidence of professionals' understanding of hastened death and their response to these concerns predominantly include countries and communities where there are no laws regulating medical aid in dying, including assisted suicide or euthanasia (Drum, White, Taitano, & Horner-Johnson, 2010; Hendry et al., 2013; Hudson et al., 2006; Monforte-Royo et al., 2011; Tomlinson & Stott, 2014). This review will gather the evidence of professionals' experiences to understand specific challenges professionals face serving patients around issues of suicide and hastened death in areas that allow medical aid in dying.

Much of the research evidence is about professionals' attitudes about assisted suicide or euthanasia and does not include information about professional experiences of unassisted suicide or hastened death (Brauer, Bolliger, & Strub, 2015; Broeckaert, Gielen, Van Lersel, & Van den Branden, 2009; Emanuel et al., 2016; Bilsen, Mortier, & Deliens, 2009; Sercu et al., 2012).

Some literature on professionals' experiences with patients around issues of suicide and hastened death include guidelines for professionals' conversations but it is

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unclear how or if these guidelines would apply in the same way where medical aid in dying is allowed (Hudson et al., 2006; Kleespies, Hough, & Romeo, 2009; Kolva, Rosenfeld, Brescia, & Comfort, 2014; Olden, Pessin, Lictenthal, & Breitbart, 2009; Rosenfeld et al., 2014; Schroepfer, Linder, & Miller, 2011; Weinberger, Sreenivasan, & Garrick, 2014). In addition, evidence of professionals' experiences with patients in hospice care who died by unassisted suicide is sparse and limited to areas where there is no legal medical aid in dying (Fairman et al., 2014; Filiberti et al., 2001; Grzybowska & Finlay, 1997; Warren & Zinn, 2010).

This review includes studies on the impact of medical aid in dying on issues of hastened death and suicide from the experiences of palliative care and hospice professionals in jurisdictions that allow medical aid in dying. Studies from areas where there is a court ruling, such as the state of Montana in the United States, or Switzerland where there is an article in the penal code that allows assisted suicide are also included. Implementation of the laws, regulation, provision of hospice care, language, and complex cultural differences vary around the world and will be considered (Burkhardt, La Harpe, Harding, & Sobel, 2006).

This literature review establishes the need for further research on issues of suicide in hospice care and contributes to my PhD thesis investigating professionals' experiences with patients about suicide and hastened death in Washington State.

3.3 Review question and literature search

The review question that I aim to answer is: What are hospice professionals' experiences of suicide and hastened death with patients in areas where medical aid in dying is allowed? To search literature answering this question I searched five electronic databases from inception to June 2017 using a strategy developed for PubMED and adapted for other databases including Academic Search Complete, AMED, CINAHL, and PsycINFO.   I searched PubMED using keywords in four groupings. The first grouping focused on terms associated with suicide or assisted suicide and included *"suicide," "assisted suicide," "assisted dying," "aid in dying*," *"death with dignity*" and *"active euthanasia"*. The second grouping included terms associated with hospice and included *"hospice care," "hospices," "hospice and palliative nursing," "palliative care"* and *"palliative medicine".* The third group specified terms about professional groups and included *"professional," "clinician" "physician", "nurse", "social worker",* and *"chaplain".* Finally, the fourth group included the terms *"experiences", "views", "attitudes", "feelings",* and *"opinions"* in the title or abstract of each citation.   I filtered out and refined my search using Medical Subject Headings (MeSH) and adapted and expanded some terms to apply to each of the databases.   I also examined reference lists of relevant studies and identified them using Google Scholar. These additional references are identified as 'citation pearls' (Booth, 2016). Appendix 2 identifies details of the searches from each of the databases and numbers of titles and abstracts reviewed. Table 3.1 below includes the identified search terms and groups used initially in PubMED and adapted for other databases:

Table 3.1. PubMED search terms

Subject Group	Search Terms Used
Suicide	"suicide"[MeSH Terms] OR "suicide, assisted"[MeSH Terms] OR "suicide, attempted"[MeSH Terms] OR "euthanasia, active, voluntary"[MeSH Terms] OR
	"assisted suicide"[Title/Abstract] OR "assisted dying"[Title/Abstract] OR "aid in dying"[Title/Abstract] OR "death with dignity"[Title/Abstract] AND
Hospice or palliative care	"hospice care"[MeSH Terms] OR "hospices"[MeSH Terms] OR "hospice and palliative care nursing"[MeSH Terms] OR "palliative care"[MeSH Terms] OR "palliative medicine"[MeSH Terms] OR "terminal care"[MeSH Terms] OR
	"end of life"[Title/Abstract] OR hospice*[Title/Abstract] AND
Professionals	"health personnel"[MeSH Terms]OR "attitude of health personnel"[MeSH Terms] OR
	professional*[Title/Abstract] OR clinician*[Title/Abstract] OR physician*[Title/Abstract] OR nurse*[Title/Abstract] OR social worker*[Title/Abstract] OR chaplain*[Title/Abstract]AND
Experience	experience*[Title/Abstract] OR view*[Title/Abstract] OR feel*[Title/Abstract] OR opinion*[Title/Abstract] OR attitude*[Title/Abstract]

Citations that did not meet inclusion criteria were grouped into categories within Endnote, a software tool managing bibliographies. Full-text articles of 46 studies were reviewed before selecting studies for quality. Some studies not meeting inclusion criteria were about patients, attitudes, involvement, and opinion pieces were completed before medical aid in dying options were authorised or from locations where it was not clear if they included professional experiences impacted by medical aid in dying. One study was excluded because it was a description of the implementation of a Death with Dignity (DWD) program in Washington State but not about professional experiences (Loggers et al., 2013). Other studies were excluded because the data were collected prior to implementation of laws (Craig et al., 2007; de Casterlé et al., 2006; Fenn & Ganzini, 1999a, 1999b; Karesa & McBride, 2016;

Wright et al., 2017), or the research primarily investigated attitudes and not experiences (Brauer et al., 2015; De Hert et al., 2015; Smets et al., 2011).

No data or evidence could be found on the impact of the legal ruling of Montana, Luxembourg, or from the country of Colombia. In addition, as of June 2017 no completed or published research could be located from Canada, where Medical Assistance in Dying (MAiD) was implemented in 2016, or the states of California, Vermont, and Colorado, where laws were implemented between 2015 and 2017.

The initial search strategy was found to miss a few important papers that for instance, Dixon-Woods, et al (2005) suggest might not fit a conventional systematic approach. I checked reference lists and tracked citations, looking at how many times a reference was cited, and I then searched those references, identifying an additional 29 citations described previously as 'citation pearls'. Duplicates were deleted and abstracts then screened against the inclusion criteria before considering study quality. An adapted version of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart in Figure 3.1 summarises the final search results:

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┌─────────────────┐        ┌──────────────────────────────────────┐
│                 │        │         PUBMed n=842                 │
│                 │        │         AMED n=236                   │
│ Identification  │        │  Academic Search Complete n= 346     │
│                 │        │         CINAHL n=382                 │
│                 │        │         PsychINFO n = 313            │
│                 │        │         Total: 2119                  │
└─────────────────┘        └──────────────────────────────────────┘
                                           │
                                           ▼
┌─────────────────┐        ┌──────────────────────┐   ┌──────────────────────┐
│                 │        │ Records after         │   │   Google Scholar     │
│                 │        │ duplicates deleted    │   │  (citation pearls)   │
│   Screening     │        │ n = 1540              │   │       N=29           │
│                 │        └──────────────────────┘   └──────────────────────┘
│                 │                   │                           ↙
└─────────────────┘                   ▼
                           ┌──────────────────────┐   ┌──────────────────────────┐
                           │ Records after         │   │   Articles excluded      │
                           │ screening citations   │   │  About patients: 23      │
                           │ for inclusion and     │   │  Before laws: 16         │
                           │ exclusion criteria    │   │ From areas without laws: │
                           │ n = 130               │   │          28              │
                           └──────────────────────┘   │  About attitude: 5       │
┌─────────────────┐                   │               │  Public perspective: 5   │
│                 │                   ▼               │ Not about professionals: 7│
│  Eligibility    │        ┌──────────────────────┐   └──────────────────────────┘
│                 │        │ Records after         │
│                 │        │ obtaining full text   │   ┌──────────────────────────┐
└─────────────────┘        │ articles and          │   │   Articles excluded      │
                           │ eligibility assessed  │   │ Data collected before    │
                           │ N = 46                │   │ laws implemented: 5      │
                           └──────────────────────┘   │ About attitude,          │
┌─────────────────┐                   │               │ perspective, or stance:  │
│                 │                   ▼               │          12              │
│   Included      │        ┌──────────────────────┐   └──────────────────────────┘
│                 │        │ Articles meeting      │
│                 │        │ inclusion criteria    │
│                 │        │ Qualitative n = 17    │
└─────────────────┘        │ Survey n = 12         │
                           │ N= 29                 │
                           └──────────────────────┘
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Figure 3.1. Literature search process: Modified PRISMA chart

(adapted from Moher et al. (2009)

3.4 Deciding what is relevant

A table of inclusion and exclusion criteria recommended for systematic reviews was developed to decide what is relevant to include in this review. Table 3.2 follows the recommendation that the review question has clearly defined terms regarding population, intervention, comparators, outcomes, and study design (PICOS) (University of York, NHS Centre for Reviews & Dissemination, 2009):

Table 3.2 Inclusion and exclusion criteria

	Inclusion	**Exclusion**
Population	Professionals in a palliative care and hospice context: nurses, physicians, social workers, chaplains working in locations where medical aid in dying is allowed	Patients, public, other carers. Locations where medical aid in dying, including euthanasia and assisted suicide is not allowed
Intervention	Hastened Death, Euthanasia, Suicide, Assisted Suicide, Physician Assisted Suicide	
Outcomes	Professionals' experiences with patients who died by suicide, self-administered medications prescribed by medical professional, or administered medications by another with intent to hasten death	Research that does not include information about direct experiences: involvement, attitudes, communication
Study design	Any research method/design	Opinion pieces; editorials
Reporting (language/time period)	English Data obtained from reports from inception to present	Studies conducted prior to implementation of the medical aid-in-dying laws, code, or ruling of each country or state

Included professionals have worked in a palliative care or hospice context with patients who intentionally hastened their death, died by suicide, or hastened their death by self-administered medications prescribed by a physician or nurse practitioner or through medically administered euthanasia. As stated in the previous Introduction chapter, hastened death is broadly defined as a death that is anticipated due to an advanced illness but intentionally accelerated with or without the assistance of a healthcare professional.

Only studies completed in areas where medical aid in dying is allowed were included. Regulations around the world vary and literature suggests characteristics of persons who have died from medical aid in dying are different in each country (Steck et al., 2013). For example, a person in the Netherlands, Belgium, Luxemburg, or Switzerland does not have to be diagnosed with a life-threatening illness to pursue assistance with dying (Emanuel et al., 2016; Kouwenhoven et al., 2013). Yet medical aid in dying in the United States requires a person to have a prognosis of six months or less and nearly 90% of patients who utilise it are under hospice care (Campbell & Black, 2014).

Opinion pieces and editorials are excluded from this study. There are many essays and commentaries published in response to proposed or passed legislation or provoked by evidence that does not directly address the research question (Gannon & Garland, 2008; Loewy, 2004; McBride, 2013; Milliken, 2004; Prokopetz & Lehmann, 2012; Saunders & Hughes, 1998). Some studies are excluded because they are not specifically about experiences (Bilsen, Robijn, Chambaere, Cohen, & Deliens, 2014).

Several studies were also excluded because they were conducted prior to implementation of the laws (Asch, 1996; Back et al., 2002; de Casterlé, Verpoort, De Bal, & Gastmans, 2006; Fenn & Ganzini, 1999a, 1999b; Ogden & Young, 2003; Willems, Daniels, van der Wal, van der Maas, & Emanuel, 2000; Wright et al., 2017), or because it was unclear how much of the data in the study represented conditions after the law was passed (Miller, Mesler, & Eggman, 2002). Finally, there are a plethora of opinion pieces in peer-reviewed journals establishing that medical aid in dying is a highly debated issue affecting professionals, but these are clearly not studies about the impact on professional experiences around issues of suicide in hospice or palliative care (Plaisted, 2013; Purvis, 2012; Smith & Pollack, 1998; Tucker, 2009; Varelius, 2013).

3.5 Characteristics of studies and quality appraisal

A total of 29 studies were included in this review. Of these studies:

- Five studies are from Belgium, nine from the Netherlands, two from Switzerland, and 13 from the United States

- Only two of the 29 studies include information about experiences of hastened death that is not assisted suicide (self-administered lethal dose of medication) or euthanasia (lethal medication injected by professional); Ganzini et al (2003) investigate the phenomenon of patients who voluntarily refuse food and fluids, and Anquinet et al (2013) compare euthanasia with continuous deep sedation

- Two studies are part of a larger survey in Europe (Van Bruchem-van de Scheur et al., 2008; Van Bruchem-van de Scheur, Van Der Arend, Spreeuwenberg, H. Huijer Abu-Saad, & Ter Meulen, 2007)

- Four papers are reported from one survey of physicians in the United States (Dobscha et al., 2004; Ganzini, Dobscha, Heintz, & Press, 2003; Ganzini, Nelson, Lee, et al., 2001; Ganzini et al., 2000)

- Four papers are from the same initial survey of hospice workers from 2001, or a different phase of the same study (Ganzini et al., 2003; Ganzini et al., 2002; Harvath et al., 2006; Miller et al., 2004)

The professionals in the included studies were primarily limited to physicians and nurses, with four studies from the United States that included social workers and one survey of chaplains (Carlson et al., 2005; Ganzini et al., 2002; Harvath et al., 2006; Miller et al., 2004; Norton & Miller, 2012). Categories of professionals studied in each country are displayed in Table 3.3:

Table 3.3. Professionals included in the study

Professionals studied:	Belgium	Netherlands	Switzerland	United States
Chaplains				Carlson et al. (2005)
Nurses only	Dierckx De Casterlé et al. (2010), Inghelbrecht et al. (2010)	Francke et al. (2016); Van Bruchem-van de Scheur et al. (2008); Van Bruchem-van de Scheur et al. (2007)		Clymin et al. (2012); Ganzini et al. (2003)
Social workers only				Norton & Miller (2012)
Physicians	Anquinet et al. (2013); J. Cohen et al. (2012); Meeussen et al. (2011)	Dees et al. (2012); Georges et al. (2008); Norwood (2007); Pasman et al. (2013); Snijdewind et al. (2014); van Marwijk et al. (2007)	Otte et al. (2016); Gamondi et al. (2017)	Chin et al. (1999); Dobscha et al. (2004); Ganzini et al. (2003); Ganzini et al. (2001); Ganzini et al. (2000); Voorhees et al. (2014)
Nurses and social workers				Ganzini et al. (2002); Harvath et al. (2006); Miller et al. (2004)
Number of studies	5	9	2	13

This review used an appraisal scale suggested by Hawker, et al (2002), that recognises the complexity of quality assessment from diverse research designs. However, critical appraisal tools are subjective, "based on the appraiser's concept of research quality" (Crowe, M. and Sheppard, L. p.87). The appraisal tool chosen for this review is utilised because the questions can be used as a guideline to assess the

strength of each study relevant to the research question. See Appendix 3 for the version of Hawker, et al (2002) question and rating system. A study is given a score between 9 and 36 based on a series of questions. Scores, study results, and comments are included in Appendix 4 (Hawker et al., 2002). All studies received a score of 20 or above and were included in this review.

Characteristics of each published paper included in this review are identified and listed by research location in Table 3.4**:**

Table 3.4. Characteristics of included studies

Reference	Participants	Study Methods	Data Year	Research Focus	Setting	Terminology Used in Study
Belgium						
Anquinet, L., et al (2013)	Two groups of physicians (n = 8) and two groups of nurses (n = 13)	Qualitative focus groups	2010	Similarities and differences between the practice of continuous sedation until death and the practice of euthanasia.	Homecare and hospital setting- palliative care unit support team	Physician Assisted Death; Euthanasia
Cohen, J., et al (2012)	Physicians 480- Flanders; 305- Wallonia	Postal survey	2008 and 2009	Cultural differences between Walloon and Flemish physicians affecting euthanasia practice	Unspecified	Euthanasia
Dierckx De Casterlé, et al (2010)	18 nurses	Qualitative in-depth interviews	2005-2006	Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium	Included palliative care units	Euthanasia
Inghelbrecht, E., et al (2010)	1678 nurses	Second phase of two-phase postal survey	2007-2008	Nurses involvement inconsistent in decisions about euthanasia or drugs to end a patients' life, and nurses administer life-ending drugs even though it is not regulated	Homecare, care homes, hospital	Euthanasia by patients' request; Administration of life ending medications without patients' explicit request

Meeussen, K., et al (2011)	205 GPs	Structured phone survey	2005-2006	Investigated how many patients expressed a wish for euthanasia, documentation of these requests, experiences with these requests, and how it was handled	Focused on patients who died at home	Euthanasia
Netherlands						
Dees, M. K., et al (2013)	32 cases, 31 relatives, 28 physicians	Qualitative interviews	2008-2009	Explores decision-making process in cases where patients request euthanasia	Homes or physicians' offices	Euthanasia
Georges, J. J., et al (2008)	30 GPs	Qualitative in-depth interviews	2002-2003	Describes experiences of general practitioners (GPs) in Netherlands dealing with a request for euthanasia from a terminally ill patient.	Unspecified	Euthanasia
Francke, A. L., et al (2016)	587 respondents (65%) Nurses and CNAs	Postal survey	2011	To give insight into Dutch nursing staff's attitudes and involvement regarding euthanasia	Unspecified	Euthanasia

Norwood, F. (2007)	10 physicians included in study	Ethnographic study: Foucauldian discourse	2001	Euthanasia, general practice, and end-of-life discourse in the Netherlands	Home	Euthanasia
Pasman, H. R., et al (2013)	11 physicians and 9 patients, 3 relatives	Qualitative Interviews	2005-2007	What happens after request for euthanasia is refused	Unspecified	Euthanasia or Physician Assisted Suicide (EAS)
Snijdewind, M. C., et al (2014)	28 physicians 26 relatives	Qualitative in-depth interviews	November 2011-April 2012	According to the physicians and relatives, what are the characteristics of the complexities that can arise from the moment someone requests EAS?	Unspecified	Physician Assisted Suicide; Euthanasia
Van Bruchem-van de Scheur, G., et al (2007)	500 district nurses-86% response rate. 81.6% (408) used for analysis	Postal survey	2003	Euthanasia and physician assisted suicide in the Dutch home care sector: the role of the district nurse	55 home care organisations	Physician Assisted Suicide; Euthanasia
Van Bruchem-van de Scheur, G.,et al (2008)	1509 nurses; 1179 responses analysed (78.1%)	Telephone survey	2003	The role of nurses in euthanasia and physician-assisted suicide in the Netherlands	Hospital, nursing homes and home care	Physician Assisted Suicide; Euthanasia

Van Marwijk, H., et al (2007)	22 physicians	Qualitative, four focus groups	2003	Impact of euthanasia on primary care physicians in the Netherlands	Primary care	Euthanasia; Assisted Suicide
Switzerland						
Otte, I. C., et al (2016)	23 General Practitioners (GPs)	Qualitative interviews	2012-2013	Barriers to professional communication about Physician Assisted Suicide	Unspecified	Physician Assisted Suicide
Gamondi, C., et al (2017)	23 palliative care physicians	Qualitative study	2015	Physician responses to assisted suicide requests	Unspecified	Assisted Suicide
United States						
Carlson, B, et al 2005	50 out of 77 hospice chaplains (65% response)	Postal survey	2003	Attitudes and experiences of hospice chaplains with patients requesting physician assisted suicide	Hospice home care	Physician-Assisted Suicide (PAS); Oregon Death with Dignity Act (ODDA)
Chin, et al 1999	14 physicians	Qualitative interviews	Report of 1998 data	First year's experience with legalised assisted suicide in Oregon	Unspecified	Physician-Assisted Suicide
Clymin, J., et al 2012	582 out of 7500 nurses	Qualitative component of email survey	2010	Nurses knowledge of the Death with Dignity Act	Unspecified	DWDA Physician Assisted Death (PAD)
Dobscha, SK, et al 2004	35 physicians	Qualitative semi-structured interviews	2000	Physicians responses to requests for assisted suicide	Unspecified	DWDA ; Assisted Suicide

Ganzini, L., et al 2003	35 physicians	Qualitative in-depth interviews	2000	Oregon physicians' perceptions of patients who request assisted suicide	Unspecified	Assisted Suicide
Ganzini, L., et al 2000	2649 of 4053 physicians (65% response)	Postal survey	1999	Physicians' experiences with the Oregon Death with Dignity Act	Unspecified	Oregon Death with Dignity Act
Ganzini, L., et al 2001	2641 physicians (65% response)	Postal survey	1999	Physicians' attitudes/experiences with end-of-life care since passage of the Oregon Death with Dignity Act	Unspecified	DWDA
Ganzini, L., et al 2002	307 nurses and social workers of 545 (72-78% response)	Postal survey	2001	Experiences of nurses and social workers with hospice patients who requested suicide assistance	Hospice home care	Assisted Suicide
Ganzini, L., et al 2003	307 nurses of 429 (72% response)	Postal survey	2001	Nurses' experiences with hospice patients who refuse food and fluids to hasten death	Hospice home care	Voluntary Refusal of Food and Fluids (VRFF) Physician Assisted Suicide (PAS)
Harvath, et al 2006	20 nurses and social workers	Qualitative interviews	Not clearly stated	Dilemmas encountered by hospice workers when patients wish to hasten death	Hospice home care	Physician Assisted Suicide; Hastened Death

Miller, L. et al 2004	306 nurses and 85 social workers (72-78% response)	Postal survey	2001	Attitudes/experiences of Oregon hospice nurses and social workers regarding assisted suicide	Hospice home care	Assisted Suicide; Oregon Death with Dignity Act (ODDA)
Norton, E. M. & Miller, P. J. 2012	9 social workers	Focus group	Since passing of the law	Social workers discuss DWDA	Hospice home care	DWDA
International (Netherlands and Oregon)						
Voorhees, J. R., et al (2014)	36 physicians	Qualitative semi-structured interviews	2007-2008	Physicians' experiences in the United States and the Netherlands	No	Physician-Assisted Dying (PAD)

3.6 Data analysis—themes

How does the literature suggest medical aid in dying affects professional experiences of issues of suicide and hastened death with hospice patients? The focus of this review is to interrogate the literature of included studies with the aim of identifying and evaluating relevant themes from diverse methodologies (Dixon-Woods et al., 2005). Nvivo, a qualitative software package, and hand coding were used to code results and discussion sections of each article and to search for key words. Each article was reviewed several times to identify codes from which three primary themes emerge. Themes include:

- Physician-assisted suicide is synonymous with the concept of suicide: studies were coded by terminology used in the research

- Professionals have a range of experiences, knowledge, and approaches when it comes to issues of hastened death and suicide: experiences were coded and categorised by type

- Implications of medical aid-in-dying laws require improved interdisciplinary communication in end-of-life care: study conclusions were coded, categorised, and summarised

3.6.1 Suicide is synonymous with physician-assisted suicide or assisted suicide

The terms 'suicide' and 'physician-assisted suicide' are synonymous in the included studies. There is almost no literature about suicide in hospice and palliative care services in areas that allow medical aid in dying. It is unclear from these articles how the terminology of the death by a purposeful overdose of un-prescribed medications would be distinguished from the death of a patient from Voluntary Refusal of Food or Fluids (VRFF) or medical aid in dying. What is termed physician assisted suicide

(PAS), might also be called Physician Aid in Dying or Physician Assisted Death (PAD), or only 'assisted suicide' in some studies. Chin, et al acknowledge that the Oregon law does not "constitute suicide" yet states, "we use the term 'physician assisted suicide' rather than 'death with dignity' to describe the provisions of this law" (Chin et al., 1999, p. 578). Only one study from The Netherlands identified patients who died by unassisted suicide, attempted an unsuccessful overdose of medications, or deliberately stopped eating and drinking when their request for euthanasia was refused (Pasman, Willems, & Onwuteaka-Philipsen, 2013). In Switzerland, the word 'physician' is removed from the term 'assisted suicide' because physicians can only be present as a private citizen at the time the patient ingests lethal medications (Gamondi et al., 2017)

Most of the included studies from the United States use the word 'suicide' in the title or in the content of their research. Several authors often use only the unqualified term 'suicide' when discussing physician-assisted suicide. Carlson et al, suggest that patients die by suicide when pursuing DWD when discussing how hospice policies may "prohibit employees from assisting the patient in obtaining the prescription or attending a suicide" (Carlson et al., 2005, p. 1164). Most authors suggest patients who request lethal medications from their physicians end their own life through suicide (Clymin, Jablonski, Jacobson, & Feldt, 2012; Dobscha et al., 2004; Ganzini et al., 2000).

Most authors acknowledge terminology variation but do not explain their choice of terms around this topic. Some authors refer to 'aid in dying,' 'legalised physician

assisted suicide,' 'PAS,' 'assisted suicide,' or the 'Oregon Death with Dignity Act' (Ganzini et al., 2000; Otte, Jung, Elger, & Bally, 2016; Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2014; Van Bruchem-van de Scheur et al., 2008; Van Bruchem-van de Scheur et al., 2007). Other authors choose 'physician-assisted death' or 'physician–assisted dying' as a capture term to include both euthanasia and assisted suicide instead of the terms 'physician-assisted suicide' or 'assisted suicide' (Voorhees et al., 2014). Suicide implies that a person has an intention for self-harm resulting in death; however, research suggests that the definition of suicide depends on who is doing the research and how the research is completed (Westefeld et al., 2000). Gamondi, et al (2017) acknowledge that there is controversy over the terminology and use 'assisted dying' as a neutral term to describe both euthanasia and assisted suicide. Whether the pursuit of medical aid in dying is considered suicide is debatable and may depend on culture or understanding of the law.

In addition, Voluntary Refusal of Food and Fluids (VRFF), also known as Voluntary Stopping of Eating and Drinking (VSED), and continuous deep sedation are sometimes characterised as hastened death and as alternatives to medical aid in dying (Anquinet et al., 2013; Ganzini et al., 2003). There is a variation of experiences and whether they are considered acceptable. Ganzini et al's, study of nurses and social workers suggest that VRFF is "... different from suicide" and as an "option when patients request physician-assisted suicide" (Ganzini et al., 2003, pp. 360, 364). A study of social workers in the United States and a study with physicians from The Netherlands were the only ones to identify 'suicide' as separate from other forms of

hastened death, suggesting suicide occurs separately from medical aid in dying and VSFF (Norton & Miller, 2012; Pasman et al., 2013).

Finally, the studies from The Netherlands and Belgium indicate that experiences with patients dying from euthanasia are much more frequent than with physician assisted suicide (Cohen et al., 2012; Dierckx De Casterlé et al., 2010; Meeussen et al., 2011; Snijdewind et al., 2014; Van Bruchem-van de Scheur et al., 2007; van Marwijk et al., 2007).

3.6.2 Professionals' range of experiences and approaches

The terms 'mentally competent' or 'mentally capable' are frequently used to determine whether a patient is eligible to get lethal medications from a physician. The literature suggests, however, that different professionals might discern and address these issues in diverse ways depending on the policy of their employer, institutional and personal interpretation of suicide, and sense of responsibility for the patient (Clymin, et al., 2012).

The studies of physicians included in this review describe a range of emotions and experiences about responding to requests for medications to end patients' lives. These emotions range from feelings of fear, frustration, and isolation to feelings that their experience improved their relationship with patients, and increased quality of life and comfort when writing prescriptions or administering lethal medications (Chin et al., 1999; Ganzini, Nelson, Lee, et al., 2001; Otte et al., 2016; van Marwijk et al., 2007; Voorhees et al., 2014). Some literature about physicians' experiences associates the words 'suicide' or 'suicidal with anxiety and fear' as the physician

struggles to assess the risk and needs of their patients (Dobscha et al., 2004; Ganzini, Dobscha, et al., 2003). The span of emotions demonstrated by these studies suggest an increased sense of responsibility for patients compared to other professionals, which may be attributed to the power they possess to prescribe lethal medications to control timing of death, and from the physicians' concerns about being able to provide comfort until death.

A study by and about social workers explicitly suggests that patients die by suicide frequently "and at any given time there is enough medication in a patient's home to kill them. It is just a matter of are they going to go through our legal processes or our system's processes" (Norton & Miller, 2012, p. 252). Other studies explore the complexity of the social worker role in understanding and identifying when a patient is at risk of suicide and when compared with nurses, indicate that social workers are more accepting of patient choices (Ganzini et al., 2002).

Nurses experience fear and ethical conflict, particularly when questions posed by patients about access to lethal medications conflicted with their own personal or religious beliefs but feel increased acceptance when patients make the decision to VRFF (Ganzini et al., 2003). Harvath et al (2006) suggest that nurses understood patient choice to hasten death by recognising "the patient's desire to control the circumstances of death was a greater factor in a patient's choice of PAS than was symptom management" (p. 204). Several authors indicate that organisational policy presents dilemmas around needing to prevent hastened death, but most speak of the critical need to establish clear guidelines for interdisciplinary team members

(Dierckx De Casterlé et al., 2010; Harvath et al., 2006; Van Bruchem-van de Scheur et al., 2008). The survey of Washington State nurses follows the notion that organisational policy presents dilemmas "of conflict or concern related to their lack of knowledge, strong personal beliefs, and uncertainty about facility or professional policies" (Clymin et al., 2012, p. 145). Overall, most nurses in these studies indicate they would support a patients' choice but did not address nurses' experience with patients who died by suicide other than through legally prescribed medication by a physician or by VRFF.

Inghelbrecht et al, (2010) however, do examine the incidence of nurses administering life-ending medications with and without a patient's explicit request for hastened death, despite nurses' direct administration being unacceptable and unregulated by Belgium's euthanasia law. There is little indication from other studies that nurses participate in euthanasia with or without the patient's consent.

There is only one study about chaplains indicating that whether or not chaplains agree with a patients' decision to hasten death, they support patients' choices. Carlson suggested that chaplain's working with patients interested in pursuing the DWDA did not influence the decision to hasten death (Carlson et al., 2005).

Professionals have a range of experiences that may be attributed to cultural differences, as explained by Cohen et al, in a study from Belgium (Cohen et al., 2012). Cohen et al (2012) write that "the influence" of a law "on a particular society... is affected by the surrounding culture" (p. 852). Understanding cultural differences,

including language, religion, and environment may be a key element to understand and interpret experiences around issues of suicide and assisted suicide.

3.6.3 Impact of medical aid in dying on communication in end-of-life care

A theme that emerges from the literature is the importance of open communication about issues of suicide among professionals and between professionals and those they serve (Dees et al., 2013; Dobscha et al., 2004; Francke, Albers, Bilsen, de Veer, & Onwuteaka-Philipsen, 2016; Norwood, 2007; Otte et al., 2016; Pasman et al., 2013). The included articles suggest that with medical aid in dying there is a tendency to view professionals' conversations with patients as opportunities to discuss what is relevant and important to the patient, thus improving end-of-life care. Studies of physicians assert that passage of the laws is associated with an increased sense of responsibility to provide optimal palliative care and serves as "a gateway to discussion of many important end-of-life issues that deserve attention" (Voorhees et al., 2014, p. 815). Ganzini et al (2001) suggest that since passage of the DWDA in Oregon, physicians have increased referrals and access to hospice care, but relationships may have been altered when a physician does not agree to prescribe lethal medications (Ganzini, Nelson, Schmidt, et al., 2001). A Swiss study of physicians indicates that while few agree to prescribe lethal medications they assume a responsibility to discuss the origin of the patient's request and seek alternatives to assisted suicide (Gamondi, et al 2017).

Studies of other professionals corroborate the research about physicians indicating "the discussion about assisted suicide opens up the box for them to ask all of the other questions they have..." (Harvath et al., 2006, p. 203). Some research, however,

indicates that communication with patients is impaired when there is understanding that organisational policy, professional code, or lack of training restricts professionals from communicating about options for care (Clymin et al., 2012). Several authors discuss the need for more training (Anquinet et al., 2013; Otte et al., 2016; Pasman et al., 2013).

3.8 Summary

As searches reveal, this would appear to be the first literature review of professionals' experiences with hospice patients related to issues of suicide and hastened death. This review finds that the literature suggests professionals' experiences of suicide with hospice or palliative care patients in areas where medical aid in dying is authorised are primarily focused on legalised self-administered lethal medications prescribed by a physician in the United States, euthanasia in Belgium or Netherlands, or assisted suicide in Switzerland. Authors of some studies indicate that experiences about medical aid in dying shift as people learn about the laws and imply that these laws may also improve quality of end-of-life care (Ganzini et al., 2002; Norwood, 2007). Identified authors of studies included in this review used diverse terminology, including the phrase 'physician-assisted suicide,' or 'assisted suicide', with minimal discussion justifying their use of terms. Overall, there is little clarity on the question of whether medical aid in dying is deemed suicide or understanding about patients who hasten their own deaths and die by suicide. Finally, the recommendations of the included studies suggest further research is needed as more jurisdictions and nations take steps to legalise medical aid in dying. These recommendations include the need to explore organisational policy affecting

professionals' ability to provide information to patients, differences between medical aid in dying, VRFF, or continuous deep sedation, and the need to increase information to provide guidance for healthcare professionals working with patients who report a desire to hasten death (Clymin et al., 2012; Dierckx De Casterlé et al., 2010; Gamondi et al., 2017; Harvath et al., 2006; Pasman et al., 2013). The review findings show that there is great variance in nomenclature and definitions that require careful analysis and are important in identifying professionals' work with individuals facing fear, pain, and suffering at end of life. The broader review of literature indicates widespread international engagement with these issues. These questions truly have global implications.

Overall, this review demonstrates that significant gaps remain in the literature on the effects of medical aid in dying on understanding of suicide issues in hospice care. Most of the surveys and qualitative studies in the United States, in particular, were completed over ten years ago, are limited to Oregon State, and limited to the topic of medical aid in dying. The literature, overall, does not address what happens to patients who are unable to or do not pursue medical aid in dying but die by suicide or hasten their death in other ways. Significant gaps remain to be explored on the scope and impact of organisational restrictions on professionals' ability to have open conversations with patients who consider pursuing medical aid in dying. In addition, there is little understanding or evidence of cultural issues related to suicide, or professionals' experiences with patients' that hasten their deaths due to limited access to information about options, including palliative and hospice care. It remains

uncertain if the implementation of medical aid in dying has shifted professionals' experiences of suicide with patients.

Understanding professionals' experiences with and interpretation of suicide can contribute to improving communication and assessment with patients around issues of hastened death and provide needed guidance. Improved communication among hospice team members about issues of suicide can help to open up and alleviate fear over what has been considered by many to be a taboo topic. If open discussion about death was, and may be still, considered taboo, then suicide is likely to trigger even deeper anxiety and fear within that taboo of death. If hospice and palliative care is indeed patient-centred, then opportunity for open conversation about whatever is important to the patient must be available. The implementation of the medical aid in dying laws has created a new dynamic in the culture of hospice. This critical review helps to place these changes and experiences in the larger context of healthcare, politics, professional ethics and standards, and human rights. The review confirms the need for research to inform or influence private organisation's policies and improve suicide assessment and training for hospice professionals.

CHAPTER FOUR

Methodology and Methods

4.1 Chapter overview

This chapter explains my rationale for adopting a qualitative research design for the study, my data analysis method, and my data collection strategy. I begin with a discussion about the theoretical position of the study and then discuss the methodological framework. Next, I describe the methods used for recruitment and the sampling process, give an overview of participants' backgrounds, and describe the data collection interviewing process. Thirdly, I provide an account of the method of analysis and explain how rigour is applied in the research. Finally, I include a description of several ethical issues, including informed consent, safety concerns, and a plan for research dissemination.

4.2 Epistemology and ontology

To understand the philosophical underpinnings of this study, it is important to first explain the ontological and epistemological positions, described respectively as the theory of the nature of being and the theory of the nature of knowledge (Braun & Clarke, 2013). Ontology is concerned with whether reality exists outside of individual beliefs, only through the material world, or where there are multiple views, perspectives, and meanings that are socially constructed (Creswell, 2013; Ritchie & Lewis, 2012). Braun and Clarke (2013) identify ontological positions on a continuum from relativism described as "reality that is dependent on the ways we come to know it" on one side to realism on the other side described as reality that is "entirely

independent of human ways of knowing about it" (p. 26-27). Critical realism lies between relativism and realism, indicating "reality exists but we can only partially know it" (Braun & Clarke, 2013 p. 26).   This study views reality as dependent on many variables and interpretation thus adopts the position of relativism.

Epistemology is concerned with knowledge and how it is attained (Creswell, 2013). Snape and Spencer (2003) recognise that the researcher is not completely independent of the research and can never fully have a neutral stance. Therefore, it is important to reflect on how my own experiences and beliefs might shape or influence the research. The epistemological assumption here is that what counts as truth is created by the process of the research (Braun & Clarke, 2013). I adopt a constructionist epistemology that suggests that reality is constructed by and between the individuals who are experiencing it (Burr, 2015). This is explained further in the next section.

4.3 Methodology

Methodology is the plan behind the chosen method of study and method is the technique or process employed to collect and analyse data (Guba & Lincoln, 1994). To find a method suitable for this research study, I considered alternative ways through which to investigate the topic that included both positivist and interpretive frameworks. A positivist approach uses quantitative methods to test hypotheses that are quantifiable and measureable (Bowling & Ebrahim, 2005), while interpretive frameworks use qualitative methods to collect and analyse data but believe "in multiple perspectives rather than a single reality" (Creswell, 2013, p. 24). An

interpretivist approach seeks to understand the meaning of the experience from the participants' perspective and recognises that what may be true for one individual may not be true for another (Bryman, 2012). Silverman suggests qualitative research provides more depth into understanding social phenomena (Silverman, 2013). In a sensitive area such as medical aid in dying, a qualitative, interpretivist approach is indicated to be most suitable since my research question asks about the experiences of professionals, and seeks to gain an understanding of participants' interpretation of suicide and the phenomenon of suicide and hastened death in a hospice context.

I adopted a social constructionist methodological framework to allow what Creswell describes as a "complexity of views" but that also recognises the social and historical meanings developed from individual perspectives informed by interaction with others (Bowling & Ebrahim, 2005; Creswell, 2013, p. 24). I recognise Gergen's interpretation of social constructionism, which places the origin of knowledge in the social processes (Gergen, 2015). Those who adopt the social constructionist position suggest that the individual's personality is developed from socially constructed ideas, and that context, culture, and communication contribute to the many ways of envisioning reality (Burr, 2015; Gergen, 2015; Raskin, 2002). Gergen states, "constructionism champions relationship" (Gergen, 2015, p. 30). Adopting a social constructionist theoretical position, I am exploring those socially constructed ideas about suicide and assisted dying and how context, culture, and language might influence the meaning of the participants' experiences. Social constructionism is used as a resource to understand that when individuals are in dialogue with each

other they "have the potential to create new and more promising ways of being" (Gergen, 2015, p. 32).

The research framework includes an inductive approach, meaning that the data direct the theme development (Braun & Clarke, 2013). As a researcher, however, I am also bringing a set of ideas that include those developed from the literature review and from my previous experience as a hospice professional. A social constructionist worldview allows the researcher to use their own experience to "make sense of the meanings others have about the world" (Creswell, 2013, p. 25). In addition, a social constructionist position examines how the language that is being used by participants may have different meanings depending on the context (Burr, 2006). These meanings also include considering how the terms and language used in the interviews are framed. Quantitative inquiry would not allow research into the depth of the experiences or raise new issues not previously considered. I used thematic analysis, described in more detail in section 4.5.

4.4 On reflexivity

Braun and Clarke (2013) advise that it would seem odd to conduct research on the perspective of participants without reporting on my own standpoint as a researcher with a professional background similar to many of those I interviewed (Braun & Clarke, 2013). A qualitative design is an approach consistent with my values and experiences as a social worker in palliative care that requires careful listening to the stories that are told about what is important to the patient. I come from a profession that actively engages in this approach. Reflexivity regarding my own experiences and

interaction with the participants was an important aspect of this research. If I had not been engaged in this work, I would have been unaware of what questions to ask and had many questions about context. I did not need to ask general questions, for example, about criteria for hospice services or team requirements to understand the context because of my knowledge and role as a hospice professional. Entering the research as an academic, I embraced formal academic frameworks giving me an opportunity to gain insight into the meaning of events for the participants while including a reflexive method considered essential in qualitative research (Alvesson & Sköldberg, 2009). Alvesson and Sköldberg suggest that reflexive methodology is both interpretive and reflective, meaning all parts of the research are the "results of interpretation" and that the researcher works to maintain awareness and critical reflection (Alvesson & Sköldberg, 2009, p. 9). Interpretation became a central aspect of the research that recognised the political context and influence on language and meaning. Reflexivity required me to pay attention and distinguish between the story that is mine and the story being told by and in relation to the participants (Gergen & Gergen, 1991).

4.5 Data collection methods

4.5.1 Recruitment

Participants, home hospice professionals in Washington State, were recruited through my professional hospice contacts, referrals, professional organizations, conferences, and meetings. The Washington State Hospice and Palliative Care Organization (WSHPCO) agreed to include a recruitment letter in their newsletter and send an email to their membership list asking those interested to contact me.

The self-selected participants contacted me by email or telephone to receive information about the study and arrange meeting times. A follow-up email was sent within two weeks of the initial contact if there was no response from a participant who had expressed active interest in the research. Appendix 5 includes information included in the newsletter and copies of any emails sent to potential participants. I provided the information sheet (Appendix 6) by email or post depending on the participant's preference. I followed up with the participant by phone (or email if they stated this as a preference), to review the information, answer any questions about the study, confirm willingness to participate, and schedule an interview type, time and location. The participant was reminded that they had the option to decline to participate in the study, to withdraw before or during the interview, or withdraw their data up to two weeks following completion of the interview.

4.5.2 Interviews

In-depth, semi-structured, and open-ended questions via face-to-face or telephone interviews were conducted to create a "portrait" of experiences collected from the viewpoints of different professional perspectives (Rubin & Rubin, 2012, p. 3). Rubin and Rubin suggest qualitative interviewing is optimal when researching sensitive and complex topics (Rubin & Rubin, 2012). An interview and example topic guide are included in Appendix 7. The guide helped to facilitate questions, but interviewing was an iterative process, thus I addressed any new issues raised by participants.

The topic guide in Appendix 7 is an example of topics that could be included in the interview depending on the nature of the stories and experiences that participants shared. Rubin and Rubin (2012) suggest that in the beginning of each interview easier

questions are asked of participants to develop rapport and empathy. I   encouraged

rapport by introducing the research topic, and asking questions about the

participants' background, profession, and length of experience. In addition, as Braun

and Clarke (2013) recommend, the interview guide was not adhered to rigidly to

allow the participant to "discuss issues that are important to them and that the

researcher hasn't anticipated and aren't on the interview guide" (p.78). Silverman

(2013) suggests that in qualitative research, departures from the interview guide

"are not seen as a problem" and "are often encouraged" (p. 204). The interviews

remained focused on the aim of the research, which was to collect stories about

participants' experiences of suicide and hastened death in their work with hospice

patients. From these stories of experiences, questions were asked to help identify or

determine what is considered to be suicide, how the Death with Dignity Act impacts

experiences of suicide, and how suicide risk is determined from patients seeking or

utilising medical aid in dying. Questions contained in the guide were helpful to probe

on a topic that might have been briefly addressed by some participants.

Four areas are included in this interview guide. First, the guide includes questions

about terminology, meaning questions might be asked about what hastened death

or desire for hastened death meant to the participant. I found that most participants

shared stories easily soon after introducing the topic, and the questions about

terminology were addressed as they spoke about specific experiences. Second, the

guide included questions about experiences to elicit stories of patients who died

using the DWDA and patients who died by suicide without assistance. Third, an area

of questions about communication was guided by literature that suggested

organisational policies and might have influenced participants' work with patients (Clymin et al., 2012; Ganzini et al., 2002). This area met the objective of understanding how or if participants' experiences have been influenced by the DWDA. Finally, additional questions were included to meet the objective of understanding how participants discern suicide risk from patients who request or utilise DWDA.

Two face-to-face pilot interviews with hospice professionals were conducted to prepare and develop questions for the study. Face-to-face interviews were encouraged but telephone interviews were also offered as an option to allow participants who feel more comfortable with this or preferred this method due to time and possible geographic constraints. Travel between some areas of Washington State can be challenging due to road and/or weather conditions, also making telephone interviews more achievable. In addition, telephone interviews are increasingly being justified for qualitative research on sensitive subjects (Cachia & Millward, 2011; Grinyer, 2012; Sturges & Hanrahan, 2004). Telephone interviews were 15 to 30 minutes longer than face-to-face visits and the participants verbalised comfort being able to tell both personal and professional stories. There were no notable differences between the quality of data from telephone compared with data from face-to-face interviews.

The interviews were digitally recorded, transcribed verbatim, and analysed solely by me. Questions were asked about participants' personal experiences and professional training, in addition to social, political, and organisational factors related to

conversations and experiences with their patients. Questions were semi-structured and open-ended to explore in more depth hospice professionals' experiences with patients around issues of suicide and hastened death.

Participants were offered the option to contact me for a follow-up telephone or face-to-face interview at their own discretion up to 2 months following their initial interview. The purpose of the follow-up interview was to allow participants to add any additional information about current experiences or respond to questions after more careful consideration. I conducted three brief follow-up interviews with participants who contacted me within the time frame. These follow-up interviews reiterated themes that had emerged, and no new issues were raised from the initial data.

4.5.3 Face-to-face interview setting

The research was conducted with hospice professionals who are employed by formal organisations providing hospice care in home-based settings in Washington State. I offered face-to-face interviews with participants in an agreed upon location where anonymity, confidentiality, and safety could be maintained for all involved. Meetings were scheduled in locations such library meeting rooms that are not isolated but where privacy could be maintained. If a participant did not agree to a meeting room option and preferred to meet in their home, I left a sealed envelope containing the address with a colleague locally who is also skilled in qualitative research and aware of safety policies and procedures regarding home visits. I called my colleague before and after the interview was completed with a contingency plan for her to contact

authorities to assure my safety if she was not contacted within a designated time frame; this contingency was not needed.

4.5.4 Sample

A purposive sample of 21 hospice clinicians were recruited in Washington where the Death with Dignity Act (DWDA) has been implemented since 2009. Purposive sampling is a common method used in qualitative research to identify a sample of individuals who have knowledge about and experience of the research topic (Creswell & Clark, 2007; Ritchie & Lewis, 2012; Silverman, 2013). Purposive sampling is a deliberate approach to ensure populations with specific characteristics and from diverse locations are included in the study (Ritchie & Lewis, 2012). I began this study with a plan to interview up to twenty hospice professionals from different types of organisations, and who worked in rural and urban communities in both eastern and western Washington.

Fusch and Ness (2015) suggest saturation is achieved when "there is enough information to replicate the study and … when further coding is no longer feasible" (p. 1413). I chose a sample that was reflective of the hospice team of professionals and was feasible for coding. I did not seek thematic saturation since there is no way to be certain if new insights would emerge with more interviews (O'Reilly & Parker, 2013). I approached the challenges of data saturation by thinking of quality data as *rich*, and quantity of data as *thick* (Fusch & Ness, 2015). Rich data were collected that I considered intricate and detailed, while thick data provided quantity and repetition of identified themes. The decision to stop sampling was made once I recruited each type of professional that worked in different locations and then

reflected theoretically on the concept of suicide, hastened death, and medical aid in dying. A total of 21 participants were finally included to assure that the sample reflected a diversity of locations and type of professional.

The greater numbers of nurses and social workers who responded to the recruitment announcement is likely a reflection of the disproportional presence of these disciplines providing home hospice services. For example, in one organisation, a participant reported there were only two physicians, but nearly 40 employees from other disciplines. The call for participants resulted in at least ten requests to be interviewed by professionals from other disciplines, or who did not directly provide home hospice services. These requests may be an indication of the importance of the topic of suicide, impact of the DWDA, and interest from professionals of all backgrounds.

Professionals were interviewed from non-profit, for-profit, sectarian, and non-sectarian organisations in diverse geographical locations around Washington State, to reflect the diversity of cultural, environmental, organisational, and professional experiences. Inclusion and exclusion criteria are included in Table 4.1:

Table 4.1. Inclusion/exclusion criteria-participants

Inclusion criteria	Exclusion criteria
• Chaplains/Spiritual care counsellors, physicians, nurses, nurse practitioners, and social workers, and who supervise interdisciplinary home hospice teams and have had experience in providing direct services to hospice patients in home or nursing home setting in Washington State • Chaplains/Spiritual care counsellors, physicians, nurses, nurse practitioners, and social workers who provide direct services that may include assessment for pain and suicide risk for hospice patients in the home or nursing home setting in Washington State • Chaplains/Spiritual care counsellors, physicians, nurses, nurse practitioners, and social workers who are currently employed as home hospice professionals with a minimum of 6 months but preferred two years minimum experience providing or supervising home hospice in Washington State.	• Hospice staff not providing direct supervision of staff or providing direct services that would include assessment of suicide risk and pain management • Non-clinical staff including administrators, schedulers, medical records staff, and others who do not provide direct hospice services to patients in the home or nursing home • Home health aides/bath aides • Hospice volunteers • Hospice staff who have not worked in Washington State • Hospice professionals who are employed by the same local hospice agency as the researcher

Table 4.2 and Table 4.3 contain descriptions of the twenty-one participants

interviewed between March and July 2015. The terms participants used to describe

themselves are the terms included in the following tables.

Table 4.2. Participant demographics

Demographics of the 21 Participants			
Type of Professional	Gender	Age range	Cultural Identity
Chaplains:3 Nurses:7 Physicians:4 Social Workers:7	Female:18 Male:3	Unknown: 1 30-39 years: 2 40-49 years: 5 50-59 years: 11 60-69 years: 2	American Indian:2 Caucasian:18 Unspecified:2

In Table 4.3, participants described more than one cultural identity, or chose not to

identify with a specific culture. Some participants described more than one spiritual

or religious background, or not spiritual at all. Others described their spirituality as

evolving, inclusive, or eclectic. Some described clear religious affiliations. Spiritual

and/or religious influences are listed here without totals because of the many

overlaps and multiple identities. For example, one person described growing up

Catholic, but also influenced by Christianity, Buddhism, and Taoism. Finally, the

primary work location identifies if the participant worked in rural or urban areas

visiting with patients in their homes or nursing home settings.

Table 4.3. Description of participants

Description of the 21 participants		
Spiritual background	Atheist, Baptist, Buddhist, Catholic, Christian, Episcopal, Jewish, nature, not spiritual, pagan, Taoist, unspecified	
Years of experience	3–5 years: 3 6–10 years: 1 10–15 years: 5 16–20 years: 3 21–30 years: 6 30+ years: 3	
Hospice experience	1–2.5 years: 2 3–5 years: 6 6–9 years: 2 10–20 years: 9 20+: 2	13 participants had experience before and after implementation of the DWDA in 2009
Primary work location	Rural:11 Rural/Urban mix: 4 Urban: 6	

Participants were employed by ten hospice organisations located in diverse locations around Washington State. The two tables below describe the different types of organisations where participants were employed, and numbers interviewed in each. I completed these tables to view them in different types of groupings. For example, the preceding Table 4.2 and Table 4.3 describe participants without distinguishing them by type of professional or where they are employed. The following Table 4.4 contains information without disclosing type of professional:

Table 4.4. Organisation type

Type of Organisation			
	# of organisations	# Participants in this type of organisation	Participating in DWDA?
Non-profit, Catholic	2	5	No
Non-profit, not religiously affiliated	6	11	3: Yes (7) 3: No (4)
For-profit, not religiously affiliated	2	5	No
	Total = 10	Total = 21	

Participants were asked about organisational policy regarding the DWDA. Seven participants were employed at three different participating organisations (described above). Four participants were employed at a total of three non-participating organisations. Table 4.5 is a more detailed description of organisation by type, numbers interviewed, and specific professional codes for individual participants:

Table 4.5. Participants interviewed and organisation type

Organisation and Participant information			
Type of Organisation	Organisation Code #	# interviewed	Type of professional with participant code #
Non-profit, Catholic (S)	1 - S	3	MD1, MSW2, RN4
	2 - S	2	MSW3, MSW6
Non-profit, non-sectarian (NS)	3 - NS	2	RN7, CH3
	4 - NS	1	MSW4
	5 - NS	1	MD4
Non-profit, non-sectarian, participating (NSP)	6 - NSP	4	CH1, RN3, RN6, MSW1
	7 - NSP	2	MD3, MSW5
	8 - NSP	1	RN2
For-profit, non-sectarian (FP)	9 - FP	3	MD2, RN5, CH2
	10 - FP	2	RN1, MSW7

Each participant identified themselves as either a physician (MD), social worker (MSW), nurse (RN), or chaplain (CH).

4.6 Analysis Method

I used thematic analysis to interpret significant themes extracted from the data, and to identify and compare individual and professional experiences. Thematic analysis provided a structure to go beyond the extracted themes to not only what was being told but also the social contexts around the issue being discussed. Thematic analysis is used widely in health research as a method that is suited to questions about peoples' experiences focused on developing patterned meanings across the data (Braun & Clarke, 2014). Joffe suggests good thematic analysis alone is a recognisable approach that moves beyond text fragments reflecting "a balanced view of the data, and its meaning within a particular context of thoughts (Joffe, 2012, p. 219)." According to Braun and Clark (2013), thematic analysis is a flexible approach that provides a six-phase process that is not necessarily meant to be rigid or sequential, depends on the theoretical framework, and follows these steps.

1. Familiarisation with the data
2. Coding
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Writing up

Appendix 13 includes an example of how this process was utilised to identify themes. Specific coding was developed from fragments of the data that directly answers the research question. The use of thematic analysis in this study allowed me to discuss the themes but stories were edited to leave out identifying elements to maintain participant, patient, and organisational anonymity. Themes were developed from codes after coding and categorising data was completed. Thematic analysis for this study was an iterative process built on the identification and comparison of how

individual, community, organizational, and political cultures impact the diversity or commonalities of experiences.

I explored Qualitative Data Analysis software (QDAS) programmes to assist in the process of analysis. Despite critiques that QDAS lacks theoretical strength, there is evidence that it can contribute depth through which to interrogate data, and visualise results by using coding trees and clustering (Bhattacharya, 2015). I chose to use QSR NVivo10 for Windows because of its ease of use and evidence that it provides increased reliability and validity in qualitative studies (Bazeley & Jackson, 2013). The visual tools of NVivo10 "allow us to see large amounts of the data condensed into a single page" (2013, p. 217).

Digital recording and note taking were used to record the stories of the participants with their consent. I listened to interviews several times to make sure they were accurately recorded. To ensure as much accuracy as possible, I listened to the recording while reading the transcription (DiCicco-Bloom & Crabtree, 2006). Note-taking alone would not provide an accurate account of the participants' stories. During face-to-face interviews a digital recorder was placed close by and visible to the participant. At the beginning of the telephone interviews the participant was reminded that their interview was being recorded and that they could request the recording to be turned off or on at any time. Following the interview, the digital recording was transferred to a password-protected and encrypted PC at the earliest time, accessed only by the researcher. I alone transcribed, edited, and analysed all the digital recordings.

I transcribed all interviews directly into a Word document, then reviewed and reformatted it before uploading it to QSR NVivo10. Transcripts were printed out to take notes, re-read, and begin the process of developing initial codes by hand before uploading to NVivo10. Each line was numbered to be able to refer to it as needed. I used NVivo10 to create a coding structure, keep track of emerging thoughts (taking notes as I coded each interview), and develop new codes. NVivo10 helped to identify the depth and richness of the themes by linking them to the data sources. For example, by using the visualisations of the coding tree, I could compare the coding of one transcript with another and view the emerging relationships and patterns. After in-depth coding of transcripts, I sorted codes into categories. These categories were re-sorted several times after additional coding of each transcript was completed, returning to the data to confirm what had been said and in what context. Themes were identified after an iterative process of coding, returning to the data, re-coding, and categorising after all coding was completed. Examples of categories of codes, a coding tree, and the process of identifying themes utilising NVivo10 are included in Appendices 11-13.

4.7 Rigour and quality assurance

The concept of rigour in research is often associated with objectivity, replication, reliability, and validity, notions often associated with quantitative studies (Davies & Dodd, 2002). Qualitative scholars Mays & Pope (2007) suggest that qualitative research requires a different set of skills representing what cannot be rated by the same measures as quantitative research. Qualitative inquiry aims to establish quality that assures that the research represents the meanings of the participants,

minimising the biases of the researcher (Padgett, 2016). As a researcher, I acknowledge that I share a similar professional identity with the participants—which helped me to gain trust—and bring my own set of beliefs and experiences to the research. The philosophical underpinnings of this research recognise the researcher as a part of the research, one that "constructs the findings...as a builder who constructs a house" (Willig, 2013). Rigour in this study refers to reliability in the care taken in the application of the research, in a reflexive open process, and also acknowledges that "interviewing is a social interaction" that includes ethics, accountability, and openness about the research process (Davies & Dodd, 2002, p.286).

Member checking and triangulation are two techniques suggested to be suitable for qualitative studies conducted within a realist rather than interpretivist framework (Braun & Clarke, 2013). Therefore, this study utilised Braun and Clarke's 15-point checklist of criteria for good thematic analysis (see Appendix 8). In addition, Yardley's quality principles are indicated as appropriate for studies adopting different frameworks that are "open and flexible" (Braun & Clarke, 2013, p. 289). Yardley's criteria (2000, 2008), with an explanation of how these were achieved, are described in Table 4.6:

Table 4.6. Yardley's quality principles

Principle	How achieved
Sensitivity to context	Being sensitive to participants' experiences and how their sociocultural context shapes accounts Being sensitive to ethical issues, and not impose researcher's meaning to the data
Commitment and rigour	In-depth engagement with the topic Thorough data collection and breadth and depth of analysis
Transparency and coherence	Transparency of how data were collected and presentation of data extracts Reflexivity through how researcher shaped the research Description of interpretation of data
Impact and importance	Practical impact for a particular group Sociocultural impact through contributing to positive social change

Yardley's quality principles adapted from Braun & Clarke (2013)

4.8 Ethical issues

The research protocol was reviewed by the Lancaster University (LU) Faculty of Health and Medicine Research Ethics Committee (FHMREC) and approved by the LU University Research Ethics Committee (UREC). A letter from the Washington State Hospice and Palliative Care Organization participating in recruitment of participants was also included in the ethics application to demonstrate support and cooperation with this research (Appendix 9).

Ethical concerns are a key component of this research and go beyond the boundaries of standard guidelines. Charmaz (2004) suggests that the emerging ethics of

qualitative inquiry requires the need to tolerate ambiguity where general ethical guidelines would not be appropriate. All ethical considerations were brought to my Lancaster academic advisors for consultation as the research progressed. Despite early concerns, there were no disclosures of participation in illegal activities or concerns about the safety of the lives, or deaths, of individuals that required a report to local authorities. However, the boundaries of what is considered ethical was a constant theme throughout this study, given that participants shared stories about being asked to participate in or discuss an experience they may have considered unethical. How the participants expressed their approach to ethical values and behaviours within interviews, and how they are in dialogue about the story of this experience, is at the heart of this research. If there was any doubt about ethical issues raised by participants, I discussed this with my academic advisors and with a skilled psychotherapist familiar with qualitative research on sensitive topics in the United States. As a researcher and as a licensed social worker, I am required to abide by a code of ethics that includes protecting participants' anonymity and confidentiality and protecting participants and those they serve from harm (N.A.S.W., 2008). However, I have an ethical responsibility to report to the authorities if a participant had reported information about being at risk of causing harm to another (DiCicco-Bloom & Crabtree, 2006; N.A.S.W., 2008), though this course of action proved unnecessary.

Rosenblatt highlighted some of the significant ethical issues experienced by bereaved families that has relevance to this study, which includes professionals who may be grieving both personally and professionally (Rosenblatt, 1995). Some of the issues

include considering how and what participants view as ethical, the importance of recognising the boundaries between therapy and research, and being prepared to co-construct "a set of ethical guidelines as the interview unfolds" (Rosenblatt, 1995, p. 155).

Confidentiality and anonymity was maintained by restricting information about participants such as if they worked in urban or rural locations and the type of organisation they worked for. Contact information about participants who consented to participate in the study was kept in a secure locked file until the research was completed. Participants were informed that if they disclosed information about risk of harm to themselves or others, that I had a duty to report, as discussed below in the following section.

4.9 Informed consent

Informed consent is a process of ensuring that participants in this research have the right to be informed about the research, and that they agree to voluntarily participate without coercion (Denzin & Lincoln, 2011; Ritchie & Lewis, 2012). Participants being interviewed by phone were sent a research consent form (Appendix 10) to review, sign, and return to the researcher via fax, post, or scanned and sent in email prior to beginning the interview. Participants were asked to review and sign the research consent form prior to beginning face-to-face interviews. No participants declined participation after initial consent. At consent, participants were made aware of the possibility that the interview might cause some distress. Participants were reminded that they had the option of removing themselves from

the study and stopping the interview at any time. The consent form also included an item covering the eventuality that participants would request a follow-up interview. The consent form included a statement that there may be limitations to confidentiality if there was concern the participant may be at risk of harm to themselves or others.

4.10 Risk of harm to participants

There was minimal risk of physical harm related to participation in this research study. There was some risk that participants might experience emotional distress due to the sensitive and emotionally provocative nature of recalling distressing experiences about dying, death, and suicide (Ritchie & Lewis, 2012). Distress was minimised with an empathetic and sensitive approach to questions and a reminder to the participant that all their responses are voluntary. Rosenblatt suggests that good interview skills on sensitive topics require empathy where research and therapeutic boundaries are unclear (Rosenblatt, 1995). Participation in this research may have been therapeutic because of the participant having the opportunity to discuss the topic, but "therapeutic intervention" was avoided (Ritchie & Lewis, 2012; Rosenblatt, 1995, p. 155). To minimise risk, participants were offered an opportunity to debrief after completion of the interviews and were provided with details of where and how to access additional support as needed. Participants were offered information about counselling and support in the beginning and at the end of the interview. Finally, participants were informed that they could withdraw from the study at any time before or during the interview and up to two weeks following completion of the interview.

4.11 Risk of harm to researcher

Ritchie and Lewis (2012) recommend arrangements need to be made to minimise any possible risk to the researcher. It was anticipated that ambiguous ethical issues might arise in the process of the research that may require consultation with supervisors and obtaining additional information before continuing.

To minimise personal risks to myself as a researcher, I maintained a relationship throughout the process of this research with a therapeutic mentor, who is also a psychotherapist skilled in qualitative research on sensitive topics. The role of the mentor was to be available to me for counselling on any personal issues that may arise because of this research. The mentor did not have access to any of the research data and was not provided with any information about participants. The mentor was available to help me maintain emotional well-being through this process.

4.12 Ethical data management

As a researcher, I am responsible for protecting the anonymity and confidentiality of participants (Bryman, 2012). To comply with the need for anonymity, participants were informed that all names and identifying features would be removed from the transcripts and a code assigned to them (Ritchie & Lewis, 2012). I maintained a list of these codes with the participants' names that will be destroyed after awarding of the PhD by Lancaster University. This coded list with names of the participants, notes, recordings, and transcriptions and any other materials that might identify the participant in any way, are kept in a secure locked cabinet in a secured research

office in my home in the United States. Participants' contact information will be kept in an encrypted computer file that only the researcher can access.

The interviews were recorded on a device that allows direct encryption to take place. The data were transferred to the computer after transcription, and then archived on encrypted files. Any data emailed to my supervisors was sent via an encrypted password-protected file. Confidentiality was maintained by using a code to identify a participant in comments without attributing any distinguishable characteristics (Ritchie & Lewis, 2012). Data obtained from the interviews will be kept securely in a locked cabinet for 10 years after the research has been completed. I will delete all the recorded and transcribed data 10 years after I have been awarded a PhD. I will also destroy all information that might identify the participants including geographical location, gender, age, or professional background after I have been awarded a PhD.

4.13 Dissemination

The primary ethical issue concerning dissemination is the need to preserve confidentiality and anonymity of the participants. The informed consent for participation in the research provided information about how participants would not be able to be identified in any way during the dissemination of the research. Possible presentations and articles limit characteristics of participants to gender and profession, organisations are not named but identified only by type of organisation, and geographic locations are limited to identification of urban or rural environments in eastern or western Washington. Articles and reports synthesised from the findings

of the research may be submitted for publications to journals and conference presentations. The final study will be shared with participants at their request.

In this chapter, I have discussed the methodology, methods, and ethical issues applied to this research. In the next two chapters, I turn to examine the themes identified from the findings. In Chapter Five, I examine the primary theme of how there is a relationship with medical aid in dying and hospice care with subthemes identified from within each professional group. Chapter Six examines themes identified from across the data set and includes issues of social justice, experiences of patient suicide, and interpretation of suicide within home hospice care. The influence of power emerges throughout the research findings and is discussed in more depth in Chapter Seven.

CHAPTER FIVE

Introduction to the findings

Findings are divided into two chapters (Chapters 5 and 6). The purpose of dividing the findings into two chapters is to separate experiences based on professional role from the experiences described across the groups. The first chapter of findings, Chapter Five, offers an analysis of the results from experiences of each specific discipline and distinguishes varied experiences based on professional role. Chapter Six presents findings identified across disciplines, meaning that the primary theme and subthemes were identified across the professional groups. Table 5.1 provides an outline of the primary themes and subthemes identified in Chapter Five and Chapter Six:

Table 5.1 Table of themes

Chapter	Themes and subthemes	
Chapter Five: Relationship of Medical Aid in Dying with Hospice Care	Physicians— *"there is a weight to it; that weight is crucial"* Nurses— *"It just seems like another option"* Social workers— *"creating a space; uncharted territory"* Chaplains— *"they don't have to go to Oregon anymore"*	
Chapter Six: Medical Aid in Dying, Hastened Death, and Suicide	Social justice:	- Affordability - Access - Culture
	Suicide:	- Using medications to hasten death - Palliative sedation as alternative for DWDA: asking us to do it for them - Voluntary Stopping of Eating and Drinking
	The blurry boundaries of suicide:	- Suicide is a loaded word - Death with dignity: There isn't a great word for this kind of death - Interpreting suicide and impact on work with patients

A primary theme identified in the analysis of the separate disciplines in Chapter Five is that, despite the professional role, when asked about experiences with suicide or

hastened death, participants spoke of experiences with patients who utilised the Death with Dignity Act (DWDA). The chapter title and overall theme is called the relationship of hospice care with medical aid in dying, because in each professional group participants identified Death with Dignity (DWD) as an experience of hastened death or suicide despite their role or place of work. Professionals interviewed for this research identified a different sense of power or responsibility over the ability to assist or support patients who have utilised medical aid in dying. Subthemes examined in this chapter are identified and organized around each of the professional groups starting with physicians, followed by nurses, social workers, and chaplains. Each role is identified by a subtheme explained further in 5.1. An introduction to Chapter Six provides additional explanations of the included themes and subthemes in that chapter.

The term 'medical aid in dying' is used in addition to DWD in these findings chapters because these are terms most participants used during the time of the interviews.

5.1 The relationship of medical aid in dying with hospice care

The overall theme from within each professional group suggests that there is a relationship between hospice and medical aid in dying containing tension and challenges, that the DWDA has impacted professionals' experiences of hastened death in hospice, and that home hospice and medical aid in dying are not mutually exclusive. Examining the experiences through the contributions made in their professional groups offers a clearer understanding of the professional role within the hospice team structure as well as their relationship with other team members, the

organisation, and with patients. Themes from within each professional group are described in Figure 5.1. The patient (and family) at the center of each group of professionals also demonstrates the collaborative process between team members essential to focus on the patient's goal.

chaplain
"they don't have to go to Oregon anymore"

nurse
"It just seems like another option"

patient and family

social worker
"uncharted territory"

physician
"there is a weight to it; that weight is crucial"
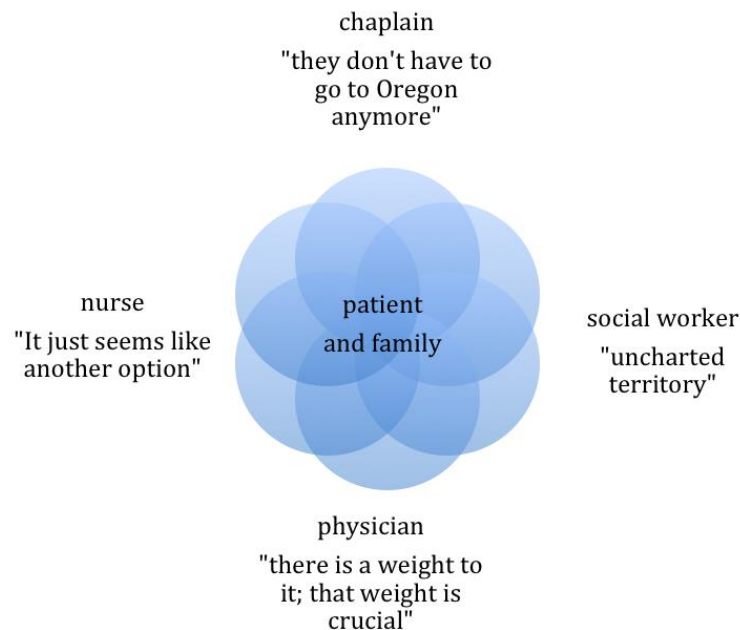
Figure 5.1 Themes by professional group

5.1.1. Physicians— "There is a weight to it; that weight is crucial."

The interviews with hospice physicians suggest they have fewer direct experiences with hospice patients in the home than participants in other professional groups. Physicians spoke about providing oversight of hospice treatment teams but that they do also work directly with hospice patients in either face-to-face visits if a patient has received hospice services for over 6 months (explained in Chapter One) or in other positions. The following Figure 5.2 demonstrates the various professional roles described by participants. Physicians identified several roles in addition to serving as

hospice medical director such as nursing home medical director, private practice, and palliative care consultation in the hospital. Three of the physicians also spoke about serving on hospital ethics committees where experiences with patients who want to pursue the option of life-ending medications are often reviewed. All participants spoke about their attitude and experience with hospice patients around the DWDA and with DWD.
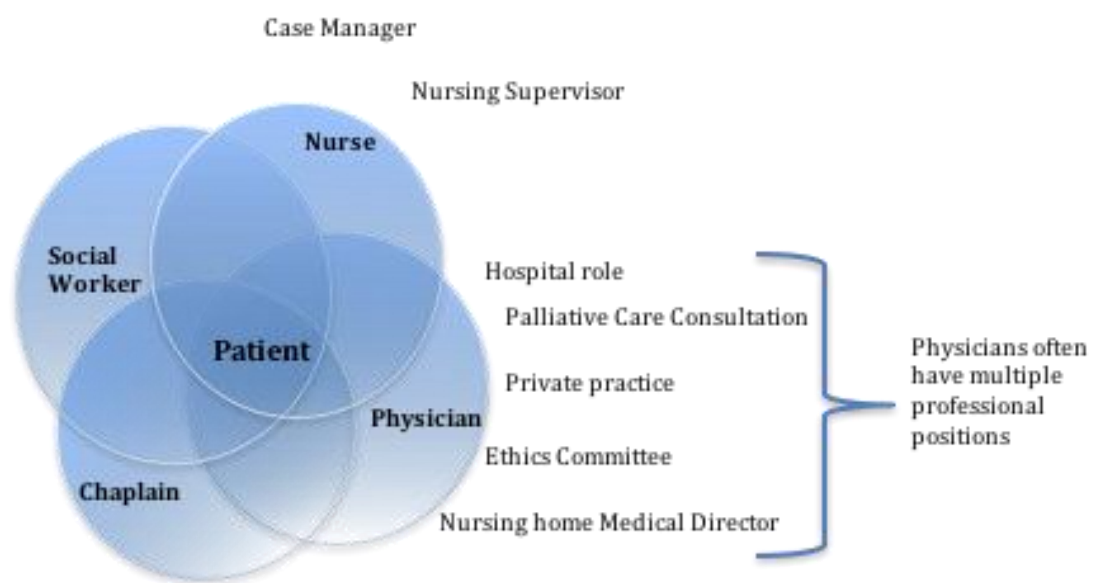
Figure 5.2. Professional roles

Patients receive medical aid in dying prescriptions from either their attending physician, who is in most cases not the hospice medical director, or they may have been referred to another physician if their physician is unable or unwilling to prescribe lethal medications. The physicians interviewed reported they are not currently prescribing medications; two of them due to personal reasons, one due to organisational policy that prohibits employees from participating in medical aid in dying, and the other due to the organisational policy that considers it to be a conflict

of roles if a physician is acting as both medical director of hospice and as a prescribing physician. The patient is likely to go to their physician most familiar with them—who in most cases will be their attending physician and not the hospice medical director. If their physician does not agree or cannot prescribe, they can seek referrals from the physician or through an advocacy organisation. Despite differences in experiences prescribing, physicians spoke openly about hospice patients known to hasten death with medical aid in dying as if it is an element of their work.

Physicians made statements that under certain circumstances they could understand a patient's wish to hasten death even when they did not support medical aid in dying. MD2, for example, had previously written prescriptions for patients requesting life-ending medications but no longer prescribes because it conflicts with his commitment to his newly found faith-based beliefs. Despite his current personal opposition to the DWDA, MD2 acknowledged the legitimacy of patient's wish to hasten death:

> *"...it is about control, ... and I don't disagree at all philosophically with people*
>
> *who want to control their end of life, the timing and so on." MD2*

All the physicians interviewed in the study expressed some degree of moral conflict with the DWDA. Some described previous experiences prescribing DWDA medications but not in their current positions as hospice medical director. MD3, however, indicated that education about and provision of home-based hospice services contributed to decreased requests for life-ending medications. Another

physician said that with hospice care, patients have more resources to help them cope with the range of emotions and experiences that might come with the dying process. Despite differences, the physicians suggest that a sense of responsibility and power that comes with being a physician that places them in a position that is different from other professionals. Both MD3 and MD1, who work in different institutions, in different parts of the state, suggest that decisions that contribute to a hastened death even when they do not administer the dose of medications or withdraw life support, where they feel they have the power of life and death, do not come easily:

> *"Terrible to be asked and you know... there is such a desire to be a fixer when you are a doctor...it makes you question yourself. And it also feels like an honor if you know the person … well enough to be confident that they are making a really well considered choice…but the first time someone ended their life with a prescription...it was a big moment.… I wrote a prescription and this person is now dead. And I won't say that I didn't feel guilty, and there is a jumble to it...there is a weight to it* [but] *I think that weight is crucial and we have that weight every time…" MD3*

> *"And when you are the one writing the prescription that is a big responsibility…and when I have withdrawn supports for patients who have died, it was totally the right thing to do, it was still very tough...MD1*

The sense of weight with the decision to prescribe life-ending medication is

suggested to be crucial. It is as if writing a prescription might not be taken seriously without this added weighted-ness. The physician does not take the patients' request for assistance to die and make the decision to help them easily or lightly. The 'big moment' making the decision to aid a patient's request to hasten death requires a constant questioning about what is right, and what is 'well considered'. It takes time, and perhaps a sense of intimacy to know the patient well enough to feel confident the right decision has been made; a decision that they can live with based on personal values or beliefs. There is a sense that the physicians question if they did enough to help the patient who has died, whether it is through medical aid in dying, withdrawal of life support, or other cause. Some of these experiences physicians suggest DWD may be heavier than other decisions, such as withdrawal of life support even when the patient is self-administering the medications independently and in their own time.

Physicians expressed feelings of increased confidence when patients are receiving home hospice care, possibly because of the team members' observations when visiting patients several times weekly in the home or nursing home setting. Physicians suggest there is a difference between patients in home hospice and patients requesting DWD in the hospital. MD3 suggests that hospice and palliative care minimises requests for DWD:

> *"...sometimes people in the hospital are suffering so much they are looking for any way out, so when patients are asking me for Death with Dignity in the hospital, when they learn about hospice they are not interested in Death with*

Dignity anymore ... the vast majority of my patients around Death with Dignity are ok and understand that on hospice if 'my pain becomes so severe medication may be given that I don't have to do that' then the vast majority of people back down from Death with Dignity." MD3

Two physicians suggested that one reason they don't prescribe life-ending medications is because they live and work in rural communities and they would not want to be targeted as the 'DWDA doctor'. This again implies feelings of burden and responsibility with making these crucial life and death decisions. Both MD2 and MD4 describe the dilemma of isolation if they were to prescribe life-ending medication. The law places physicians in a precarious position of power and vulnerability, especially if they are isolated:

"Too much power…One, I'm isolated, and two, is at the end of the day, when we take away everything, I don't want to be a part of it…. you take away palliative care, you take away the knowledge of medicine, you strip it down to the basics. I don't want to hand someone a loaded gun. Go shop for your own gun. Buy it yourself...I can understand why someone couldn't go through the legal steps too…and I know people who are dying don't have the means. And I like the law, but don't make me a part of it." MD4

"I'll just say for me personally in a semi-rural community where I wear a lot of different hats, literally from day to day ... I would personally have to be very careful about the conversations I have and the level of participation I would

have...” MD2

Both MD4 and MD2 express conflict with prescribing life-ending medications. Palliative care is indicated by MD4 as being the 'knowledge of medicine', implying that medicine is not about hastening death, but about comfort and allowing a natural process. MD4 conveys that writing a lethal prescription is akin to purchasing a gun for a patient and can better live with the patient's death by suicide without assisting in any way. MD4 reflects what other physicians expressed, that they are supportive of the law, but don't feel able to participate as a prescriber because they might be targeted by members of their community. In the process of the interview, however, MD3 realised the importance of taking an open stance in support of medical aid in dying:

> *“...usually I am talking about it with hospice colleagues where we are all very accepting of it as a right...but it's reminding me that there is a whole lot of people out there that think it's immoral or wrong... it is something that belongs in our community, the ability to use the Death with Dignity law, but there are lots of places where it is a super-hot topic, and we are not allowed to talk about it...” MD3*

Overall, physicians' experiences suggest that there are emotional, professional, and ethical challenges that come with being a professional responsible for DWD even when they are not the physician who prescribes the medication. The 'weight' or burden associated with caring for patients who seek DWD indicates a sense of

unwanted power that comes with a death considered to be unnatural or hastened.

5.1.2 Nurses— "It just seems like another option."

Overall nurses' stories indicated that they view medical aid in dying as another option for patients facing end of life despite some who have personal or moral conflict with the law. Nurses' stories, however, suggest that there is a relationship with hospice even when a patient's choice may conflict with their own personal beliefs. This may be attributed to the ability of hospice nurses to focus on the patient's goal more easily when the care setting is in the patient's home. This relationship is demonstrated in the quotes of two nurses:

"... she approached us about it and we explained she needed to talk to her doctor about the actual mechanics, getting the medications and go through all the legal hoops that had to be done... and she had a chance to say goodbye... thank ... and talk to people and things she had on her mind. She was able to do that life work." RN7

"I have to say, well, I can tell you what the medications are, and the way you take the medications, but I really need you to talk to [social worker] *about it. First you take the Reglan[4], you know, and then you take the ondansetron[5],*

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[4] Reglan is a brand name for metoclopramide, a medication used to treat gastroesophageal reflux disease
(https://www.fda.gov/downloads/Drugs/DrugSafety/UCM176362.pdf)
[5] Ondansetron is used to prevent nausea and vomiting
(https://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm271924.htm)

and then you wait half an hour, and then you mix the secobarbitol, we tell

them to mix it with a little vodka..." RN6

RN7 and RN6 are employed in different organisations in different parts of the state. The nurses spoke openly about their understanding of the DWDA process in both stories. RN6 suggests that when asked by patients she feels some limitations about what she can share because the organisation identifies a specific professional to assess and work with patients requesting DWDA. Yet she felt able to share the practicalities of the process when asked. RN7, on the other hand, who works with an organisation considered non-participating, did not explain the process, but supported the patient's option. Both nurses indicated they worked consistently to support patients' wishes even if the wish is to use the DWDA.

Nurses' stories imply that the relationship of hospice to DWDA is enhanced by the intimacy of the connection between nurses and patients when patients are seen in their own homes. This intimacy is described particularly in rural communities where patients and hospice professionals are often familiar with each other especially if they live and work in the same area. RN1, who had difficulties accepting the patient's choice, said that another staff person was related to the patient, which is not unusual in rural areas where few staff are available to serve the community:

"...Not sure I agreed with it, … I want to be supportive of patients…in their

choices, but first I was uncomfortable with it ... I went back and spoke to my

administrator about this. … who was a great support … and in this situation,

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the whole family was on board. As her disease progressed … she had a lot of

nausea and couldn't eat very well …." RN1

RN1 faced a dilemma evoking a sense of power and responsibility, like participants from other disciplines, to support the patient's decision to utilise medical aid in dying. Assistance from the administrator helped to alleviate her discomfort; however, this leads one to question how she might have proceeded if she did not feel she could continue to work with the patient. These types of ethical dilemmas are not limited to medical aid in dying in more rural communities. Nurses, like other professionals in this study, are often told by their employers that they can refuse to work with patients who choose to take DWDA medications if it conflicts with personal beliefs. But participants interviewed said they would be with and care for a patient even if they did not agree with the patient's decision to ingest life-ending medication.

RN3, who is employed at an organisation that discourages professionals from being involved in the DWDA process, told a story of a patient she had known many years. Her experience with this patient suffering from a prolonged dying process, suggested an intimacy in the relationship that developed from consistent weekly visits in the patient's home. While the organisational policy discouraged this nurse from being involved in the DWDA process, her supervisors supported her when it appeared to be in the best interest of the patient:

"I have…. been present for two of many DWD deaths... company policy does

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not want us engaged in the process, but will allow it if I am specifically asked

... And it just seemed ...appropriate that she would be asking me to be there

to make sure everything would be ok from a nursing perspective... It was

great ... And she died ... And I let my supervisor know about her dying process

and I felt that it appropriately made sense that I be there." RN3

Participants were often surprised at how some of the deaths were, in fact, celebratory. It is as if the decision to control timing of death allowed an opportunity to face the reality of death and avoid a prolonged dying process. RN2 remarked that speaking of being happy for someone about this experience might be considered 'weird' but also senses a shift in attitude as medical aid in dying becomes understood as an option at end of life rather than something to fear:

"I've cared for several patients who then went on to use their prescription...I

have not heard of any bad experiences… yeah it just doesn't seem so

unsettling to me anymore … it just seems like another option ... one patient

literally died with a smile on his face. He just had this wonderful interaction

with everyone he loved and how amazing that he had that experience of

knowing what people would have said after he was gone…I know that might

sound weird, but I was happy for him." RN2

Both RN5 and RN6 expressed conflicted feelings about some experiences with patients who died with DWDA:

"I have mixed feelings about it. Because I have seen that we can give people quality of life at the end and it gives them the opportunity to resolve life stresses ... I don't know for this man if it ever would have happened. I mean he didn't even tell his siblings that he was dying. He didn't know how to tell them. Dying on hospice can make death a beautiful experience." RN5

RN5 implied that a natural death on hospice can be beautiful, allowing for time to say goodbye and communicate with family members. This suggests that some DWDA deaths may be avoided by patients, depending on the circumstances of the individual. RN6 expressed emotional distress when supporting one of her patient's decisions to control timing of death through DWDA:

"... it was hard to see him, all of his family surrounding him, he wanted me to come to confirm death after he had taken the meds, which I did. But one minute I was talking to him and having a very deep conversation and then he was gone ... I have the feeling that Death with Dignity is like a C-section for the convenience of the doctor and ... the patient, you know, I'm going to have this planned delivery so I know exactly what time I'm going to deliver and know exactly what day, so that it doesn't interfere with my life ... and so, to keep it clean. That kind of bothers me. There should be some mystery to life." RN6

The 'scheduled C-section', as stated by RN6, dismisses the possibility that the 'labour' of the dying experience might offer something beneficial even though it might be

difficult and painful. Control over the timing of death is associated with the loss of the mystery of this dying time, which may be important for those with faith-based or spiritual beliefs who regard suffering as a part of life and death. It is as if they miss an opportunity to experience the process of dying that may be just as much about living. Despite the conflicted feelings about patients who seek DWDA, both RN5 and RN6 continued to support their patients' wishes. RN6 developed a relationship with the patient who could trust that she would be present to confirm death if he chose DWDA. RN6 witnessed not only the death but also experienced the process of caring for the patient while he was dying in the intimacy of his own home.

The following experience of RN7 is an example of how some participants described patients concerned that they needed to keep the intention to pursue DWD from the hospice team members:

> *"I think we had him on for a couple months ... and at first they didn't tell us that they were thinking about Death with Dignity. I think they were afraid that we were going to be negative about it ... So they were relieved to discover that we weren't going to stop them or shame them but that we were just going to be supportive. He actually did not even let us know when he was going to do it. He just one evening said I am done, and took the medications and afterwards the wife called the hospice nurse." RN7*

The experience of RN7 signifies that while professionals may support the patients' wishes, there remains stigma and fear associated with medical aid in dying. A sense

of shame may have prevented the patient from initially sharing his intentions. The patient's sense of relief that they could be honest about their plan to pursue DWDA may have increased the ability of team members to address his overall well-being. He could then speak openly about his concerns and trust team members to ease symptoms associated with the illness. His choice to control timing of death was not mutually exclusive from care given by the hospice team even though they may not have been present at the moment of death.

Nurses and other professionals spoke about patients accepting hospice services only because it was recommended by a DWDA advocacy organisation. RN2 spoke about a woman who was initially reluctant to accept home hospice services because she did not want involvement of hospice team members when she took the medications. RN2 said she was employed in a hospice organization allowing professionals to be present at time of death from DWD and speak openly about the option:

> *"...And she told us right off the bat when she signed up for hospice that she had already signed up with death with dignity and already gone through all of the steps with getting a doctor and then another doctor to sign off on it and…she actually had the prescription in her home... but later she made the decision to take the medication... and then we got a call from her family who said that it was very peaceful... and she just nodded off and stopped breathing. It was incredibly low key and non-traumatizing for everyone." RN2*

The 'low key' approach described above, suggests that the impact of the death was

not much different from the anticipated deaths of other hospice patients; that DWD is one of several options a patient might pursue within the context of their life and death. RN4, who worked for a Catholic organization, shared a story about another female patient:

> *…I came to do the hospice admission in the home after she had just met …to be prescribed Death with Dignity medications…she, and her family, had come to peace with the fact that she didn't want to live like this anymore. And we have a policy at our organization...we are not allowed to discuss these options with our patients. And in this situation the patient was already educated about all of it so there wasn't anything that I would have told her that would have violated the policy…I explained to her that hospice care could still come and be involved with her end-of-life care, but that we would not be allowed to be in the home with her at that time she chose to take the medications, but that we could be on call...And the family understood that…so I know that she had gotten to make her choice…RN4*

Patients appeared to choose hospice secondary to their decision to pursue DWD in both stories told by RN4 and RN2. The nurses worked for organisations with different policies about participation with medical aid in dying. Both patients accepted hospice services, and both ingested the medications without the presence of hospice professionals.   The nurses had no personal conflict with the patient's choice but the policy of RN4's employer influenced the degree to which she could educate her patient about legal options. The differences in employers' practices suggest that

professionals may be influenced by policy but also demonstrates how medical aid in dying is integrated into their care despite the policy. Organisational policy often indicates that hospice is distinguished from aid in dying (discussed in the next section), but participants suggest that when patients are aware of and pursue the option of medical aid in dying it cannot be ignored as part of their care.

5.1.3 Social workers— "Creating a space; uncharted territory."

The social workers interviewed had various perspectives on how the relationship of medical aid in dying is integrated with hospice, but all responded with stories about their experiences with the DWDA. Social workers, like those in other disciplines, often described themselves as advocates for patients' options even when the option was about seeking DWD:

> *"In hospice, a lot of times it is just about being there and listening to the person and creating a space for them... I thought that this was a very difficult thing that she was going through and you know I was going to be there for her as much as I could within my role."* MSW3

MSW3 above described her experience providing counselling for the patient as she went through the DWDA process in a way that she may have described working with other patients facing a natural death. The social worker said her role was limited by organisational policy regarding her ability to educate and inform about the DWDA process. When the patient made the decision to pursue DWD, the social worker 'created a space' to allow the patient to control timing of death and continue to receive the support from hospice professionals. However, social workers may feel

limited by their positions depending on where they are employed.

The following comments demonstrate how social workers in different hospice organizations might advocate for or be with patients who die utilising DWD. MSW5 voiced that where she works, social workers have an integral role educating patients about options; however, MSW7 reports limitations:

"...especially the social workers are tasked with helping the patients deal with the timeline, and written requirements. ... in general, that is the one way of guaranteeing that peaceful death ... Death with Dignity. And I have been really blessed to be with ... patients during that process ... and get to experience that type of death versus one where you are waiting, you are doing the vigil, or like the sudden death..." MSW5

"We can help them ... What we can't do is we can't sit with them ... while they take the pills. We can be there before and after...and we have been..." MSW7

MSW7 put forward that there are times when they can be present and times when they cannot, but that most professionals work with the patient regardless of their choice. MSW7 understood that the guidelines of her organisation only allowed her to be present before and after but not during the time the patient ingests the medication. The law does not prohibit any professional from being present. How social workers and other professionals provide education, counselling, and support may depend on their employer.

The contradiction of the DWDA as being both separate yet integrated into hospice care was prevalent among professionals who seemed to struggle to make sense of policies that did not conform to their own personal or professional ethical standards:

"I find the intersection between Death with Dignity and hospice really interesting because we are trying to keep them very distinct programs, ... but the reality is ... that most people that are doing Death with Dignity are on hospice.... This is uncharted territory for the culture...." MSW1

MSW1 offers that most people who request DWD are receiving hospice services even though the organisation she works for identifies a separate program for patients pursuing DWD. MSW1 continued to work with the family members coping with the grief from what she described as 'uncharted territory'. Even when it is suggested that DWD is considered 'separate' from hospice, the relationship between the professionals working with the patient and family continues. Most social workers and nurses interviewed, however, said they were prohibited from bringing up the option of DWD unless the patient initiated the discussion. The 'uncharted territory' MSW1 refers to may mean that as professionals have more experiences, they and the organisations they work for map out clearer guidelines as they find their way.

Social workers who work for Catholic organisations that publicly oppose the DWDA imply that professionals do, in fact, work directly with patients who pursue medical aid in dying. The following comments from social workers that work for two different Catholic organisations indicate that professionals having open conversations with

patients about DWDA may be impacted by these policies, but continue to work openly with patients throughout the dying process. Social workers infer that as more patients die with DWD, organisational policy is shifting toward supporting patients' wishes:

> *"Well, personally...I love that I live in a Death with Dignity State......that is my own personal belief system being able to choose how you die, and I work for an agency ...that publicly opposes Death with Dignity, and doesn't participate with Death with Dignity...we actually have a reputation in the community of being dismissive of patients and not supporting them... she took the medications to end her life... I was able to be a part of her end-of-life experience ... but I also did it as an employee ... I'm assuming it would have been different if I worked for a participating organisation ..."* MSW2

MSW2 expressed her own views that the organisation she works for has a reputation of being dismissive of patients who pursue DWD and she has found herself struggling to support the patient as part of her role as a hospice social worker. How much MSW2 felt she could communicate with her patient about DWD is vague but she provided counsel within her role to support patient goals. MSW2 suggests that if she worked for a participating organisation she would not have had to be concerned about the reputation of her employer as unsupportive of patients' options and policy would have allowed her to be present at time of her patient's planned death. Other comments, however, indicate that as medical aid in dying becomes an option familiar to patients, policies are shifting:

"I think that now they are realising how crazy making our policy is and they are revisiting it to make it easier for us to deal with because it is...how do you give emotional support and yet then if they talk about doing the act are you going to stop giving them emotional support around that? It's not really possible to be supportive of a person, you are either supportive of a person and are there in their corner, or are being judgmental, like a parent..." MSW3

"...For me it is a fine line of following the policies but also wanting to do what I can to support my patient in investigating this." MSW6

These comments from social workers indicate their roles are blurry when it comes to how they support a patient who pursues medical aid in dying. MSW3 implies that her employer policy is patronising, which parallels reports of other organisations that also have a reputation of being dismissive of DWD. The conflicts between organisational policy and professional role present increased challenges when the professional believes their role is to support the patients' choice. MSW3 and MSW6 indicate that their positions as social workers are compromised when they feel their professional role conflicts with policy and might cost them their job. This may contribute to their feelings of powerlessness to support the patient's goal, or, alternately, asserting power by interpreting policy or practice in ways they believe are right. As MSW6 suggests, it is treading a 'fine line' between the organisation and the patient's wishes. Social workers, however, demonstrate differences in how they might be influenced by policies and work with patients who pursue DWD:

"every single one of them [social workers and chaplains] *has been at the bedside and felt honoured and....there have been celebrations prior to them utilising the medications, quiet moments...."* MSW5

"I am not allowed to support Death with Dignity, my organisation has told me that. I have absolutely, legally, professionally, no need to know what the law is...I'm not allowed to support it...If they want me to be trained in it in my job, they will train me in it ... MSW3

MSW5, who works in what is considered a participating organisation, mentions overall positive experiences working with patients who have pursued DWD. MSW3, however, voiced that if she is told that she has no need to know about the law then she cannot counsel openly about the DWDA process and alternatives that might help the patient. This suggests that organisations that regard the DWDA as separate from hospice care cause confusion and blur the boundaries about their role when a patient might ask for information about the DWDA options. In the following comment, MSW4 sought her own education about the DWDA. After speaking with the director of an advocacy program, she returned to her work cautious about her support for the DWDA:

"And after talking with the medical director for [Death with Dignity advocacy organisation] *... I would say my impression after seeing the work that we as hospice practitioners do, including the options that encompass palliative*

sedation, that patients who are in distress can be treated with dignity and

comfort in most scenarios..." MSW4

Hospice care, as MSW4 suggests, may have the care needed to avoid medical aid in

dying and implies that alternatives such as palliative sedation may seem to be more

acceptable when a patients' dignity or comfort are compromised.

5.1.4 Chaplains— "They don't have to go to Oregon anymore."

The three chaplains interviewed for this study all told stories about experiences with

hospice patients who died with medical aid in dying. Stories were shared that

demonstrated an intimacy with patients' experiences and support for patients'

choices similar to the experiences of nurses and social workers. CH3 described

experiences with patients who have hastened their deaths:

> *"...They used to say, well, I have to move to Oregon. Well, they don't have to*
>
> *move to Oregon anymore. And so, for religious people who might be*
>
> *considering hastening, it is a double whammy. As for non-religious people, 'it's*
>
> *like, hey, my life sucks, it's not worth it, but I don't want to hurt my family."*
>
> *CH3*

CH3 suggests medical aid in dying may be more difficult for family members to

accept if the patient or their family is religious. It is as if the pain from this type of

loss is doubled when a patient dies from an intentional hastened death. The pain of

going against religious beliefs and the knowledge that their death could hurt family

members causes patients to consider other options. A contradiction remains

between what is acceptable for religious people and what is possible with DWDA. CH3 summarized this contradiction with a story about how his own views shifted when someone he had known died using medical aid in dying:

"...I might have done the same thing in his circumstance...I understand completely why he did it, the integrity with which he approached his decision and the way he involved his family... his dying made it extremely real. And I sat with a lot of dead bodies, ...watched them die and go from life to death ... So, I have...a real strong sense of that...but still to have this deliberate purposefulness, was a [most] *sobering thing that I've ever experienced ...CH3*

CH3 recounts how his personal experience created a shift in attitude about what might be acceptable. The 'sobering' thing suggests he might not have thought he could accept a 'deliberate purposeful' control over the timing of death. This shift in thinking emerged as a thread throughout this study. After most personal and professional experiences, professionals interviewed come to a greater acceptance of patients' need for autonomy and respect for what it might mean to suffer, even when they feel professionally or personally opposed to the DWDA. CH1 summarised the intimacy of the experience meeting with patients in their homes that might be different than in clinical settings:

"...also, it is important to know that some boundaries have to be very flexible because of the nature of the work. It is like no other work...we are inside people's homes. And it is not just coming in ... Bing, 50 minutes ... got to go ... I

mean I could spend hours with people." CH1

The nature of working with patients in their own environments, as CH1 indicated, requires professionals to be flexible with both their own personal views, and their time. CH2 spoke of the contradiction among religious staff who might be opposed to medical aid in dying yet continue to support and have been present with patients while they go through the process of ingesting the medications.

> *"It's not a policy that is written that you can't do this.... you know... unspoken rules that run organizations. Where they expect you to go in and tie it up with a bow and make them feel better. And make them say a nice prayer to cl*ose it up*....We need to make space for talking about these issues."* CH2

CH2 expressed how, as a chaplain, assumptions are often made about beliefs. There are what is considered 'unspoken' rules or expectations about professional roles and responsibilities. CH2 also implied that policy might be covert and that there are assumptions about the chaplain role. Chaplains demonstrate that despite expectations from others they also have power and a sense of responsibility in their role to work in coordination with, but independent from, these unspoken rules.

Professionals of all disciplines suggest that they work autonomously from others when working in the home and that there is frequently an overlapping of roles. CH1 demonstrated professional autonomy with her stories of support for patients who hastened death:

"When I am with a patient it is my experience with a patient. I don't really have a sense of the organization when I am doing my work…do you know what I mean? …when you are out in the field you are out by yourself, so nobody is going to know about my conversation …" CH1

CH1, who did not work for a religious institution, made the comment above in response to a question about organisational policy regarding medical aid in dying. This comment implies a sense of autonomy in her work independent of the organisational policy that suggests a separation of the DWDA from hospice. This sense of autonomy was conveyed by many of the other professionals who described driving from one visit to another serving patients in the patient's home setting. The home appears to offer a place where patients might feel they can have more honest conversations with professionals around life and death issues than they would in a more clinical environment.

5.2 Conclusion

Participants across all professions interviewed suggest that despite conflict and challenges demonstrated by personal beliefs and organisational policy, that DWD is an option provided and supported within the context of interdisciplinary hospice care if and when it is a patient-initiated request. Hospice care is not mutually exclusive from medical aid in dying for patients who choose it and have information, education, and resources about options. The next chapter examines themes that emerged from across professional groups highlighting issues of suicide, culture, and economic disparities.

CHAPTER SIX

Introduction: Social justice and DWDA, suicide and hastened death, and the blurry boundaries of suicide

The relationship of medical aid in dying to hospice care, a primary theme examined in the previous chapter, is only one aspect of hastened death and suicide that emerged from this research. This chapter, separated into three sections, examines themes identified across professional groups. The first overall theme of this chapter, social justice and the Death with Dignity Act (DWDA), is distinguished by different types of experiences that are impacted by the DWDA. This theme explores how participants from across professional groups identified challenges of the DWDA that are associated with the subthemes of affordability, access, and aspects of culture. The second theme, labelled 'hastened death' and 'suicide', investigates experiences recognised as hastened death and suicide outside of the DWDA. These experiences are identified in three subthemes: using medications to hasten death, using palliative sedation as an alternative to DWD, and voluntary stopping of eating and drinking. The overall theme explores how participants identify the blurry boundaries of suicide and distinguish suicide from a hastened death. This theme examines challenges participants experienced defining suicide in a hospice context and are described in the following subthemes: 'suicide is a loaded word', 'Death with Dignity', and 'interpreting suicide and impact on work with patients'. Each theme is examined below.

6.1 Social justice and DWDA— *"Out of reach for a lot of our patients"*

6.1.1 Affordability

Most participants explained that in their experience, DWD is not available to all hospice patients. Nurses, physicians, and social workers spoke about disparities in healthcare, including high cost that often prohibits patients from pursuing DWD. Availability of DWD depends on patients' ability to afford medications:

> *"...the cost of the medication now is putting it out of reach for a lot of our patients...so this medication that was used early on was $280 when the Death with Dignity law was passed...It is now $3000."* MSW5

> *...She has seen the two physicians and now has the prescription for the medications. She has not had it filled yet because it costs $1200..."* MSW6

The quotes from these social workers suggest that there is limited access to the DWDA due to the high cost of medications. They approached these challenges in the same way they might have advocated for patients around limited access to other resources: referring to the advocacy organisation for assistance and continuing to counsel on the conditions that led to the desire for DWD. In some cases, it was an emotional relief for the professional when patients died a natural death.

> *"...the only thing I know is she was saving her money… for the medication … she didn't have … it was expensive…"* RN1

> *"the cost of medications for death with dignity is so high that it is a barrier for*

so many people..." MD3

These comments indicate that patients experience challenges not only through the process of obtaining a prescription but also by discovering unanticipated financial barriers. These challenges presented a conflict to some who felt in an unexpected position of responsibility and power over the decision to provide options to prevent patients from suicide. The availability and cost variability of medications prescribed by physicians for medical aid in dying have been explained in the background section 2.2.

6.1.2 Access

Professionals from all disciplines indicate that communication about a desire for hastened death is common but observe that in most cases patients die a natural death. Concern, however, remains that some patients may hasten death or die by suicide when access to DWD is limited. MSW7 described a patient who tried to pursue DWD but could not find a physician or assistance to complete the paperwork for the request:

"...she was in bed at the end and for months she couldn't move well and people had to come to her...she kept saying... I want to do this Death with Dignity... She actually found it hard to not eat and drink...Wanted it over.... But she couldn't do the paperwork, couldn't go anywhere and didn't have a doctor who would do it for her as well." MSW7

In this story, the patient explored other options to hasten death, such as stopping

eating and drinking, and desired to have legal lethal means to hasten death. MSW7

recalled this story among many other stories of patients who asked for assistance but

died a natural death.

It may also be difficult finding a pharmacy able or willing to fill the prescriptions.

MSW1 described several experiences that included stories of patients having

difficulty finding a pharmacy that had the medications to dispense:

"… we had a few years of … people buying hundreds of dollars worth of drugs

and then not using them… and then there wasn't the drugs available for the

next person because they couldn't be returned." MSW1

MSW1 explains that limited supply and difficult access to medications makes it a

challenge for anyone who wishes and is eligible to utilise the DWDA. Patients who

don't use dispensed medications are prohibited from returning these to the

pharmacy, thus exacerbating the limited availability.

6.1.3 Culture

Several participants expressed how social and cultural inequities affect limited access

to any healthcare options, including DWD for many patients. Medical aid in dying

may not be a priority for patients who do not have access to general healthcare,

including pain management and curative treatment options, because of distrust of

the dominant biomedical system.

The bioethical principle of autonomy assumed to be a societal norm in the United

States, and purported to be a reason why patients choose to pursue DWD, is challenged in stories shared by professionals about patients who may be undocumented, uninsured, or from the Indian Nations:

"...feel like the system is screwing them instead of supporting them... the family wants what is best for the patient as the final goal even if there are drug issues with the patient or many other issues, they still do pretty good with caring for their loved ones ..." MD4

As MD4 articulated, hospice patients she serves who are members of Indian Nations are unlikely to seek DWD because of distrust that they are being offered all healthcare options. The planning required with DWD may not succeed when the system that created it is distrusted as suggested by others:

"the Indians don't do that. They don't do any preplanning and they don't...it's just something, you just don't talk about." RN7

"There is always the sense...this fear, this distrust at first, ... and also, working with a lot of Native American people, you don't want some white woman who looks like your basic social worker... it's like, who is she trying to get?" CH2

RN7 explains that she is familiar with members of Indian Nations who do not speak openly about death or anyone who has died. Communication about preplanning a death for oneself or another is often unacceptable. CH2 emphasized the fear and

distrust, recognizing how her own role as a white professional might perpetuate the distrust, particularly when experiences with other professionals, such as social workers, might have caused trauma in the past.

Participants also commented on experiences with patients of Asian heritage, suggesting that most would not be interested in DWD for several reasons:

> *"It tends to be with Vietnamese patients that are Buddhist and they tend to be very stoic. Suffering is a part of life and you know they are very reluctant to take medications to decrease their symptoms …."* RN2

> *"Some people won't talk about funeral home or planning until the person dies... in the Asian culture they just don't do that. The Buddhists don't because I feel like if they even mention it, it will bring on the death ... we don't even talk about the word hospice. People are extremely uncomfortable with that, especially the elderly...."* MSW3

These comments address the challenges of communicating about most aspects of an anticipated death. Both RN2 and MSW3, who describe themselves as Caucasian, bring their own set of belief systems about what it might mean to another to be 'stoic', to have 'suffering,' or what might bring on a death. Their experience, however, demonstrates that medical aid in dying may not be a priority or even of interest for patients of many different ethnic or religious backgrounds.

Cultural disparities include challenges in serving patients who may be undocumented

and with access to limited or no healthcare at all prior to their hospice admission:

"...if you have the language barrier alone, negotiating the medical system for simple things ... and you are illegal ... you have no insurance and now you are dying ... but when you break it down to access, when you break it down to someone who has limited education, limited ability to get in a car and drive somewhere, limited ability to communicate with a doctor effectively... if you say, here is the packet of information, ... people who can't read ... So they have so many layers of obstacles that is not really fair." MD4

MD4 suggests that providing information alone is not enough to inform and educate everyone about options, and an abstract concept is of little use to patients with no health insurance. Information alone is of little or no value when patients lack transportation and financial resources they need for other necessities. Getting simple daily needs met is challenging for many people facing end of life. Patients may potentially be at risk of increased suffering that often accompanies advanced illness if they lack resources, making it less likely that they would utilise the DWDA. Social workers also commented on how information about choices is not the only obstacle to helping patients access different options:

"Some people can't do the paperwork...Some can't leave the house... one didn't have a doctor who would do it for her as well...." MSW7

The comment of MSW7 highlights an array of inequities that are experienced by

hospice patients who are vulnerable socioeconomically, live in more rural areas of the state, or are from diverse ethnic and cultural groups. Patients may not be able to fill out the forms or have the physical capacity to get out of bed due to illness. These inequities—such as access to necessities including healthcare—influence how or if DWDA impacts their lives and options if they are facing death.

6.2 Suicide

6.2.1 Hastened death— "Using medications to commit suicide"

Participants shared several stories about patients who were considering DWD but pursued alternative means to hasten death. Both of the following stories indicate how discussing suicide is relevant in the discourse of experiences with DWD. Reasons why patients did not begin or complete the process of DWD in these stories include not having information about legal options or the desire or ability to follow through with the DWD process. In some stories, the death of the patient was entered as suicide on the death certificate. In other stories, the cause of death was listed as the disease depending on whether the death was reported as a suicide:

> *"One very ill woman with advanced cancer took all of her comfort medicines in a suicide attempt...she was thinking about pursuing death with dignity, but she didn't…she just took all of her meds…she ended up dying of a medicine overdose, and so technically it was a suicide that we had to put on her death certificate, but if it was a death with dignity, you put the cause of whatever the terminal illness was…so that's a pretty big distinction there…It's a fine line but it is a distinction."* MD1

The distinctive 'fine line' discussed by MD1 emphasises that because the death wasn't within the guidelines of the DWDA and instead from an overdose of prescribed medications, it is called suicide. But, in the end, the patient has controlled timing of death in both situations. This fine line—the boundary between what is and is not classified as suicide—is very blurry, especially when the cause of death is not listed as suicide, but the professional is aware the patient used hospice medications to hasten death:

> *"...a couple of incidents where patients have ended their own lives with the hospice prescribed medication, ... at least in one case it wasn't someone who was pursuing death with dignity, and in another case, it was somebody who was actively pursuing the Death with Dignity law....so they used their hospice related medications to commit suicide."* MD3

Patients may not know, however, how much medication will be effective to end life, and if they would suffer in the process of taking the medication.

MSW5 told stories of patients who went through the process of medical aid in dying but then hastened death with an intentional overdose from drugs obtained illegally or medications saved from previous prescriptions, because of their lack of access to legal life-ending medications from local pharmacies:

> *"... and everything was going along and then he got his prescription, and the pharmacy didn't have his medication, saying they would have to order*

it....and at that point in time, he was frustrated with the whole process and took all of his morphine and all of his Lorazepam that was in the home, and became unconscious and died." MSW5

Thus, MSW5 explains that lack of access to DWDA medications was the cause of this patient dying of an overdose from comfort medications that were prescribed to him, but not prescribed for ending life. However, the death of this patient was not identified as a suicide by the hospice team or the coroner, another indication that open discussion about the patient's death could cause additional grief for families or complications for the professional who may be held accountable if the death is deemed a suicide. If the social worker assessed the patient for suicidal ideation and found them not to be at risk then they could not necessarily be held responsible; however, they might feel responsible for the death. In some cases, participants suggested that family members knew and supported a patient's intent to hasten death. However, all healthcare providers are required to report when patients are at risk of harm to themselves, which may cause some professionals to feel conflicted when determining and reporting risk when a patient seeks but is unable to obtain DWD and intentionally ends their life in another way.

Participants also shared stories of patients who took an intentional overdose of medications years prior to the passing of the DWDA. Several of these deaths were not identified as suicide:

"I think some of those patients took more morphine and more Lorazepam just

to, I wouldn't say commit suicide, but make themselves just go out unconscious." RN6

RN6 thinks that patients purposefully hastened their death with hospice medications, and the circumstances of these deaths were not discussed openly as suicides, or intentionally hastened deaths. MSW1 had also experienced similar situations:

"I have direct experience with a patient who took all of his medications... knowing that the nurse and I were coming ... And he had expired... And because when he was on hospice the cause of death is presumed to be the disease process ... it was not classified as suicide by the coroner, it was classified as death by disease... he was sitting upright when we found him, and his medications were not there, so it seems like that's what it was, given what I knew about him ...it was his desire to be in control of how he died, even though he didn't use a formal program that was sanctioned culturally and legally." MSW1

The stories of MSW1 and RN6 both indicate that patients receiving home hospice services have died by suicide both before and after the DWDA was implemented. Healthcare professionals want to support the patient to end suffering, however, it is as if they are put in the position of power betraying the patient if they call a death from intentional overdose a suicide. Participants imply that these stories are not easily shared and that lack of open communication about these deaths cause added emotional distress. Professionals may be afraid to speak openly about suicide

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because they feel responsible for not being able to help someone experience a natural death free from pain and suffering.

6.2.2 Palliative Sedation as an alternative to DWD— "Asking us to do it for them"

Palliative sedation was brought up by several of the participants as an alternative to DWD for patients who have intractable suffering. Palliative sedation is primarily defined by participants as being medications administered to the patient to provide relief from symptoms, resulting in unconsciousness:

"usually patients are in facilities, hospitals" MD1

"we have an excellent policy on palliative sedation…it involves an ethics consultation immediately, that it involves everybody involved in the case" RN4

"There are probably different definitions of it… if you are giving someone a combination of morphine or some other combination of Lorazepam or other benzodiazepine you are sedating them palliatively as death approaches so I find that to be palliative sedation" MD2

Others said that palliative sedation was unavailable in more rural areas due to lack of staff to administer and monitor it safely. Some participants commented that palliative sedation is oral medications administered by carers of patients at home in consultation with hospice nurses but were unaware if there is an organisational policy around this practice. The diversity of experiences indicates that the understanding or implementation of palliative sedation is inconsistent among

participants.

MD3 points out that the high cost for a legal lethal dose of medications has become a bigger issue because patients who cannot afford the medications are asking for alternative options:

"And one of the reasons why it has become a bigger issue is because the cost of medications for death with dignity is so high that it is a barrier for so many people ... that were pursuing death with dignity now, that would have it if they could afford it, are now asking us to do it for them so to speak..." MD3

In this comment, MD3 explains that palliative sedation was offered for patients who could not afford or were not eligible for medical aid in dying. Participants from more than one organization spoke of the use of palliative sedation as an alternative to DWD. In the following story, MSW5 describes how patients who cannot afford the medical aid in dying medications could request palliative sedation through hospice services. The patient felt suicide would be difficult for his family to accept and could not afford the DWD medications. Palliative sedation, provided by the hospice service, was used as an alternative for this patient:

"... we had a patient who couldn't utilise the death with dignity process, pain was controlled... but in his mind, there were other pieces of the pain puzzle that was going on...a lot of psychosocial pain... He had done the process but couldn't afford the medication. And he said that he would take all of his pain

meds if he could do it but didn't want to do that to his family and he was miserable...he asked for palliative sedation...he wanted to sleep the rest of the time." MSW5

MSW5 says that the patient's physical pain was controlled but that his mind was suffering despite all efforts to address his suffering.

"I had a patient who had quite a bit of pain... He wanted to die in the worst possible way. He asked about death with dignity ... He had a history of depression ... but in the end because we were committed to helping to end his suffering he was titrated on pain medications until he was comfortable, which took us to palliative sedation in this case." MSW4

MSW4, employed at a different organisation from MSW5, describes a similar situation but where the patient would not be eligible for DWD because of his history of depression. In both cases, palliative sedation was used and considered an alternative to DWD. Hospice professionals assist in providing palliative care that supports and pays for medications used for palliative sedation for patients suffering from severe and refractory symptoms.

6.2.3 Voluntary Stopping of Eating and Drinking

Voluntary stopping of eating and drinking (VSED) was discussed by most participants as another way patients sought to hasten death. This was unrelated to access of DWD in most of the stories. Participants did not identify VSED as a form of suicide but acknowledged that hospice patients might have hastened death from days to

potentially several months using this method.

"She said I am going to stop eating and drinking on a certain date, and she said I want to know that you will be there to support me, ... and the nurse visited at least once a day and she monitored her suffering, her grimacing, and she would help the husband medicate ... and I think it took about 5 days. And when she was gone, it was an amazing experience. We didn't have support after that ...We didn't have permission to openly ... talk about it."
MSW7

Most of the participants from all the disciplines thought that patients who voluntarily stopped eating and drinking had control over their deaths. However, as indicated by this participant, openly communicating about patients' choices is not always supported in the organisation or with other team members. Indeed, MSW7 considered that discussing VSED was taboo within her organisation or team. Participants did not comment on whether there was organisational policy about VSED, but there might have been what has been called 'unwritten rules'. Staff who work with a patient may feel emotionally isolated from professional scrutiny, but support the patient's decision independently from the team, as explained by MSW4 and MD1:

"I went to see him the first time for the hospice information session. The first question he asked me is how would you feel about my decision to stop eating

and drinking. And I said well, I will respect your decision to stop eating and

drinking and he said ok you can be my social worker." MSW4

"I remember being just a little uncomfortable ... but the bottom line is as her

doctor I am there to support her ... in her decisions." MD1

In both of these comments the participants supported the patient's decision despite personal discomfort. These statements suggest less of a taboo within the team emphasising patients' choice as primary. MD1 expressed discomfort but supported the patient with her decision when he might not have been able to support her if she had chosen DWD because his employer would not likely have allowed it.

"it took her 15 days to die…she was discerning about every aspect of her life

during this period, and she let me in and that you know, the amazing

trust…this is what is so beautiful about this work … the level of trust that

happens." CH1

CH1 demonstrates what most participants describe: that the intimacy of their experiences in home hospice promotes a trust in the relationship with the patient that is not easily found in the clinical setting.

"She couldn't get death with dignity, which she really wanted. So, she decided

to stop eating and drinking and she died within about 2 weeks." RN6

RN6 suggests VSED as an alternative to DWD, and she had no conflict in supporting this patient's wish. The goal of hospice care is comfort and quality of life, and not to hasten death. In some stories, it is suggested that VSED is slightly more acceptable to professionals and within organisations than DWD or suicide, but a cultural taboo clearly remains if not all feel that they can speak openly about these experiences. Hospice professionals struggle between helping someone to live as well as they can until the end of their life and supporting them with their desire to control timing of death. But in the preceding stories, there were several statements referring to a level of trust patients had with the staff member and what it takes to facilitate a life facing illness and dying.

6.3 The blurry boundaries of suicide

6.3.1 "Suicide is a loaded word."

Participants presented a range of emotions when speaking about experiences with patients who died by suicide. This raises questions about how an experience was noted as suicide and how participants defined suicide. This section examines participants' interpretations of suicide, and the terms participants used when speaking about medical aid in dying.

There is a range of uncertainty about what is considered suicide. Participants from each discipline considered suicide as a loaded word containing painful emotion and meaning:

"Because suicide is a loaded word in our culture. Some people...are angry for not trying harder...suicide has all this religious background...technically it is illegal, but what are you going to do, go arrest the person after they have killed themselves?" RN4

Many of the professionals interviewed have the understanding that suicide is illegal even though this is not true in the United States (Mishara & Weisstub, 2016). RN4 thinks that this understanding is guided by religious beliefs. It is as if the act of suicide is committing a crime that is only punishable in the afterlife.

"Suicide is such a loaded word...such a loaded word.... Suicide.... in some cases, there is anger behind that, certainly hopelessness and helplessness, but anger as well" MSW6

MSW6 believes a range of emotions influence the experiences of professionals communicating about suicide. Both RN4 and MSW6 suggest that when someone takes their life, loved ones might experience anger because only the survivors seem to be the ones punished. However, professionals also indicate that they experience these emotions, including feelings of helplessness when patients succeed in hastening their own death.

"Suicide is such a loaded word, but people should have the right to make that decision" RN6

"That word is a huge barrier to understanding...it is a loaded word. When discussing the law with families or patients we do not use the word suicide for sure. But I don't think it helps us to pretend that our patients aren't actively taking their own lives...." MD3

MD3 believes avoiding the use of the word 'suicide' makes it easier to discuss DWDA as an option yet acknowledges that technically it could be called suicide when patients are actively taking their own lives. The comments of MD3 and RN6 indicate that despite the use of the term 'suicide' it could be a rational decision to hasten death.

"Suicide has all this stuff attached to it." CH1

CH1 expresses what professionals of all disciplines suggest, that strong emotions are attached to the word 'suicide'. Participants had a range of emotions and experiences indicating suicide is not easily discussed.

Professionals' interpretations of suicide highlight the problem of the blurring between discerning death by suicide while in hospice care from death with legal life-ending medications as a form of suicide. MD3 summarised what many participants of all professional groups expressed about these blurry lines:

"... and I think the open conversation about where the blurry lines are morally and ethically in terms of assistance in the line between physician aid in dying

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and euthanasia versus suicide. I think those blurry lines should always be explored" MD3

Having open communication for professionals to speak about the uncertainties about suicide and issues of hastened death is a common theme among all participants.

6.3.2 Death with Dignity— "It isn't a great word for this kind of death."

When describing experiences with patients who died with a legal lethal dose of medications, participants expressed difficulty using the word 'suicide ':

"I've had one patient that has actually gone through with it...who did die with physician assisted.... I hate to use the word suicide.... she took the medications to end her life." MSW2

MSW2 did not want to use the word 'suicide' when describing a patient who used the DWDA to hasten death. It is as if she felt an obligation to call it suicide but was uncomfortable describing that the patient had died in this way. In contrast, MSW7 notes the need for more language to describe death from DWD; that different language makes the act of hastening death with DWD more comfortable and acceptable:

"I wish we had more language. I wish there was another word for it ... A word besides suicide. It isn't a great word for this kind of death." MSW7

And RN7 goes even further, avoiding this definition altogether:

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"I try to stay away from assisted suicide. That sounds a bit rough." RN7

Professionals interviewed all appear to agree that the language of suicide does make a difference, even when they might have felt the patient has the right to make the decision to end their life. Using the word suicide, however, has negative influences on other aspects of life and death, such as financial matters and life insurance. Some faith traditions prohibit persons who die by suicide from having certain funeral rituals, or from being buried in sacred ground. An intentionally hastened death is taboo when it is called suicide, at least in the culture of the participants. Use of different language softens the reaction and experience for those who do not feel suicide or hastening of death should be prohibited in all cases.

Table 6.1 demonstrates that nearly all of the participants (18) interviewed identified the term 'death with dignity' or the acronyms DWDA or DWD when describing experiences with patients around the legal option to request a lethal dose of medications to end their lives. Some participants used more than one term:

Table 6.1. Terms used by participants

TERMS	PARTICIPANT
Aid in dying or medical aid in dying	
Assisted death, physician-assisted death	MD1
Assisted dying	
Assisted suicide	MSW7, RN7
Death with dignity	MD1, MD3, MD4, CH1, CH2, MSW2, MSW3, MSW6, MSW7, RN5, RN7
DWDA	RN1, MSW1 MD4
DWD	MSW1, MSW4, MSW5, RN2, RN3, RN4, RN6
Physician aid in dying	MD3, MSW4
Physician-assisted suicide, PAS	CH3, MD2

Only two participants used the word 'suicide' when describing DWD experiences with patients. Two others, MSW7 and RN7, mentioned suicide but also referred to death with dignity when describing experiences. Only two participants, MD3 and MSW4, identified physician aid in dying as a term. The name of the Act is the primary influence of the language used by participants; however, when a participant said they felt morally conflicted with DWDA, they were more likely to use the term physician assisted suicide.

The terms we use for DWD do make a difference according to most of the participants. When medical aid in dying is called 'physician assisted suicide', RN4 considers the term itself places the burden on the physician rather than the act that is technically committed by the patient:

"So, physician-assisted Suicide. That bugs the shit out of me and here is why… it uses the word suicide …and it says physician assisted, so it puts all of the emphasis on the physician. The physician isn't the one dying…the physician isn't the one making the choice … it puts the burden on the physician. It makes the physician responsible." RN4

This comment by RN4 implies that combining the word 'physician' with the term 'assisted' is a contradiction because the physician is not assisting in the action of the patient ingesting the medication, and in many cases, is not present at the time of ingestion. RN4 challenges the physician's experience, set out in the previous chapter, that they have feelings of responsibility yet it is the patient causing their own death

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when they are dying. Use of the term 'suicide', coupled with the role of physician, conflicts with the act itself.

Interpreting suicide was found to be challenging for most of the participants. Cause of death can sometimes be ambiguous, making it difficult to differentiate between a suicide death and a natural death. A continuum of experiences was described that might be best illustrated in Figure 6.1. Natural death is on the left side of the arrow, with suicide on the far right of the arrow. Medical aid in dying is in the middle, with other described causes of death on the side of suicide or the side of natural death. This figure suggests what many participants suggested: that boundaries between them are blurry. The arrow pointing up and down (the vertical axis) considers how a perception of medical aid in dying and some forms of hastened death are a form of rational suicide, though this differs among individuals.
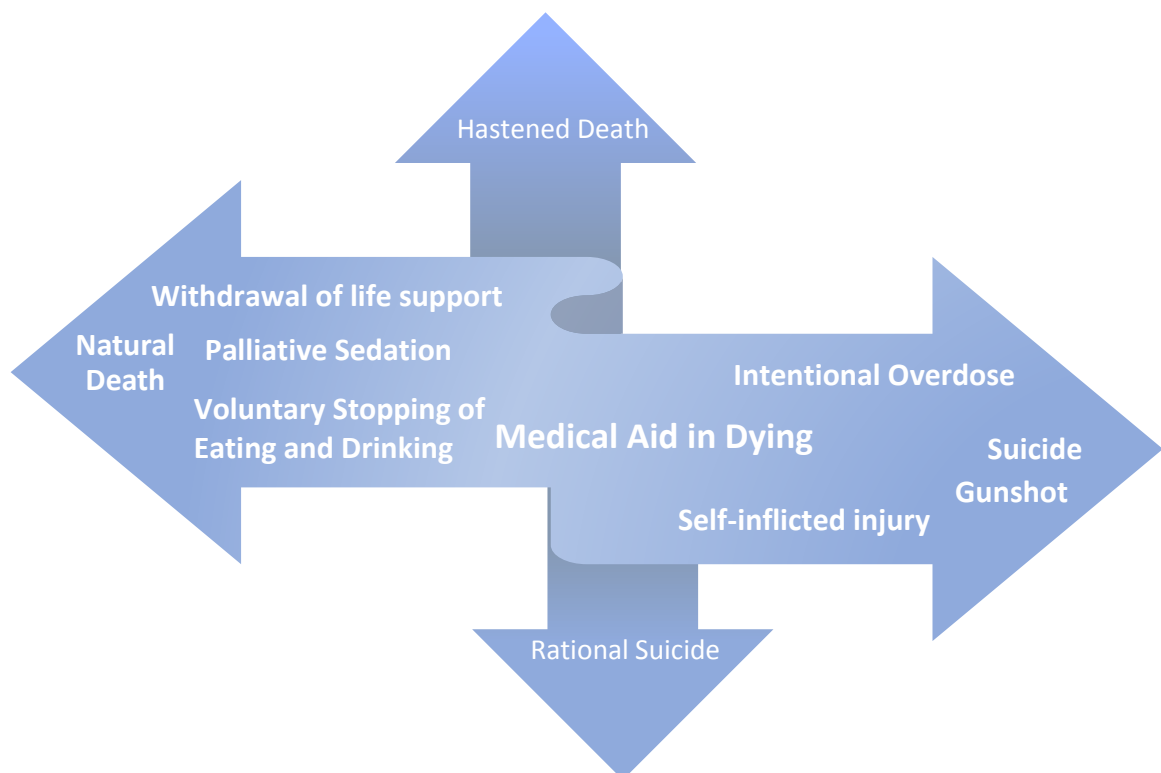

Figure 6.1. Interpretations of hastened death and suicide

Death was anticipated in all the stories and interpretations of suicide and hastened death. How patients died, however, affected professionals based on their relationship with the patient, the cause of death, and the organisational system involved. Most of the participants explained that they referred to the social worker to assess patients at risk of suicide. Some of the most challenging stories were those shared about patients who tried to end their lives with a gun, and sometimes successfully did so:

"He had…fear of getting into pain… so I am not sure he trusted us in hospice that we could mitigate pain if he got into it…he shot himself in the head. He left a suicide note, and apologised to his family for leaving a mess… never saw it coming, there was no depression notable leading up to his suicide." MSW4

MSW4 felt that the patient had not previously demonstrated suicidal ideation or intent. This death, like many other suicides described by professionals, caused emotional distress among staff, and made it difficult for them to know how to prevent a violent death, when their purpose is to help patients to be comfortable. If the patient had been identified as a suicide risk, determining how to implement safety measures and mental health treatment to prevent suicide, in addition to treatment for physical symptoms associated with the advanced disease, may require hospitalisation against the patient's will. However, in the following case the risk was apparent:

".... And they wanted control over what was going to happen and they were

not going to hang around after a certain point...the family knew, the children

knew, the wife knew… he was the one who said "You know I wouldn't let my

dog go through this. I feel I deserve the same." He went out one day on the

lawn and killed himself so he didn't splatter anything in the house.   I talked to

him til the cows came home about alternate methods. But he wasn't having

it." MSW7

This story shared by MSW7 indicates that both she and the family were aware of the

patient's risk of suicide, were unable to prevent it, and were accepting of the

patient's decision to die. In this story, the patient lived at home in a rural setting,

which may also be an indication of an overall lack of options, including suicide

prevention in rural areas. But the social worker implied that despite her efforts to

counsel the patient, there were also no structured ways to communicate and treat

suicidal intent with other team members to prevent this violent death.

"... and we had one person who attempted to shoot themselves ... That was in

hospice in a home. He missed." CH3

Patients who killed themselves with a gun or other violent method where cause of

death was obvious were identified as a suicide. Participants' reactions to these

experiences suggest the risk of causing emotional and physical harm to others,

including hospice staff and family members, is tremendous. Participants shared

several traumatic stories of arriving at a patient's home to find they had died by

gunshot wound, and in some cases the patient had not yet died. Some of the

participants reported that when a patient is referred to hospice care the staff screen for guns in the home. If there is any indication that there are guns in the home, staff can request that the guns be removed to provide home hospice service to ensure safety for the patient, family members, and hospice staff. However, patients and families might still have access to guns even if they indicate there is no access to them or the guns are locked up. In most of these stories, participants said they did not identify the patient as a suicide risk, but as patients who valued independence and autonomy, much like patients who might seek DWD. This raises the question of the difference in suicide assessment for someone who is physically healthy with a depressive illness from one with an advanced disease. The stories of participants emphasise that despite efforts to reduce the risk of a violent death, patients still die violently by suicide under some circumstances such as with guns.

Participants expressed feelings of conflict and powerlessness regarding needing to prevent suicide on the one hand, supporting patient autonomy on the other, and discerning suicide risk, as MSW2 explains:

> *"You know you have to intervene if someone is suicidal, ... I will always follow the law ... I had a client ... very mentally ill, and terminally ill ... We made a plan. He did eventually die from his disease process, but that actually stuck with me...I said, you know, sometimes, I think people do have the right to kill themselves...so the law and social work values are not always in line with my personal values..." MSW2*

MSW2 referred to a comprehensive suicide prevention initiative in Washington State that includes mandated reporting and training for professionals (Washington State Department of Health, 2016b). The act of suicide is not illegal but professionals are mandated to report to authorities if a patient is known to be a suicide risk. The dilemma, MSW2 notes, comes from feeling that the law regarding the need to report a patient at risk for suicide conflicts with her role to support patient autonomy. She identifies the difference between someone who would be considered suicidal due to depression or mental illness from someone who does not want to experience decline and dependence from illness.

"... hospice patients fall in another category. I'm not going to sit here and make a plan for how to keep someone alive ...this is not the purpose of end-of-life counselling..." MSW7

MSW7 points out that distinguishing a suicidal patient from a patient who seeks to hasten death is not so simple because hospice patients are dying anyway. Some social workers suggested that traditional psychiatric treatment is not available for patients with advanced illness:

"...if somebody is so desperate and can't go on living, who am I to stand in their way. You know, maybe it is hard for me if my goal is to make them more comfortable. Maybe if they do commit suicide or do hasten their death, I'm going to have to deal with that... I don't think ethically I can stand in their way. I think arresting someone for trying to commit suicide is stupid. Like

really, like closing the barn door after the horses left. Society has to make a

change." RN6

In the quote from RN6, she may be referring to the fact that someone who is at risk of harm to themselves could potentially be hospitalized against their will if they are determined to be suicidal. RN6 makes the point that suicide is a crime that can be punished, yet feels it is her duty to support her patients wishes if she feels she cannot help them feel more comfortable and they wish to die. Suicide is not a crime in the United States, but a cultural taboo persists that it is unlawful (Mishara & Weisstub, 2016):

"I give great reverence to life and the idea of ending a life is no little thing so I

don't feel like I have any kind of like, strong political feelings about people's

rights, but I do feel like it should always give us pause to consider what is

happening with that person and to help them ... explore all of their thoughts

and feelings around ending their life or hastening their death ... it is no little

thing and should be treated in that way." MSW6

MSW6 explains that allowing patients to communicate their fears and desire to hasten death needs to be taken seriously and with skilful care. As she says, "it is no little" thing for professionals to witness countless experiences of suffering and patients who successfully ended their lives despite the interdisciplinary team and hospice support. This experience presents a conundrum for most of the participants who had contradictory emotional responses ranging from feelings of responsibility

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for some deaths, to strong reactions in support of equality, patient autonomy, and the right to control the timing of death.

RN3 summarised what many participants expressed after being interviewed for this study: hospice professionals feel isolated and alone and need to communicate about issues of suicide and hastened death:

> *"Probably the biggest thing in the last five years is that everything has changed and everything is computerised and we have very little social contact with one another in the field so I work alone all the time and I find it isolating and it leaves me starved for somebody to talk about my job." RN3*

There were many stories of patients who were either unable to complete the process of DWD and instead chose to stop eating and drinking, take an intentional overdose of medications, or end life with a gun. The lack of ability to provide free access to lethal medication, coupled with patients withholding information on their intentions to hasten death, would suggest professionals have limited ability or power to intervene. The results of this research suggest that patients receiving home hospice care hasten death with or without the DWDA, which is not often shared openly with each other.

In the previous two chapters, I explained themes identified from within and across professional groups. During data analysis, I began to realise how much issues of power apply to the participants interviewed for the study and to the patients they

work with: people who are sick, dying, and may also be marginalised and disadvantaged. In the next chapter I bring together the themes to examine theories of power as applied to key conclusions of this study.

CHAPTER SEVEN

Discussion

Dame Cicely Saunders, founder of the modern hospice movement, was keen to emphasise that, "what we are doing" in hospice care, "is not managing the dying patients but managing terminal illness in itself in order to leave the patient as free as possible to manage this part of life" (Saunders, 2005, p. 96). In this statement, Saunders draws attention to an individual being free to manage their own experience of living and dying. Care of the dying, in other words, is caring for a patient's illness, not caring for their way of life and death but being with them to address spiritual, emotional, and physical pain, what Saunders called 'total pain' (see Clark, 1999). This statement by Saunders led me to question how palliative care professionals are managing illness and leaving patients free to manage their own lives. It implies that professionals have power over one aspect of the individual—the illness—and are handing the individual power to decide how they want to live and die.

Saunders is known for her clear objection to euthanasia, and in personal letters mentioned that it, "should be unnecessary if terminal cancer patients are properly cared for" (Saunders, 2005, p. 14). Saunders doesn't clarify, however, what it means to be properly cared for or what might happen, as the participants in the study suggest, when an individual's wishes for life and death are unavailable or inaccessible. Saunders recognised that the 'wish to die' is a wish that is not necessarily acted upon (2005, p.48). This research is about professionals' experiences and response to patients who attempt to take control over their lives and deaths,

with or without assistance, but raises the question of what happens when these decisions are in the 'management' of the medical professionals and a patient feels powerless.

This study began with the aim of understanding hospice professionals' experiences with patients who have died by suicide and hastened death. The objectives included gaining an understanding of how professionals identify suicide and how they discern between patients at risk of dying by suicide or when patients are considering utilising the Death with Dignity Act (DWDA). Assessing suicide risk is confusing if, as the results of this research suggests, the interpretation of suicide is blurry. From a social constructionist point of view, a question about the language of suicide and discourse needs to be considered in a broader social context. In social constructionism, discourse theory refers to the way we think and say something, what we do, and what can be done to us, all of which can be attributed to the work of French philosopher and social theorist, Michel Foucault (Burr, 2006). Discourse, according to Laclau and Mouffe, can be defined as representation, as opposed to being purely linguistic (Van Brussel & Carpentier, 2014: Laclau & Mouffe, 1985). Thus, if a professional is uncertain about what is suicide, they feel reluctant to label an intentionally hastened death as suicide, or if they feel the patient's decision to intentionally hasten death outside of the DWDA is rational, then a different view or approach to suicide assessment and prevention might be required than has been traditionally expected. Discourse theory is investigated further in the next section.

The findings of the study recognise that both intentionally hastened death, and suicide, are aspects of hospice care that are rarely acknowledged. These deaths are often assumed to be exclusively about Death with Dignity (DWD), but hastened deaths also include suicides that are not with the assistance of a legal lethal prescription. If the patient chooses to die by suicide or by a legal lethal prescription, they take the power of life and death into their own hands. Prescribing physicians, however, have the power to decide if a patient can obtain the DWDA medications but then place the power of timing of death in the persons' own hands, thus suggesting this is suicide as a medicalised intervention (Karsoho, Fishman, Wright, & Macdonald, 2016; Salem, 1999). This led me to question the experience of power in the relationship between the professional and the patient who hastens death or dies by suicide. To answer this question, I will first examine theories of power, explain the concept of the three dimensions of power as developed by Lukes (2005), and then apply these concepts to each of three key conclusions.

7.1 Applying the concept of power to this research

My research results identified that people who are sick and suffering submit to the authority of the medical profession who have some power over how they live and die. The professionals who work with them also submit to the power of the organization or government that governs their practice. To help make sense of the phenomenon of power, I examined theories that included the concept of bio-power, or 'bio-politics', conceived by Michel Foucault (Rabinow & Rose, 2006). Foucault discussed how power is present in all aspects of life, all levels of society and how one must look beyond the people who "submit to it and reveal the problem of
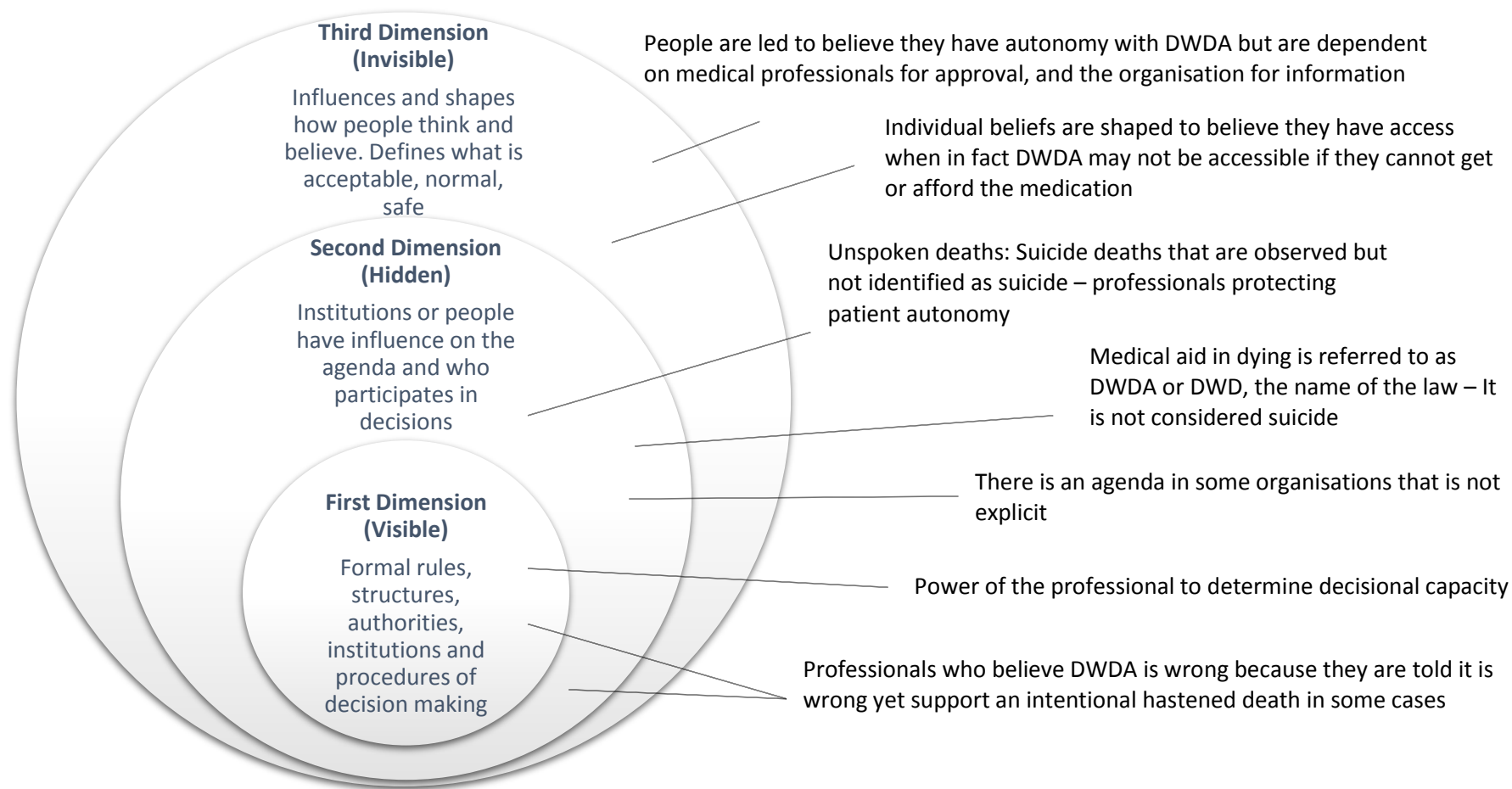
domination and subjugation" (Foucault, 2003, p. 27). Bio-politics is simply defined

here as a power over life and death (Agamben, 1998; Rabinow & Rose, 2006). I

subsequently examined the phenomenon of power developed by sociologist Steven

Lukes, who suggested a three-dimensional view that positions many levels and

aspects of power within a framework (Lukes, 2005). Lukes argues that a three-

dimensional view helps us to understand power that is not only visible and

measurable, but also aspects of power that are invisible and unobservable (Lukes,

2005). Lukes asks fundamental questions about domination and what causes those

who are dominated to acquiesce to power (Dowding, 2006). Lukes presents three

distinctive views of power that are explained in Table 7.1:

Table 7.1. Lukes' three dimensions of power

Lukes' Three Dimensions of Power	
One-Dimensional View *"focus is on behaviour in making of decisions in which there is an observable conflict of interests" p. 19*	Focus on: • Behaviour • Decision making • Observable, overt conflict • Preferences revealed by political participation
Two-Dimensional View *Considers "ways in which decisions are prevented from being taken on potential issues over which there is an observable conflict of interests" p. 25*	Focus on: • Decision making and non-decision making • Issues and potential issues • Observable and non-observable conflict • Subjective interests
Three-Dimensional View *Considers how people acquiesce to power by believing the values that oppress them or are resigned to them*	Focus on: • Decision making and control over political agenda • Issues and potential issues • Observable and latent conflict • Subjective and real interests

Adapted from: Lukes, S. (2005). Power. A radical view. The original text with two
major new chapters: Basingstoke: Palgrave Macmillan, p. 29

Figure 7.1) is an adapted model of Lukes' three-dimensional view of power developed by advocates and educators, VeneKlasen and Miller, that further helps to understand power in the context of this research (Gaventa, 2006; Lukes, 2005; VeneKlasen, Miller, Budlender, & Clark, 2007). VeneKlasen and Miller build on Lukes' three-dimensional view that does not see power as a purely negative consequence of domination, suggesting instead that "power is dynamic and relational, rather than absolute" (VeneKlasen et al., 2007). Figure 7.1 demonstrates how these dimensions may be viewed as interrelated, and interdependent, meaning that in some experiences there is a dynamic process between and within the different views. The first dimension is embedded in the second and third dimensions. A dynamic process of power often identifies a dominator having power over an oppressed, but elements of power do not have to be strictly negative as seen in some of the examples beside the figure:

Third Dimension (Invisible)

Influences and shapes how people think and believe. Defines what is acceptable, normal, safe

Second Dimension (Hidden)

Institutions or people have influence on the agenda and who participates in decisions

First Dimension (Visible)

Formal rules, structures, authorities, institutions and procedures of decision making

People are led to believe they have autonomy with DWDA but are dependent on medical professionals for approval, and the organisation for information

Individual beliefs are shaped to believe they have access when in fact DWDA may not be accessible if they cannot get or afford the medication

Unspoken deaths: Suicide deaths that are observed but not identified as suicide – professionals protecting patient autonomy

Medical aid in dying is referred to as DWDA or DWD, the name of the law – It is not considered suicide

There is an agenda in some organisations that is not explicit

Power of the professional to determine decisional capacity

Professionals who believe DWDA is wrong because they are told it is wrong yet support an intentional hastened death in some cases

Adapted from:
VeneKlasen, L., Miller, V., Budlender, D., & Clark, C. (2007). *A new weave of power, people and politics: the action guide for advocacy and citizen participation*: Practical Action Pub.
Lukes, S. (2005). Power. A radical view. The original text with two major new chapters: Basingstoke: Palgrave Macmillan

Figure 7.1. Three Dimensions of Power

In the first dimension, there are formal rules and structures of decision making that are visible.   The first-dimensional view, also called the one-dimensional view (Lukes, 2005), can be explained as the individual that wins the argument in a conflict is the one who possesses the power. The first-dimensional power may also include the authority that establishes clear boundaries about what is right and wrong. An authority may be an individual, an institution, or the people within the institution who assert power over others who must abide by the rules. In this first-dimensional view, the physician has the authority, or power over life and death, to determine if a patient is eligible for the DWDA. This one-dimensional view is power that is visible, observable, and measureable.

The second-dimensional view, also called the two-dimensional view, refers to the one who controls the agenda in the power relationship. For example, the law that is created by those who have decision-making power influences the terminology used to describe the law. A concrete example of this second dimension is with study participants who use different terms for DWDA. The Death with Dignity Act is not referred to as 'assisted suicide', 'assisted dying', or 'physician assisted dying', but primarily referred to and discussed using the name of law, DWDA, or DWD. The decision making might be covert or overt in the second dimension, but there is a hidden agenda if all are not involved in the decision-making process. Institutions might also have an agenda that is not explicit in policy. The policy of some institutions refers to the law as 'assisted suicide', suggesting hidden values that are against the DWDA.   The institution uses words that can influence meaning and beliefs of others working for them, which is also a factor of the third dimension. This

is demonstrated by the different interpretations and implementation of policy by participants who worked for the same organisation and are uncertain what to believe is true about policy or the law. Another second-dimensional view includes the professional who has reason to believe a patient died by suicide but chooses not to report the death as a suicide, thus controlling the agenda and protecting survivors from suffering the social, ethical, religious, and legal consequences of a suicide death.

The third dimension is about the unobservable, invisible conflicts that arise in a power relationship—when those in power shape the thinking of those who are governed by the law. This approach attempts to identify less measurable phenomena and hegemonic processes that operate at an institutional and societal level. Culture, customs, and religion have power that is very hard to measure, but can be applied to different settings (Dowding, 2006; Lukes, 2005). In the context of this study, individuals are led to believe they have the option to use the DWDA, but, in fact, they do not if they do not have access to information about DWDA, if there is a limited supply of medications, or if they cannot afford the drugs. In the third dimension, truth is hard to see and talk about.

Van Brussel and Carpentier (2014) describe how discourse about death has gone from denial of death, where it was hidden from public view, that suggests not knowing about imminent death makes it a lie and unreal, to death becoming institutionalized, and made public through hospitalizing individuals as they are dying and following death through the process of issuing death certificates. Death

discourse has, thus, shifted from a medical rational approach in the eighteenth century to a 'medical revivalist' alternative in the late twentieth century (Van Brussel & Carpentier, 2014). Revivalist discourse is described as the hegemony of the current death awareness and palliative care movements striving to have a 'good death'. "Requested death is perhaps the ultimate contemporary expression" of the modern efforts to control death (p. 106). This ideal good death in this modern revivalist death awareness movement is when "the dying person is in control of her/his own death" but is in conflict with the discourse of the palliative care movement that emphasises the goal of a natural death focused "less on independence, autonomy, and awareness in defining dignity (p. 20-21). Discourses provide a framework that can help to understand some of the stories about patients who have hastened their deaths that were not with medical aid in dying and help to understand the conflict between the palliative care professionals, the institutions, and the patients that they work with who are seeking control and autonomy.

Individual beliefs about autonomy are shaped by the law, with an emphasis on choice rather than acquiescing to strict regulations, the power of the physician to determine eligibility, and an organisational structure that controls the information. In the preceding Figure 7.1, the first and second dimensions are embedded in the third dimension, meaning some aspects of policy implementation can be aspects of all dimensions. A professional may believe the DWDA is wrong because they are told it is wrong, or they might be convinced to support a patient who chooses the DWDA when it is against their own beliefs. In both situations, the professional navigates between the first and third dimensions, suggesting interpersonal and moral conflicts

that might arise from these experiences between knowledge and understanding of right and wrong. I now elaborate on these concepts of the three-dimensional view of power by applying them to the key conclusions of this study.

7.2 Key conclusions

By examining professionals' experiences of suicide in a hospice context, I found three key conclusions. First, the findings support the concept that some suicides with patients who have advanced illness are considered rational. Medical aid in dying is one form of 'rational suicide' that implies "a person can make a well-reasoned decision to die" (Werth & Holdwick, 2000, p. 511). There is literature documenting a history of voluntary, sanctioned suicide among those who are elderly, and suffering with pain (Fontana, 2002; Richards, 2017). Some cultures, including Eskimo, Norse, and Samoan, accept suicide among persons facing end of life (Battin, 2015b; Ingram & Ellis, 1992; Jamison, 2011; Matzo, 1997), and there remain a few conditions that make a case for suicide as a rational act (Downing, 1970; Graber, 1981; Werth, 1992; Werth & Holdwick, 2000).

Second, I argue that the perceived taboo of suicide limits open conversations among professionals about suicide. The DWDA, however, creates an opportunity for dialogue about what is often emotionally and ethically complex. Some of these complex issues are found to include financial and rural inequities, how interpretation of organisational policy about the DWDA might limit professionals' care of patients, and how personal and religious beliefs impact experiences. I also observed that where patients live, what knowledge they have about options, and how patients are

supported by their community and family make a difference to the professionals and how they are influenced in their work.

Finally, the research results indicate that medical aid in dying and home hospice care are not mutually exclusive. This does not mean that hospice professionals offer DWD among an array of palliative care options, but that professionals work with patients regardless of the choices they make about their death, particularly when the choice is medically sanctioned.

Only two of the 21 study participants said that they can offer the DWDA as an option for patients who do not initially bring it up themselves. Some participants strongly suggested that to adhere to organisational policy, they do not provide information or referral about the DWDA but others indicated they would go against policy to give information to their patients, demonstrating the power of the professional to have influence over the agenda. Medical aid in dying, however, is only available when patients have information, meet the DWDA eligibility criteria, have access to and can afford the medication, a different example of how formal rules in the first-dimension influence approach. There is a relationship between all who are involved, and a relationship between hospice and the DWDA process.   Hospice professionals work closely with their patients who choose it as an option and support their patients with these options even when it might conflict with their own beliefs.

7.2.1 Rational suicide

These findings support the concept of rational suicide for someone who is considered mentally capable, diagnosed with a life-threatening illness, who made the decision for hastened death without coercion, and followed a process of making the decision to die (Werth & Holdrick, 2000).   Regardless of whether hospice professionals assist their patients to hasten death, there are some individuals who will succeed in hastening their own death, and some who will potentially create more harm with a failed violent or botched attempt. The individual may take their death into their own hands, but in the third dimension of power, the individual may not have freedom if the system has influenced their ultimate choice to kill themselves without assistance. Suicide is not unlawful in the United States, but the unobservable dimensions of power include the emotional and legal repercussions that often result from this type of death.   It is up to the individual professional to decide if they can assist or support the patients who are receiving home hospice services to pursue the DWDA.

This study demonstrates that hastened death and suicide are most often interpreted by professionals as people who die with the DWDA. When patients die by Voluntary Stopping of Eating and Drinking (VSED), and medication toxicity, however, these deaths appear to be regarded as rational by some of those interviewed for this study. Some participants called these deaths 'suicide' yet seemed to feel these deaths were different from other, more violent suicide deaths. Professionals are also reluctant to call these deaths suicide because to do so would imply that they failed in enabling a natural death, especially in cases where they did not report that a patient was a

suicide risk.   This is another example of the third dimension of power; when participants indicated that they acquiesce to the power and do not speak about these suicide deaths. As Lukes states, "one can consent to power and resent the mode of its exercise" (Lukes, 2005, p. 150). Professionals consent to institutional policy and restrictions, acquiescing to power as instruments of the larger institution. If these deaths are called 'rational suicides', however, the power is left to the professionals, carers and family members, to determine the mental capacity of the individual who has died, and if the decision to die is considered 'well-reasoned'. The individuals who hasten death are not necessarily powerless, but risk consequences that may not be rational.

Medical aid in dying is only one form of rational suicide, but in fact we might benefit from looking at these other aspects: including patients who die by VSED, or patients who might intentionally overdose on medication. VSED may be one aspect of rational suicide that professionals interviewed felt more likely to support and even offer as an option for some patients. Professionals have the power to make the decision to offer and support the patient because VSED is considered morally acceptable, legally permissible, and not a form of 'assisted suicide' but requires the support of carers and health professionals to manage possible unpleasant symptoms (Menzel, 2016; Pope & Anderson, 2011). This suggests the second dimension of power since professionals have the power or believe they have the power to control the agenda of how support might be given to the patient. Other hastened deaths may be considered rational for some people, but are laden with difficult emotional consequences for the carers, families and others. Some of these suicides may be a

consequence of the limited access to the DWDA and would benefit from being a focus of concern.

Medical aid in dying specifies a framework for the DWDA, a government regulated rational suicide, the formal rules indicating this is the first visible dimension of power, where one is dominated by the authority of another. The framework is implemented by the regulations of this 'rational suicide' required by the DWDA. This regulated 'rational suicide' may be one reason why participants in the study spoke initially about deaths by DWD, power in the first dimension that is visible, when asked about patients' suicide. The regulation of DWD makes it permissible to speak openly about the subject, as if DWD is the only way that individuals hasten their deaths. The problem, however, is when access to the approved 'rational suicide' is limited and patients die violent, and potentially difficult, deaths. The unpredictable outcome of the limitations of the DWDA is that unsupported suicides continue to occur, many hospice professionals feel powerless to discuss or prevent these deaths, and the law lives in tension with traditional views that any death by suicide is 'wrong'.

However, professionals in this study were not powerless in the face of domination, despite, as Lukes asserts, "the radical maintains that people's wants may themselves be a product of a system which works against their interests" (Lukes, 2005, p. 38). An example of this is with the social worker who commented that the organisation she works for does not want her to talk about or provide education about the DWDA.

She says she cannot give information about it, yet she works with the patient supporting the individual choice for what she considers to be a 'rational suicide'.

The definition of suicide, in general, is unclear when someone is suffering and the goal is providing patient-focused care. It may conflict with personal, moral, and professional obligations. The findings of this research suggest defining suicide is often blurry, especially when professionals empathise with patients who do hasten death. Employing the concept of rational suicide might help professionals working with patients in hospice and palliative care to navigate the blurry boundaries of suicide, bringing the hidden, second dimension of power into visibility. The second-dimensional view is the power to control the agenda of what is defined as suicide and culturally acceptable, even for those who have a conflict with a patient's decision.

7.2.2 Taboo of suicide

Interpretation of suicide is challenging in a culture where open dialogue, even in circumstances where it might be considered rational, is taboo. Participants in this research used the word 'taboo' when asked about suicide, suggesting suicide is forbidden (Chapple et al., 2015). Chapple et al (2015) indicate the taboo of suicide is associated with feelings of "shame and blame" that is different from emotions expressed from other losses or deaths (p. 622). The DWDA, however, indicates that this death is somehow 'less suicide' than the individual who takes an intentional overdose of saved-up prescribed medication, or the individual who does not have access to medical aid in dying, and chooses to end their life by gunshot. This and other research demonstrates that VSED also seems to be acceptable (Ganzini et al.,

2003). When the action of hastening death is not considered suicide, it pushes the boundaries of religious and other authorities when open discussion of suicide—even in circumstances where it might be considered rational—is taboo. Calling DWD, or medical aid in dying, by the name 'suicide' creates the potential for insurance benefits to be affected, religious death rituals to be restricted, or family members to suffer and possibly try to hide the cause of death (Oregon Public Health Division, 2016).

The laws in the United States distinguish between a death from DWD and a death by suicide, as described in the background chapter. This leaves the professional in the position of power to determine when to distinguish, or at least question, if a patient died by suicide. They put themselves at risk if they suggest that a patient, for example, overdosed on medications to hasten their death. Professionals are bound in the first dimension of power to report to legal authorities when confronted with ethical and moral dilemmas if there is any indication that a patient is a risk of harm to self. The medical aid-in-dying laws can reinforce and maintain taboos but can also challenge taboos. The laws have the potential to reduce the suffering experienced by family members coping with the effects of religious and economic consequences of suicide, and to reduce these ethical dilemmas faced by professionals—but only if the patient has the social, cultural, and financial capital to utilise the law.

When a community's healthcare system is dominated by a religiously sponsored system, including hospice services, then the norms associated with the church institutions play a powerful role in determining how suicide is discussed,

acknowledged, and responded to beyond just the regulation and language of the law, another aspect of the third dimension. This powerful cultural influence was cited by several of the professionals interviewed. Organisations that have vague or uncertain guidelines have influence over those they serve to think they are making autonomous decisions. This vagueness is the third dimension of power that silences professionals' ability to tell the story when it is about suicide.

The taboo, however, transcended Catholic settings and was widely described as a source of frustration and a barrier to fulfilling their professional responsibilities. This is best reflected by participants who said they did not speak openly in teams about how patients intentionally hastened death without the DWDA and who indicated that open discussion might risk their employment.

7.2.3 Medical aid in dying and hospice

The results of this research indicate that hospice care and medical aid in dying cannot be treated as separate facets of end-of-life care, especially when most individuals who use the DWDA are referred for and utilise hospice services. The process of maintaining rigorous boundaries is challenging when hospice professionals are working with patients who are dying with DWDA drugs. The policy of several organisations discourages professionals from being present during the time that patients ingest the lethal dose of medications. Yet, despite these policies, there are occasions when health professionals chose to remain with the patient, empowering both themselves and the patient. Professionals, however, were interviewed during a time of profound institutional, legal, and cultural shifts because medical aid in dying laws have passed in two more states in the United States, the District of Columbia

also in the United States, in Canada, and in Colombia since 2015. These broader shifts are experienced by professionals who are impacted by organisational policies that seem to be contradictory, underdeveloped, or invisible. They demonstrate they are governed by a set of rules that are difficult to achieve in practice.

Professionals may be limited in how they respond to requests for DWD because of personal or institutional restrictions, including their own lack of knowledge about the law. However, participants in this study, most of whom are nurses and social workers, supported patients' choices to hasten death with DWD or unassisted non-violent deaths. They witnessed patients dying with DWD medications, and when possible referred patients to an advocacy organisation to find a physician who would agree to prescribe, and they withheld information on some intentionally hastened deaths without DWD. The debate between the hospice movement discourse to control symptoms of the dying process to promote a 'natural death' and the right-to-die movement to control timing of death is, perhaps, what Van Brussel and Carpentier (2014) describe as the 'good death' versus the 'heroic death'. A heroic death—described as a death that is rational, controlled, and supporting autonomy and independence—is in this context also a good death, emphasising that an individuals' wishes are heard as they die naturally, potentially surrounded by family within their community.

Policy provides guidelines and a framework, but how policy is translated into practice might be different than the policy makers intended. This is seen in at least half of the organisations where professionals were employed and is not limited to religious or

secular employers. From a Foucauldian perspective, however, power is not fixed, is ever changing, and is 'multi-directional' (Polifroni, 2010). Professionals do not easily acquiesce to power, meaning they are not convinced to believe policy is exactly as it is stated. Lukes described this as a "minimal view of freedom," suggesting the authority has 'less' power until it infringes on one's freedom (Lukes, 2005, p. 115). Power is not dependent on a hierarchical structure but changes as truth and knowledge change. Organisations have power over what knowledge might be disseminated by professionals, but individuals might then interpret and implement the policy in a different way than originally intended. In the three-dimensional view of power, however, patients are vulnerable to the interpretation and implementation of policies, meaning they are made to believe they have control when they do not.   During a time of shifting policy and practice, professionals are innovative and creative in interpreting policies that work to maintain the integrity of the relationship with patients being served in the intimate setting of the home.   This research indicates that the shift toward integration of medical aid in dying with hospice care will continue, but not necessarily be offered as an option among an array of options at end of life.

7.3 Contribution to practice

"Getting to understand power may begin as a personal process where the simple act of talking about it openly can help people grapple with the controversy and discomfort surrounding the topic." (VeneKlasen et al., 2007)

There are several implications resulting from this research that can affect policy, practice, and future research. This research brings the invisibility of the topic of suicide in hospice care into visibility, exposing the hidden dimensions of power and

making known the unintended consequences of broader inequities affecting the provision of palliative care. Policies designed to strengthen participation and inclusion of groups that have not been involved in decision making about issues that affect quality of life and death make visible the invisible dimensions of power.

I adapted a tool developed by VeneKlasen et al that can be utilised to apply the three dimensions of power to implications of this research for future policy, and practice. Table 7.2 includes examples of each dimension of power in one column, followed by a column of examples and implications:

Table 7.2. Implications of dimensions of power

Dimensions of power	Examples	Implications for policy and practice
FIRST Visible: Making and enforcing of rules Policies, laws, regulations, implementing mechanisms	- DWDA legislation and regulation - Power of professional to determine mental competence - Policy requiring suicide assessment	- Access to palliative care - Lobbying for access to affordable healthcare - Survey professionals about suicide in areas where DWDA is legal to develop suicide assessment/treatment specifically focused for people with advanced illness
SECOND Hidden: Setting the agenda *Exclusion & de-legitimisation* Groups excluded from decision making process	- Inexplicit agenda by some organisations - Name of the law is terminology used - Lack of affordable care options and access to palliative care	- Participatory research on value of autonomy vs. community focused on: individual, familial, communal, and cultural aspects of dying - Include diverse groups in decision making about DWDA related to quality of life and death - Expand the scope of DWDA terms - Safe care option
THIRD Invisible: Shaping meaning, values *Socialisation and control of information* Processes, practices, cultural norms and customs that shape people's understanding	- People are told they have options but options are not accessible - Taboo of suicide - Cultural norm that guns are safe - Notion of autonomy not a value for everyone	- Education regarding legal options, including VSED - Open communication about incidence of suicide among people with advanced illnesses - Sharing stories, speaking out about experiences with suicide - Investigate impact of access to guns on violent death among patients with advanced illnesses - Research on the effect of suicide on family

Adapted from:
VeneKlasen, L., Miller, V., Budlender, D., & Clark, C. (2007). *A new weave of power, people and politics: the action guide for advocacy and citizen participation*: Practical Action Pub.

As noted by MD4 *"... there is a huge obstacle for rural patients ... these people don't even have enough gas money ... such huge obstacles in the way".* When people do not have access to basic needs to survive, they cannot think about access for medication to die. Those whose voices are not included in the decision-making process regarding medical aid in dying need to be included in policy decisions affecting options for living and for dying. Table 7.2 suggests a response to this hidden dimension of power is to include diverse groups in decision making about quality of life and death that would address cultural differences and inequities. From my findings, it seems that an unintended consequence of the DWDA is that it perpetuates disparities, protecting the interests of those who respect autonomy and control despite the intention of broadening options at end of life. The DWDA is available to the few who are eligible, can navigate the formal process, and can afford or have access to information about how to get resources to pay for the physician visits and the medications. However, individuals with less social, cultural, and financial capital and therefore less power, who have life threatening illness, still die from uncontrolled and distressing deaths by suicide while receiving hospice care.

Medical anthropologist Dominique Memmi suggests "self-determination is a central feature of contemporary bio-politics", as medical aid in dying supports the growing need for autonomy in this culture (Memmi, 2003). Medical aid in dying might be an acceptable shift toward the expectation of individual autonomy rather than the state being responsible for life and death decisions. But it continues to conform to regulation that she calls a "new type of social control." Medical aid in dying is acceptable, and not considered suicide, for those that fit within the guidelines and

criteria. But the data collected from Oregon and Washington indicate that it is for the educated, white, and mostly socially or politically privileged population. Others who live in more rural communities, are poorer, or are less educated have reduced access to healthcare and do not have the same choices over life and relief from suffering with palliative and hospice care or medical aid in dying. The privileged few who know about their options may avoid a painful death and the stigma associated with suicide and they are supported by a self-determined life closure.

The discussion of these issues raises the question about outcomes for individuals with a life-threatening illness who are not eligible for the DWDA, do not have knowledge or access to the DWDA process, and hasten death in other ways. Participants in the study described how patients overdose on medications, suffocate, or shoot themselves, options that in some cases cost nothing or much less than the medical aid in dying drugs. Others might choose to voluntarily stop eating and drinking, which can be challenging and require dependence on the support of their families or caregivers (Quill, 2015). The response to these examples of the invisible third dimension of power can be found by speaking out about experiences of suicide and hastened death as demonstrated by Table 7.2.

Institutional policies and professionals use a wide range of vocabulary that includes use of the term 'assisted suicide'. To call medical aid in dying 'suicide' makes it confusing when public policy is simultaneously focused on suicide prevention (Washington State Department of Health, 2016b). This exposes how professionals are trying to prevent a particular kind of unsanctioned suicide or supporting what

they might feel to be a rational decision. Professionals may not have the resources, training required, and time needed to discern what might be determined a rational decision. These complex issues need to be in the hands of not only the physician but all those involved, including the team members, carers, and family members. This is the foundation of palliative care: that it is patient and family-centred care by an interdisciplinary team (National Hospice and Palliative Care Organization, 2015). Suicide assessment and treatment options to meet the needs of people who have life-threatening illness must be an integrated part of care. Treating underlying depression, feelings of hopelessness, and being a burden is only part of the issue.

Those who advocate for medical aid in dying should be made aware of the social justice implications suggested by the results of this study: that it is not accessible for everyone due to cost, access to a physician or pharmacy to distribute the medications, and that the medications may be difficult to self-administer. Questions have arisen about what happens to the lethal medications if a patient does not use them, implications of symptoms and reactions from the medications, and in some cases, the possibility of taking several hours to die after ingestion (Oregon Public Health Division, 2016; Washington State Department of Health, 2016a).

Those who are opposed to the DWDA should be aware that there are some individuals suffering from a terminal illness who will try to take their lives in a violent or unsafe way, with or without the DWDA. Providing a legal provision for a safe death with the support of a palliative-care team of professionals can make the difference between a botched or violent suicide attempt and a natural death or a

death from medical aid in dying.

7.4 Literature in relation to findings: contribution to knowledge

The key themes identified in the literature search provided a context in which to examine themes identified in the research, and to explore gaps in the knowledge about suicide and hastened death in areas where medical aid in dying is allowed. This research confirmed the results of the findings from the literature review in chapter two: that the concept of assisted suicide is often synonymous with medical aid in dying or DWD and DWDA. Studies completed in areas where medical aid in dying is allowed often have used the term 'assisted suicide,' but there is evidence of a language shift as more countries are moving toward legalising euthanasia and 'assisted suicide' (Ebbott, 2010; Westerhoff, 2017). None of the studies included in the literature review investigated overall issues of hastened death and suicide in areas where medical aid in dying is allowed. Ganzini et al's (2003) research on nurses' experiences with Voluntary Refusal of Food and Fluids (VRFF), Anquinet et al's (2013) investigation of continuous sedation until death, and Pasman et al's (2013) study of euthanasia requests that were refused, are indications that hastened death is not only about assisted suicide, euthanasia, or medical aid in dying.

There have been several research studies indicating that there is a sort of 'euthanasia underground' suggesting that with or without medical aid in dying, patients diagnosed with terminal illness do seek ways to hasten their death to avoid suffering and, in some cases, are assisted by someone else (Asch, 1996; Magnusson, 2004; Richards, 2016). These studies, however, were not completed in locations where

euthanasia or medical aid in dying laws were implemented at the time this research was completed, though some may seek to go to Switzerland where assisted suicide is available for nonresidents (Richards, 2016). Back et al's (2002), qualitative research about clinician and patient interactions in Washington State revealed that some of the patients did receive clinician assistance to hasten death several years before the DWDA was implemented. Magnusson's (2002) research of covert euthanasia in areas where medical aid in dying is not allowed, suggests that patients and their families are at risk of experiencing negative unintended consequences from a violent suicide.

Studies do not take account of the intimacy inherent in home hospice care as suggested by findings of this research. Hospice professionals working with patients in the home are not directly monitored by others as they would be in an institutional environment and spend longer times with patients than they might in the clinical setting. In rare circumstances, lack of monitoring could lead to an abuse of power as demonstrated in the case of Dr. Harold Shipman, who in 2000 was found guilty of murdering significant numbers of his patients in the United Kingdom (Baker, 2004; Ramsay, 2001). This study did not reveal any information about healthcare professionals consenting to help kill a patient.

7.5 Study limitations

There are several limitations to this study. This study is not generalisable but provides a foundation for a measurable study including surveys about suicide in hospice care across professional groups.

My experience and role as both a hospice social worker and a researcher impacted the results of this research. Braun and Clarke (2013), however, emphasise the researcher has an active role "in the research process and in constructing knowledge" and comes with "values, interests and standpoints that shape our research" (p.303). Reflective notes were taken throughout the research and used to help distinguish my previous experiences from the experiences of participants I interviewed. For example, these notes revealed my interest, early in the interview process, in the stories of unassisted suicides rather than deaths from the DWDA. It was in the process of additional interviews that I realised the importance of the initial responses of the participants to the research question. Participants' knowledge of my role as a hospice social worker may also have influenced their responses to questions, possibly inhibiting them from sharing experiences or how they discussed their role in the process. They may have wanted to tell me something because I was a social worker, or perhaps refrained from telling a story because of my previous role. In addition, my own experiences, values, and beliefs shaped the interpretation and how I might have viewed and preferred to include some of the comments over others. In addition, my desire to ask additional probing questions in the interviews to elicit more stories may have influenced the responses. Some of the stories resulting from these questions may not have been about first-hand experiences. Thus, the stories shared may have been altered in the retelling, and not a true reflection of the death.

This study did not include other groups such as nurse assistants who may have important roles, contributions, and additional information about professional team

approaches to working with patients on issues of suicide and hastened death. Some of the groups not included in this study also have much experience and potential knowledge about patients who died by suicide or DWD. An investigation of the experiences with these other groups could be an area for further research, however, recruitment in this study focused on professional groups identified to have an active role in assessment and communicating with patients about the DWDA and suicide.

The results of this study are impacted by the sample of the participants who were self-selected after responding to an email invitation and follow-up phone calls. Those that responded may have had a specific agenda to discuss that may have biased the results. Some participants said they volunteered to be interviewed because they specifically wanted to support a social worker completing this research. Most participants identified as white, educated, and experienced. Results would likely have been different with a more ethnically and socially diverse sample. Their knowledge of my professional role as a social worker could have biased the results and may have prevented some of them from freely discussing topics. For example, participants may not have felt able to discuss active participation in euthanasia, when or if they had information about an illegal act, protecting either themselves, a third party, or myself from this knowledge.

This study is dependent on the reports from the memories of the professionals during the time of the interview. Some participants who had worked with hospice patients over 6 years could not remember if the story they were reporting occurred before or after the implementation of the DWDA. This may have biased results about

how or if the DWDA influenced the stories of suicide.

Finally, some concepts went unexamined due to the limitations of this study. These include the important concept of moral distress experienced by many of the participants, which is described as "the experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards" (Varcoe et al., 2012 p. 59). Participants in this study expressed conflict with decision making and coping with organisational constraints. Experiences of moral distress may constitute an independent thesis topic worthy of deeper inquiry.

7.6 Conclusion

In this chapter, I have applied Lukes' three-dimensional views of power to key conclusions resulting from this research. Participants empower themselves to support patients who choose assistance in dying and often despite hospice policy governing practice differently. How professionals relate to power is key to how they manage the integration of medical aid in dying in their work with hospice patients. Professionals interpret some suicides to be rational but discerning suicide risk from rational suicide is challenging when there is no open dialogue among team members. Understanding and acknowledging the limitations of palliative care and the hospice system is critical if the goal is to relieve suffering for patients at end of life.

CHAPTER EIGHT

Conclusion

This research is the culmination of many years of reflection about the subject of suicide and hastened death among people who are dying. When I initially began this research, there were only two states in the United States that had passed the Death with Dignity Act (DWDA): Oregon and Washington. Since July 2015, when interviews were completed, four more jurisdictions in the United States passed medical aid in dying laws, and Canada implemented Medical Assistance in Dying (MAiD). Initial research results from California and Canada indicate that the profile of patients is similar to those from Oregon and Washington; white, educated, and from middle to upper income levels (Li et al., 2017; Oregon Public Health Division, 2016).

The results of this research indicate that despite the DWDA, hospice patients in Washington State are at risk of suicide, but in some cases these suicides might be considered rational. The legalisation of medical aid in dying, considered by some to be a rational form of suicide, does not necessarily mean that there is a decrease in patients who die by suicide (Richards, 2016, 2017; Werth & Holdwick, 2000). It is very difficult to measure the incidence of patients who do hasten their death, if the suicide is not identified as a suicide. This research demonstrates that suicide, rational or not, continues to be a crucial and unexamined facet for some individuals facing the end of their lives in home hospice care. The reflections of professionals in this research study indicate that some people experience suffering on some level that is not alleviated when dying takes too long.

Hastened death is not only about medical aid in dying, but the reality of medical aid in dying offers an opportunity for public dialogue about the blurry boundaries of suicide and hastened death, access to care, palliative care, and safe options for the few individuals who seek to control timing of death.

Patients are hastening their deaths in ways that are sometimes violent and can lead to uncertain consequences. Simply preventing people from having access to lethal means will not alter their feelings of hopelessness and feelings of burden. Medical aid in dying or suicide is not the solution to the larger issue of lack of affordable community care options for someone who is facing loss of autonomy, or feelings of being a burden, important issues for those seeking to use the DWDA (Lee & New York Acad, 2014). Having a safe and legal option gives some people who have knowledge and information about medical aid in dying an element of power over their lives that, paradoxically, may minimise their desire to die and encourage them to utilise palliative care (Wang et al., 2015).   Finally, medical aid in dying is not available to all people, and all persons facing end of life do not have access to or interest in going through the formal process. Very few patients will end their lives utilising DWDA or die by suicide, but some of them will. If palliative care is truly patient centred, with the goal of minimising suffering, then palliative care professionals need to have open communication with patients and each other about legal and safe options to live until they face the possibility of a comfortable and safe death.

8.1 Areas for future research

This study contributes to understanding that the issue of hastened death in hospice care goes beyond a discussion of the DWDA. These areas include the critical need for further research that focuses more precisely on how social inequities in healthcare affect suicidality, and increases an understanding of how professionals, carers, and family members are impacted by these deaths. There are many additional areas to expand on this research including utilising the research results to design and implement a broader survey of professionals about suicide and hastened death in areas where medical aid in dying is legal or allowed. The results of this broader survey could be implemented across cultures and represent a greater number of participants to contribute to a better understanding how or if medical aid in dying laws are impacting both reported and unreported suicides among individuals who are terminally ill and are receiving hospice or palliative care.

Little is known about the management and treatment of suicide risk for patients on home hospice care in jurisdictions where medical aid in dying is allowed. Though there have been some studies about suicidality among hospice patients in the United States, these have not been in areas where medical aid in dying was legal at the time of the research (Arnold, 2004; Fairman et al., 2014; Washington et al., 2016). This research only begins to discuss the management of patients at risk of suicide. There is a paucity of evidence, however, about access to effective nonpharmacological treatment options in home hospice such as Dignity Therapy or Meaning Centered Therapy for home hospice patients who continue to have desire to die manifested in statements, or indications that they may hasten death; for example, a gun stored

closely by them, or stored-up medications (Breitbart, 2016; Chochinov et al., 2005; Fitchett, Emanuel, Handzo, Boyken, & Wilkie, 2015). Continued research in this area can contribute to developing guidelines for professionals to evaluate and serve those suffering toward end of life.

Van Brussel and Carpentier (2014) offer a discourse-theoretical analysis emphasizing hegemony focusing on the construction of meaning of euthanasia in Belgium, however, they do not investigate incidents of unassisted suicide and the relationship with the medical revivalist period mentioned in the introduction to this chapter. Using a discourse-theoretical analysis applied to the results of this research would be an additional area of investigation to develop an understanding of discourse and construction of meaning of unassisted suicide and medical aid in dying.

Research is indicated on the concept of moral distress, discussed briefly in section 7.5 on study limitations. Lack of or poor communication and continuity among team members have been suggested as causes of moral distress and interventions are needed designed to understand and minimise moral distress (Whitehead et al., (2015).

Research investigating violent deaths in the United States has been completed in several states, and at the time of writing is underway in Washington State (Centers for Disease Control and Prevention, 2017). The information being collected includes data about suicide deaths and physical factors related to these deaths. Very limited data, however, are available on the circumstances of these deaths, including severity

of disease and if hospice or palliative care services were involved with severely ill patients that died by suicide. It would be important to understand how or if physical factors contributed to an individual's suicide if the individual was receiving hospice or palliative care services. A retrospective investigation of coroners' reports to collect data on how many individuals who died by suicide were diagnosed with chronic or life-threatening illness and the circumstances surrounding these deaths would also help to understand the social justice implications of these deaths. In addition, an in-depth examination of suicides by guns may help the understanding of the impact of access to guns among those facing serious illness. These data have the potential to contribute to the development of education and training for palliative care professionals to understand suicidality and influence how suicide assessment and treatment is implemented with individuals coping with advanced illness.

Finally, research with family members of hospice patients who died by suicide would contribute important knowledge about the impact of these deaths on bereavement and the moral dilemmas that they face to help professionals consider all aspects of care.

8.2 Final words

This study began as an exploration of suicide from the perspective of hospice professionals working with patients who sought hastened death. The experiences of these professionals reveal that interpretation of suicide within hospice is not clearly defined, and yet despite lack of clear boundaries on the definition of suicide within hospice services, some of these deaths due to health and social inequities,

existential, physical, or emotional suffering are considered rational. The goal of palliative care to provide relief from suffering remains central. This leaves open the question of how palliative care and hospice may achieve this primary goal. This study encourages necessary dialogue on a subject that has been widely considered taboo.

May efforts focus at looking more deeply into the limitations and the potential of palliative care to ease suffering for all facing living and dying.

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Appendices

Appendix 1. Terminology examples in literature

Term	Abbreviation	Description	Authors defining term
Assisted suicide	AS	Someone makes the means of death available but does not act as the direct agent of death	Clymin et al, 2012
Aid in Dying, Assisted Death, Assisted dying	AiD	Removes physician from responsibility for patients' death since medication is self-administered	Tucker and Steele, 2007
Death with Dignity Act	DWDA	Legislation enacted in Oregon, Washington and Vermont allowing competent terminally ill adults to request lethal medications to end their lives	Death with Dignity National Center, 2017
Euthanasia, Active Voluntary		Someone other than the patient uses the means to intentionally end the patient's life	Snijdewind, 2014; Steck, 2013; Van Bruchem-van de Scheur, 2008; van Marwijk, 2007
Hastened death		Action that will likely result in death occurring sooner than it would have had this action not been taken	Werth, 2004
Physician Aid in Dying	PAD	Represent the physician role in assisting with a patient-centred decision, removing "suicide"	Ganzini, et al 2001

Terminology used in studies, continued

Term	Abbreviation	Description	Authors using term
Physician Assisted Death, Physician Assisted Dying	PAD	Removes the word "suicide"	Quill, 2012; Werth et al. 2003
Physician Assisted Suicide	PAS	Medical practice involves a physician assisting a terminally ill, competent adult in dying by writing a prescription for lethal dose of a drug to be self-administered by the patient	Ganzini et al., (2001); Ganzini et al., 2006
Patient Directed Dying	PDD	Patient is controlling the act of dying	Jablonski, et al 2012
Rational Suicide		The concept that suicide is not always irrational depending on the circumstances	Werth, 1992; Werth, 1999; Werth 2002
Voluntary Stopping of Eating and Drinking	VSED	A patient making a conscious decision to stop all food and fluids	Quill, 2012
Voluntary Refusal of Food and Fluids VWFF	VSED	Competent patients decide to forgo eating and drinking to hasten death within the context of a terminal condition	Harvath, et al., 2004; Quill and Byock, 2000

Appendix 2. Searches

Search	Add to builder	PubMED Query. 6.06.17	Items found
#13	Add	Search (((((((((("suicide"[MeSH Terms]) OR "suicide, assisted"[MeSH Terms]) OR "suicide, attempted"[MeSH Terms]) OR "euthanasia, active, voluntary"[MeSH Terms])) OR (((("assisted suicide"[Title/Abstract]) OR "assisted dying"[Title/Abstract]) OR "aid in dying"[Title/Abstract]) OR "death with dignity"[Title/Abstract]))) AND (((((((("hospice care"[MeSH Terms]) OR "hospices"[MeSH Terms]) OR ("hospice and palliative care nursing"[MeSH Terms])) OR "palliative care"[MeSH Terms]) OR "palliative medicine"[MeSH Terms])) OR "terminal care"[MeSH Terms]) OR (("end of life"[Title/Abstract]) OR hospice*[Title/Abstract]))) AND ((("health personnel"[MeSH Terms]) AND "attitude of health personnel"[MeSH Terms]) AND ((((((professional*[Title/Abstract]) OR clinician*[Title/Abstract]) OR physician*[Title/Abstract]) OR nurse*[Title/Abstract]) OR social worker*[Title/Abstract]) OR chaplain*[Title/Abstract]))) AND (((((experience*[Title/Abstract]) OR view*[Title/Abstract]) OR feel*[Title/Abstract]) OR opinion*[Title/Abstract]) OR attitude*[Title/Abstract])	842
#12	Add	Search (("health personnel"[MeSH Terms]) OR "attitude of health personnel"[MeSH Terms]) OR ((((((professional*[Title/Abstract]) OR clinician*[Title/Abstract]) OR physician*[Title/Abstract]) OR nurse*[Title/Abstract]) OR social worker*[Title/Abstract]) OR chaplain*[Title/Abstract])	891690
#11	Add	Search (((((((("hospice care"[MeSH Terms]) OR "hospices"[MeSH Terms]) OR ("hospice and palliative care nursing"[MeSH Terms])) OR "palliative care"[MeSH Terms]) OR "palliative medicine"[MeSH Terms])) OR "terminal care"[MeSH Terms]) OR (("end of life"[Title/Abstract]) OR hospice*[Title/Abstract])	93791
#10	Add	Search (((((("suicide"[MeSH Terms]) OR "suicide, assisted"[MeSH Terms]) OR "suicide, attempted"[MeSH Terms]) OR "euthanasia, active, voluntary"[MeSH Terms])) OR (((("assisted suicide"[Title/Abstract]) OR "assisted	55504

		dying"[Title/Abstract]) OR "aid in dying"[Title/Abstract]) OR "death with dignity"[Title/Abstract])	
#9	Add	Search ((((experience*[Title/Abstract]) OR view*[Title/Abstract]) OR feel*[Title/Abstract]) OR opinion*[Title/Abstract]) OR attitude*[Title/Abstract]	1428552
#8	Add	Search (((((professional*[Title/Abstract]) OR clinician*[Title/Abstract]) OR physician*[Title/Abstract]) OR nurse*[Title/Abstract]) OR social worker*[Title/Abstract]) OR chaplain*[Title/Abstract]	889232
#7	Add	Search "attitude of health personnel"[MeSH Terms]	138209
#6	Add	Search "health personnel"[MeSH Terms]	438357
#5	Add	Search ("end of life"[Title/Abstract]) OR hospice*[Title/Abstract]	25353
#4	Add	Search "terminal care"[MeSH Terms]	45465
#3	Add	Search (((("hospice care"[MeSH Terms]) OR "hospices"[MeSH Terms]) OR ("hospice and palliative care nursing"[MeSH Terms])) OR "palliative care"[MeSH Terms]) OR "palliative medicine"[MeSH Terms]	53774
#2	Add	Search ((("assisted suicide"[Title/Abstract]) OR "assisted dying"[Title/Abstract]) OR "aid in dying"[Title/Abstract]) OR "death with dignity"[Title/Abstract]	3615
#1	Add	Search ((("suicide"[MeSH Terms]) OR "suicide, assisted"[MeSH Terms]) OR "suicide, attempted"[MeSH Terms]) OR "euthanasia, active, voluntary"[MeSH Terms]	54714

Search ID	CINAHL Search Terms	
S14	S10 AND S11 AND S12 AND S13	(382)
S13	S8 OR S9	View Results (459,611)
S12	S1 OR S2 OR S3	View Results (16,143)
S11	S4 OR S5 OR S6 OR S7	View Results (49,736)
S10	TI experience* OR TI view* OR TI feel* OR TI opinion* OR TI attitude* OR AB experience* OR AB view* OR AB feel* OR AB opinion* OR AB attitude*	View Results (306,053)
S9	TI professional* OR TI clinician* OR TI physician* OR TI nurse* OR TI social worker* OR TI chaplain* OR AB professional* OR AB clinician* OR AB physician* OR AB nurse* OR AB social worker* OR AB chaplain*	View Results (434,155)
S8	(MH "Health Personnel") OR (MH "Attitude of Health Personnel")	View Results (40,304)
S7	TI end of life OR TI hospice* OR AB end of life OR AB hospice*	View Results (25,119)
S6	(MH "Terminal Care")	View Results (12,405)
S5	(MH "Palliative Care")	View Results (22,436)
S4	(MH "Hospice Care") OR (MH "Hospice and Palliative Nursing")	View Results (10,033)
S3	TI assisted suicide OR TI assisted dying OR TI aid in dying OR TI death with dignity OR AB assisted suicide OR AB assisted dying OR AB aid in dying OR AB death with dignity	View Results (2,192)
S2	(MH "Euthanasia")	View Results (2,440)
S1	(MH "Suicide") OR (MH "Suicide, Assisted") OR (MH "Suicide, Attempted")	View Results (13,891)

Search Options	PsychINFO Search 9.06.2017	
S12	(S6 OR S7) AND (S8 AND S9 AND S10 AND S11)	View Results (313)
S11	S6 OR S7	View Results (329,041)
S10	S4 OR S5	View Results (29,417)
S9	S1 OR S2 OR S3	View Results (36,158)
S8	TI experience* OR TI view* OR TI feel* OR TI opinion* OR TI attitude* OR AB experience* OR AB view* OR AB feel* OR AB opinion* OR AB attitude*	View Results (975,407)
S7	TI professional* OR TI clinician* OR TI physician* OR TI nurse* OR TI social worker* OR TI chaplain* OR AB professional* OR AB chaplain* OR AB physician* OR AB nurse* OR AB social worker* OR AB chaplain*	View Results (316,741)
S6	DE "Health Personnel" OR DE "Health Personnel Attitudes"	View Results (33,358)
S5	TI end of life OR TI hospice* OR AB end of life OR AB hospice*	View Results (23,894)
S4	DE "Hospice" OR DE "Palliative Care"	View Results (12,890)
S3	TI assisted suicide OR TI assisted dying OR TI aid in dying OR TI death with dignity OR AB assisted suicide OR AB assisted dying OR AB aid in dying OR AB death with dignity	View Results (1,863)
S2	DE "Euthanasia"	View Results (1,662)
S1	DE "Suicide" OR DE "Attempted Suicide" OR DE "Assisted Suicide"	

Search ID#	Academic Search Complete Search Terms 09.06.2017	Actions
S11	S7 AND S8 AND S9 AND S10	View Results (346)
S10	S5 OR S6	View Results (739,271)
S9	S3 OR S4	View Results (60,776)
S8	S1 OR S2	View Results (32,876)
S7	TI experience* OR TI view* OR TI feel* OR TI opinion* OR TI attitude* OR AB experience* OR AB view* OR AB feel* OR AB opinion* OR AB attitude*	View Results (1,953,268)
S6	TI professional* OR TI clinician* OR TI physician* OR TI nurse* OR TI social worker* OR TI chaplain* OR AB professional* OR AB clinician* OR AB physician* OR AB nurse* OR AB social worker* OR AB chaplain*	View Results (722,806)
S5	SU health personnel OR SU health personnel attitudes OR SU health personnel experiences	View Results (30,718)
S4	TI end of life OR TI hospice* OR AB end of life OR AB hospice*	View Results (53,277)
S3	SU hospice care OR SU (hospice and palliative care nursing) OR SU palliative care OR SU palliative medicine OR SU terminal care	View Results (17,327)
S2	TI assisted suicide OR TI assisted dying OR TI aid in dying OR TI death with dignity OR AB assisted suicide OR AB assisted dying OR AB aid in dying OR AB death with dignity	View Results (5,432)
S1	SU suicide OR SU suicide assisted OR SU suicide, attempted OR SU euthanasia	

AMED Search Terms 09.06.2017		
S7 AND S8 AND S9 AND S10	Search modes - Find all my search terms	View Results (236)
S10	S5 OR S6	View Results (34,651)
S9	S3 OR S4	View Results (15,952)
S8	S1 OR S2	View Results (2,338)
S7	TI experience* OR TI view* OR TX feel* OR TI opinion* OR TI attitude* OR AB experience* OR AB view* OR AB feel* OR AB opinion* OR AB attitude*	View Results (26,872)
S6	professional* OR clinician* OR physician* OR nurse* OR social worker* OR chaplain* OR professional* OR clinician* OR physician* OR nurse* OR social worker* OR chaplain*	View Results (32,163)
S5	TX health personnel OR TX health personnel attitudes OR TX health personnel experiences	View Results (5,244)
S4	TI end of life OR TI hospice* OR AB end of life OR AB hospice*	View Results (6,162)
S3	TX hospice care OR TX (hospice and palliative care nursing) OR TX palliative care OR TX palliative medicine OR TX terminal care	View Results (15,104)
S2	TI assisted suicide OR TI assisted dying OR TI aid in dying OR TI death with dignity OR AB assisted suicide OR AB assisted dying OR AB aid in dying OR AB death with dignity	View Results (932)
S1	TX suicide OR TX suicide assisted OR TX suicide, attempted OR TX euthanasia	View Results (2,141)

(Hawker et al., 2002)

Studies were given a rating of 1-4 on each of these items from very poor to good respectively, as suggested by Hawker, et al (2002):

1. Abstract and title: Did they provide a clear description of the study?
Good   Structured abstract with full information and clear title.
Fair   Abstract with most of the information.
Poor   Inadequate abstract.
Very Poor   No abstract.

2. Introduction and aims: Was there a good background and clear statement of the
          aims of the research?
Good   Full but concise background to discussion/study containing up-to-
          date literature review and highlighting gaps in knowledge.
          Clear statement of aim AND objectives including research questions.
Fair   Some background and literature review. Research questions outlined.
Poor   Some background but no aim/objectives/questions, OR   Aims/objectives
but   inadequate background.
Very Poor   No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?
Good   Method is appropriate and described clearly (e.g., questionnaires included).
          Clear details of the data collection and recording.
Fair   Method appropriate, description could be better. Data described.
Poor   Questionable whether method is appropriate. Method described
          inadequately.
          Little description of data.
Very Poor   No mention of method, AND/OR Method inappropriate, AND/OR No
details   of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?
Good   Details (age/gender/race/context) of who was studied and how they were
          recruited.
          Why this group was targeted. The sample size was justified for the study.
          Response rates shown and explained.
Fair   Sample size justified. Most information given, but some missing.
Poor   Sampling mentioned but few descriptive details.
Very Poor   No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
Good   Clear description of how analysis was done. Qualitative studies: Description of
how   themes derived/respondent validation or triangulation.
          Quantitative studies: Reasons for tests selected hypothesis driven/
          numbers add up/statistical significance discussed.
Fair   Qualitative: Descriptive discussion of analysis. Quantitative.

Poor   Minimal details about analysis.
Very Poor   No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary
        ethical approval gained? Has the relationship between researchers and
        participants been adequately considered?
Good   Ethics: Where necessary issues of confidentiality, sensitivity, and
        consent were addressed.
        Bias: Researcher was reflexive and/or aware of own bias.
Fair   Lip service was paid to above (i.e., these issues were
        acknowledged).
Poor   Brief mention of issues.
Very Poor   No mention of issues.

7. Results: Is there a clear statement of the findings?
Good   Findings explicit, easy to understand, and in logical progression.
        Tables, if present, are explained in text. Results relate directly to aims.
        Sufficient data are presented to support findings.
Fair   Findings mentioned but more explanation could be given. Data presented
        relate directly to results.
Poor   Findings presented haphazardly, not explained, and do not progress logically
        from results.
Very Poor   Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable
        (generalizable) to a wider population?
Good   Context and setting of the study is described sufficiently to allow comparison
        with other contexts and settings, plus high score in Question 4 (sampling).
Fair   Some context and setting described, but more needed to replicate or
        compare the study with others, PLUS fair score or higher in Question 4.
Poor   Minimal description of context/setting.
Very Poor   No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and
        practice?
Good   Contributes something new and/or different in terms of
        understanding/insight or perspective. Suggests ideas for further research.
        Suggests implications for policy and/or practice.
Fair   Two of the above (state what is missing in comments).
Poor   Only one of the above.
Very Poor   None of the above

Appendix 4. Appraisal Findings and Comments

Authors	Score	Findings	Comments
Anquinet, L., Raus, K., Sterckx, S., Smets, T., Deliens, L., & Rietjens, J. A. (2013)	36	Differences between continuous sedation and euthanasia (some participants stated that the distinction between the two is sometimes blurred or even non-existent, especially when medication is increased disproportionally or when sedation is induced too early)	At least 10 participants worked in Palliative Care unit. This study is included because it is suggested that continuous deep sedation is used in conjunction with assisted dying in Flanders. Cultural, social, legal factors, and organisational differences explain variability in use of continuous deep sedation, and as a choice where euthanasia is allowed.
Carlson, B, et al 2005	35	Chaplains divided with responses to request for physician assisted suicide. Chaplain discomfort suggested as wanting to avoid influencing a patient's decision, and conflict with belief about PAS. Chaplains overall did not believe they had strong influence on patients' decision.	This study did not investigate experiences with patients who might have intentionally hastened death or died by an unassisted suicide.
Chin, et al 1999	23	Main study focused on patients and patient data. 14 physicians were interviewed about challenges associated with writing a prescription for lethal medications.	Data obtained from first year of DWDA/limited to one paragraph of data from interviews with physicians. There is limited information about how these interviews were conducted.
Clymin, J., et al 2012	28	Fear of job loss, ethical conflict and challenges responding to patient questions, lack of knowledge and need to refer elsewhere for information about DWDA emerged as predominant themes.	Strength: First identified study about nurses and DWDA Limitation: did not identify nurses working with patients with advanced disease.

Cohen, J., Van Wesemael, Y., Smets, T., Bilsen, J., & Deliens, L. (2012)	36	Results of physician surveyed: Walloon physicians more often not to administer lethal drugs and more likely to administer palliative sedation. Flemish physicians have better notion of legal obligations and Walloon physicians less likely to consult second physician and report officially.	Use of descriptive questions in survey of physician suggests more value neutral responses.
Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Elwyn, G., Vissers, K. C., & van Weel, (2013)	35	Five main themes emerged: (1) initiation of sharing views and values about euthanasia, (2) building relationships as part of the negotiation, (3) fulfilling legal requirements, (4) detailed work of preparing and performing euthanasia and (5) aftercare and closing.	Making decisions about euthanasia demands a proactive approach towards participants' preferences and values regarding end of life, towards the needs of relatives, towards the burden placed on physicians and a careful attention to shared decision-making.
Dierckx De Casterlé, et al (2010)	36	Flemish nurses wish to be and are are involved in 7 stages of euthanasia process (before request, confronting the request, decision making, preceding euthanasia, carrying out euthanasia, immediate aftercare, later aftercare).	There is no indication from this study that patients might seek to die by unassisted suicide.
Dobscha, SK, et al 2004	36	Requests for PAS facilitated discussion. Physicians expressed discomfort about managing symptoms, and issues of abandonment.	There is no indication that physicians spoke about patients who died from unassisted suicide.
Francke, A. L., et al (2016)	36	Majority of nurses want to be involved in euthansia decision making and not all aware that they are not allowed to administer lethal drugs.	There is no indication that nurses experienced patients who might have hastened death unassisted despite suggestion that they have frequent contact at end of life.
Gamondi, C., Borasio, G. D., Oliver, P., Preston, N., & Payne, S. (2017)	36	Swiss palliative care physicians report being involved in assisted suicide decision making with their patients but are not willing to prescribe lethal medications. Instead they seek alternatives after exploring the origins of patients' requests. Education about structured ways of communicating with patients about assisted suicide is recommended.	There is no mention of alternatives offered for patients who are refused assisted suicide and if patients refused assisted suicide by palliative care physicians are dying by suicide or seeking other alternatives to hasten death.

Ganzini, L., Dobscha, S. K., Heintz, R. T. & Press, N. 2003	36	First study of two from same qualitative study of physicians. Suggest how care might be improved with patients requesting assisted suicide.	Results theoretical, not generalizable. Informants reviewed and verified material before publishing.
Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A. & Lee, M. A. 2000	36	Challenges physicians faced with DWDA: unwanted publicity, difficulty obtaining medications, understanding requirements of law, ambivalence. Concern about depression with patients but not less concern about vulnerable populations being affected.	Strength: large sample with 65% response. Difficult to generalise. Physicians opposed to law unlikely to respond to survey.
Ganzini, L., Nelson, H. D., Lee, M. A., Kraemer, D. F., Schmidt, T. A. & Deloit M. A. 2001	36	Physicians more likely to refer to hospice, and conversations with patients about DWDA perceived to be more helpful; physicians not fully informed about prescribing prescriptions.	Physician skill in pain and symptom management not assessed. Study about whether physician skills improved may not be attributed to DWDA.
Ganzini, L., Harvath, T. A., Jackson, A., Goy, E. R., Miller, L. L. & Delorit, M. A. 2002	36	Patient background is described; depression described as less likely factor to wishing for PAS, hospice care may be refused by 20% of patients who die by PAS.	73% returned survey; social workers and nurses agree that patients request PAS because they want to control circumstances of death.
Ganzini, L., Goy, E. R., Miller, L. L., Harvath, T. A., Jackson, A. & Delorit, M. A. 2003	36	Nurses report of patients who stop eating and drinking because they wish to die. Nurses rated quality of death an 8 on scale of 1-9.	Based on nurses perceptions, but unclear if nurses reported on patient's inability to eat and drink due to disease.
Georges, J. J., The, A. M., B. D, O.-P., & van der Wal, G. (2008)	36	Dealing with requests for euthanasia is very challenging for GPs, although they feel committed to alleviate a patient's suffering and to promote a peaceful death.	There is no indication that patients pursued an unassisted suicide or intentionally hastened death after conversation with physician or that this aspect was investigated.

Harvath, T. A., Miller, L. L., Smith, K. A., Clark, L. D., Jackson, A. & Ganzini, L. 2006	33	Suggests several challenges hospice professionals face when patients request PAS, including that PAS is antithetical to hospice goal. Professionals feel sense of responsibility to dissuade patients from persuing PAS.	Suicide is investigated only as it applies to assisted suicide. There is no indication that professionals experienced patients intentionally hastening their own deaths.
Inghelbrecht, E., Bilsen, J., Mortier, F., Deliens, L. (2010)	36	Nurses were involved in decisions about euthanasia but not consistently. In euthanasia , 40% of nurses were involved in preparation of life ending drugs and administered drugs in 12% of cases. In cases of life ending drugs without patient's consent/request, nurses administered drugs in 45% of cases	Nurses administer life-ending medication without request by patient more often and without legal regulation. By law physicians are supposed to discuss euthanasia requests with nurses but they don't always. No data was collected about a patient's intent to hasten death or die by suicide without nurse assistance.
Meeussen, K., Van den Block, L., Bossuyt, N., Echteld, M., Bilsen, J., & Deliens, L. (2011).	35	One of seven terminally ill patients dying at home under the care of a GP expresses a euthanasia request in the last phase of life but only 19% of those who requested were granted.	There is no indication that there were some experiences or knowledge of patients who died by unassisted suicide.
Miller, L. L., et al. 2004	36	Social workers more supportive of ODDA compared to nurses. Professionals need to be prepared for conversations with patients about PAS. Hospice and PAS not mutually exclusive.	From same survey as Ganzini, et al 2003, 2004.
Norton, E. M. & Miller, P. J. 2012	20	Professionals desire to comply with law but faced with competing organizational values.	Small sample size. There is a suggestion that suicides happen all the time that are unaccounted.
Norwood, F. (2007)	36	Story of discussions that occurred from end of life experiences. Talk about euthanasia conforms to at least 5 stages; initial euthanasia request, written declaration, second opinion appointment, scheduling euthanasia, and euthanasia death.	There is no indication that there were unassisted suicides.

Otte, I. C., Jung, C., Elger, B., & Bally, K. (2016)	35	Three themes: concerns for their own psychological well-being, conflicting personal values, understanding of professional role	No mention of patients who die by unassisted suicide. Only the topic of assisted suicide or assisting a patient to 'commit suicide'.
Pasman, H. R., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2013)	32	Patients who are refused may be silent about their risk, and quality of life may be further diminished. At least one patient tried die with overdose and another intentionally VSED	Patients were not diagnosed with a terminal prognosis and not on hospice. A few patients did choose to hasten death unassisted.
Snijdewind, M. C., van Tol, D. G., Onwuteaka-Philipsen, B. D., & Willems, D. L. (2014)	36	The results show that complexities can be categorized into relational difficulties and complexities that arise because of unexpected situations. Process toward EAS may be disrupted, influenced by physician and relatives. Communication is key to prevent complex situations.	Investigation limited to complexities around requests for euthanasia or physician assisted suicide. It is uncertain if patients died by suicide unassisted if their request was rejected.
Van Bruchem-van de Scheur, G., Van der Arend, A., Abu-Saad, H. H., Spreeuwenberg, C., Van Wijmen, F., & Ter Meulen, R. (2007)	36	22.3% of 278 cases patients spoke about request with district nurse first; 49.8% of 267 cases nurses were not involved in GPs decision making, and 13.3 of 264 cases attended administration of lethal drugs; district nurses provide some aftercare to surviving relatives in 80.3% of 264 cases. communication between GPs and district nurses needs improvement.	Part of a larger study of nurses' role in end of life decision making. Investigation limited specifically to physician assisted suicide and no investigation of patients who might have intentionally hastened death without assistance.

Van Bruchem-van de Scheur, G., Van der Arend, A., Abu-Saad, H. H., Spreeuwenberg, C., Van Wijmen, F., & Ter Meulen, R. (2008)	36	There is a large difference between role of nurses in home-care and hospital settings. Consultation between nurse and physician needs improvement, as their role varies in the various stages of the euthanasia process. Suggestion that multidisciplinary institutional guidelines are needed	It is suggested that if a euthanasia request was not granted that 37.2% of the nurses held empathy for the patient. The study did not investigate if these patients were supported and if some of them hastened death in other ways.
van Marwijk, H., Haverkate, I., van Royen, P., & The, A.-M. (2007)	28	Euthanasia has a major impact on PCPs. Their relationship with the patient, their loneliness, the role of the family, and pressure from society; more training recommended.	There is no mention of unassisted suicide or patients who might have hastened death in other ways.
Voorhees, J. R., Rietjens, J. A., Van der Heide, A. & Drickamer, M. A. 2014	36	Discussions of PAD opens up conversations strengthening doctor-patient relationships.	Results of study in two countries; PAD regulation differs in each country. Limited to perspective of physician.

Appendix 5. Recruitment letters

Recruitment letter, flyer, emails, and follow up information

Hospice professionals' experiences with patients about suicide and desire for hastened death in Washington State

Email invitation to participate in this study for WSHPCO membership and list:

Hi!

I am inviting you to participate in a research study I am conducting with home hospice professionals working in Washington State. The purpose of this research study is to understand home hospice professionals' experiences with patients around issues of suicide or desire for hastened death in Washington State.

If you are working as a chaplain/spiritual counsellor, nurse, nurse practitioner, physician, or social worker providing or supervising home hospice services in Washington State you may be eligible to participate in this study.

It is important to know that participation is voluntary and any identifying information about participants will be omitted.

If you are interested in learning more, please call me at 1-503-395-7930 or email me at s.gerson@lancaster.ac.uk. You are welcome to distribute the attached flyer to any interested colleagues. I am happy to answer questions, and send you additional information about this study at your request.

Thank you for your time and consideration. I look forward to hearing from you.

Sheri Mila Gerson, LICSW, ACSW
Olympia, Washington
PhD Student in Palliative Care
Lancaster University, UK

s.gerson@lancaster.ac.uk
US Mobile: 1-503-395-7930

Email invitation to participate in this study for hospice professionals who have expressed interest in this research:

Hi,

I am writing to you because you previously expressed interest in research I am conducting with home hospice professionals in Washington State. I have now started recruitment and would like to invite you to participate in this research. You are welcome to distribute the attached flyer to colleagues who may also be interested in participating in this research.

The purpose of this research study is to understand home hospice professionals' experiences with patients at risk of suicide or who have expressed desire for hastened death.

You may be eligible or know others eligible for this study that are working as a chaplain/spiritual counsellor, nurse, nurse practitioner, physician, or social worker providing home hospice services in Washington State. I want to understand what desire for hastened death might mean to professionals from different disciplines and areas around the state, and how their experiences might influence communication with patients at risk of suicide or considering a hastened death.

Any identifying information about participants will be omitted and the identity of participants who choose to be included in this study will be kept anonymous but extracts of interviews may be included in the analysis and final summary. It is important to know that participation is voluntary.

If you are interested in learning more, please call me at 1-503-395-7930 or email me at s.gerson@lancaster.ac.uk.   I will answer questions, and send you additional information about this study at your request.

Thank you for your time and consideration. I look forward to hearing from you.

Sheri Mila Gerson, LICSW, ACSW
Olympia, Washington
PhD Student in Palliative Care
Lancaster University

s.gerson@lancaster.ac.uk
US Mobile: 1-503-395-7930

Follow – up email to participants who have expressed interest in the research, but did not respond to first email contact. This will only be sent once two weeks after the initial email if there is no response to the first email:

Hi,

You have expressed interest in a research study I am conducting in Washington State with home hospice professionals. I am following up to ensure that you did receive the first message.

The purpose of this research study is to understand home hospice professionals' experiences with patients at risk of suicide or who have expressed desire for hastened death.

You may be eligible or know others eligible for this study that are working as a chaplain/spiritual counsellor, nurse, nurse practitioner, physician, or social worker providing home hospice services in Washington State. I want to understand what desire for hastened death might mean to professionals from different disciplines and areas around the state, and how their experiences might influence communication with patients at risk of suicide or considering a hastened death.

Any identifying information about participants will be omitted and the identity of participants who choose to be included in this study will be kept anonymous but extracts of interviews may be included in the analysis and final summary. It is important to know that participation is voluntary.

If you are interested in learning more, please call me at 1-503-395-7930 or email me at s.gerson@lancaster.ac.uk.   I will answer questions, and send you additional information about this study at your request.

If I do not hear from you in the next two weeks, I will understand that you are unable to participate in this study. Thank you for your time and consideration.

Sheri Mila Gerson, LICSW, ACSW
Olympia, Washington
PhD Student in Palliative Care
Lancaster University

s.gerson@lancaster.ac.uk
US Mobile: 1-503-395-7930

Health & Medicine | Lancaster University

Participant Information Sheet

Hospice professionals' experiences with patients about suicide and desire for hastened death in Washington State

My name is Sheri Gerson and I am conducting this research as a student in the Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to understand experiences of home hospice professionals with patients at risk of suicide or who have expressed a desire for hastened death in a state that has passed the Death with Dignity Act. I want to understand what desire for hastened death might mean to professionals from different disciplines and organisations and how this might influence communication with patients considering a hastened death.

Why have I been approached?
You have been approached because you work as a home hospice professional providing or supervising direct services that address the comfort and well being of patients facing end of life. You could be a chaplain, nurse, nurse practitioner, physician or social worker.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part in this study. If you do decide to participate, you will be able to withdraw up to 2 weeks from the day of the interview.

What will I be asked to do if I take part?
If you decide you would like to take part, you will be asked to schedule a meeting at a convenient and agreed upon location with me for an interview lasting 1-2 hours. You will also be asked to complete and sign a consent form to participate in the study. You will be asked questions about your experiences related to the topic. You may also choose to have a follow up interview of up to 1 hour within two months of the initial interview to add any additional comments about your experiences related to the research topic.

Will my data be identifiable?
The data collected for this study will be stored securely and only I will have access to this data:

- o Audio recordings will be completed on a device with encryption capability. Only I will have access to the recordings. Recordings will be destroyed and/or deleted after the award of the PhD.
- o Hard copies of notes taken during interviews will be kept in a locked cabinet.

- o The files on the computer will be encrypted (that is no-one other than I will be able to access them) and the computer itself password protected. The computer data will
  be deleted and I will destroy any information identifying you after the award of the PhD by Lancaster University.
- o At the end of the study, hard copies of data will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- o The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else is at significant risk of harm, I will have to break confidentiality and speak to my supervisors. If possible, I will tell you if I have to do this.

What will happen to the results?
The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal or for conference presentations.

Are there any risks?
There are no major risks anticipated with participating in this study. However, if you do experience some distress following participation you are encouraged to inform me and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Whilst there are no direct benefits to taking part, many people who take part in research find participating interesting.

Who has reviewed the project?
This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact me:
Student researcher - Sheri M. Gerson: s.gerson@lancaster.ac.uk   Tel: 1-503-395-7930

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr. Anne Grinyer
Senior Lecturer in Health Research
Division of Health Research,
Faculty of Health and Medicine,
Lancaster University, Lancaster LA1 4YD
Email: a.grinyer@lancaster.ac.uk
Tel: 01524 592677

If you wish to speak to someone outside of the Faculty of Health and Medicine Doctorate Programme, you may also contact:

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University, Lancaster LA1 4YD
Email: r.pickup@lancaster.ac.uk
Tel: (01524) 593746

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Emergency and referral service**:**
24-HOUR CRISIS LINE: 866-4-CRISIS (866-427-4747)
KING COUNTY 2-1-1: DIAL 2-1-1
800-621-4636 (M-F 8am-6pm)

For therapy or mental health referrals:
Washington State Psychological Association (wspa@wapsych.org)
PO Box 95168
Seattle, WA 98145-2168
Phone: (206) 547-4220

Interview Discussion Guide

This research is to gather the experiences of home hospice professionals around the issues of suicide and hastened death in Washington State. I am interested in hospice professionals' experiences with patients about desire for hastened death (DHD) and the terminology that is used in discussing these topics.

The questions below are an example and may be adapted depending on the participants' responses and if they require additional probing.

Questions are separated by terminology, experiences, communication, and discernment; however, questions and responses overlap between these elements:

Terminology: Definition of terms
- What does hastened death mean to you in your work with hospice patients? Tell me what desire for hastened death for hospice patients means to you.
- What terms are used in your agency/organisation? With patients? With other team members?

Experiences: Clinical/professional experiences with suicide/DHD
- Tell me about the experiences you have had with patients about suicide and hastened death in the way that you have described? This may include patients at risk of suicide, or requesting information about or intent to pursue the Death with Dignity Act.
- How have you experienced patients who hastened their deaths or died by suicide?
- How have these experiences shaped your ability or experience with other patients or families you have worked with?
- What are your experiences with team members when working with patients communicating desire for hastened death or around issues of suicide?

Communication: Organisational policy and professional ethical codes regarding suicide/PAD including assessment, management and training of suicide risk
- How do organisational policies where you work inform decisions about how you work with patients communicating desire for hastened death? Is there anything that you are not allowed to discuss with your patients?
- Does your agency/organisation have a policy around suicide risk and/or DWDA?
- If you worked prior to the passing of the DWDA legislation, how has the DWDA affected your experiences with patients overall? With patients communicating DHD?
- Other influences on your experiences with patients on these topics?

Discernment: Discernment between suicide risk and hastened death
- How has your training in suicide risk assessment, management, and treatment applied in the home hospice setting?
- How is the suicide assessment training that you received applicable with your clients?
- How do you discern between a hospice patient at risk for suicide vs. a patient who has hastened their death utilizing the DWDA (if they have had this experience), or discussed other methods (voluntary withdrawal from food and fluids, palliative sedation, other)? Does your hospice have a protocol for coping with these topics? What are they

Appendix 8. Criteria for good thematic analysis

A 15 - Point Checklist of Criteria for Good Thematic Analysis (Braun & Clarke, 2006)

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for accuracy
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original dataset
	6	Themes are internally coherent consistent and distinctive
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described
	8	Analysis and data match each other –the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'

10 November 2014

Sheri Mila Gerson, LICSW
1962 Orchard DR NW
Olympia, WA 98502

Dear Ms. Gerson,

The Washington State Hospice and Palliative Care Organization (WSHPCO) is a membership organization of 36 of the 37 hospices and over 20 palliative care providers and others working to improve statewide hospice and palliative care services.

WSHPCO is responding to your request to recruit hospice professionals for the research you are undertaking to complete a thesis as a PhD student in Palliative Care at Lancaster University in the UK. We understand that the title of your research study is:

"Hospice professionals' experiences with patients about suicide and desire for hastened death in Washington State"

WSHPCO is confirming that you will have access to our membership through the organization's weekly newsletter. We will also email your research request to all members to recruit participants for your study when you are prepared to begin your research. Please contact us again at that time.

We appreciate your interest in this study, as there is an overall lack of research into many facets of end-of-life care, both from the patient and the professionals perspective.

Thank you,

Anne E. Koepsell, MHA, BSN, RN

Anne E. Koepsell, MHA, BSN, RN
Executive Director

Appendix 10. Research Consent Form

Consent Form

Hospice professionals' experiences with patients about suicide and desire for hastened death in Washington State

We are asking if you would like to take part in a research project about hospice professionals' experiences with patients concerning suicide and desire for hastened death.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Sheri Mila Gerson. Email: s.gerson@lancaster.ac.uk   Phone: 1-503-395-7930

Please initial below

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study

2. I confirm that I have had the opportunity to ask any questions and to have them answered.

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.

4. I understand that audio recordings will be kept until the research project has been examined.

5. I understand that my participation is voluntary and that I am free to withdraw my data within two weeks after the interview is completed without giving any reason.

6. I understand that once my data has been transcribed, anonymised and incorporated into themes it might not be possible for it to be withdrawn.

7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

8. I consent to information and quotations from my interview being used in reports, conferences and training events.

9. I understand that any information I give will remain confidential and anonymous. However, if there is concern that there is a risk of harm to others, or myself, the researcher may need to share this information with her supervisors or relevant authorities.

10. I consent to Lancaster University and the researcher keeping written transcriptions of the interview for 10 years after the study has finished.

Appendix 11. Initial categories and codes identified across data set

Categories

VRFF	Death with Dignity Meds	Palliative Sedation
VRFF as an option	Practicing to pass the test	Call it assisted suicide
VRFF not taking life (suicide)	We are going to do what makes sense	alternative to DWD
VRFF passive	don't tell anyone	Alternative to suicide by gun
Don't always talk about it	Uncharted territory	Spouse felt he killed patient
Rural Story	Intentional Overdose	Self-inflicted gunshot
Palliative Sedation barrier	unreported	He was a part of that gun
Cultural differences	Reported as suicide	Impact on staff
higher suicide rate	Is it euthanasia	really messy
access to PC differences	DWD process too hard	I wouldn't let my dog go through this

DWDA	Perceptions -suicide	DWDA Terminology issues
Feelings of responsibility	sometimes people have right to kill themselves	actively pursuing Death with Dignity law
not part of natural process	haven't arrived	assisted suicide
die on own terms	suicide is a loaded word	commit suicide
DWDA is suicide	control at end of life	hate term Death with Dignity
mixed feelings	put to sleep like with a vet	physician assisted suicide
can't pretend we can always manage pain	law and profession not always in line with my values	never going to use suicide with DWD
no value in unnecessary suffering	who am I to stand in their way	Participant in the death with dignity program
couldn't do it myself	hate the word suicide	call it what it is
more willing to bend rules		determined life closure
religious/faith		Initiative 1000
DWDA like C-section		physician aid in dying
Dilemma/Distress	Grey Areas	Policy interpretation
did I make a mistake	honest communication	Chinese wall
feeling like a	many unknowns	my experience separate from

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failure		organisation
not knowing who is in control	blurry lines	patient must bring it up
suicide as medical emergency	boundaries should be flexible	cannot be present
helping pts avoid suicide	unintended consequences	attitude toward policy
I just want to do it right	slippery slope	not allowed to give information

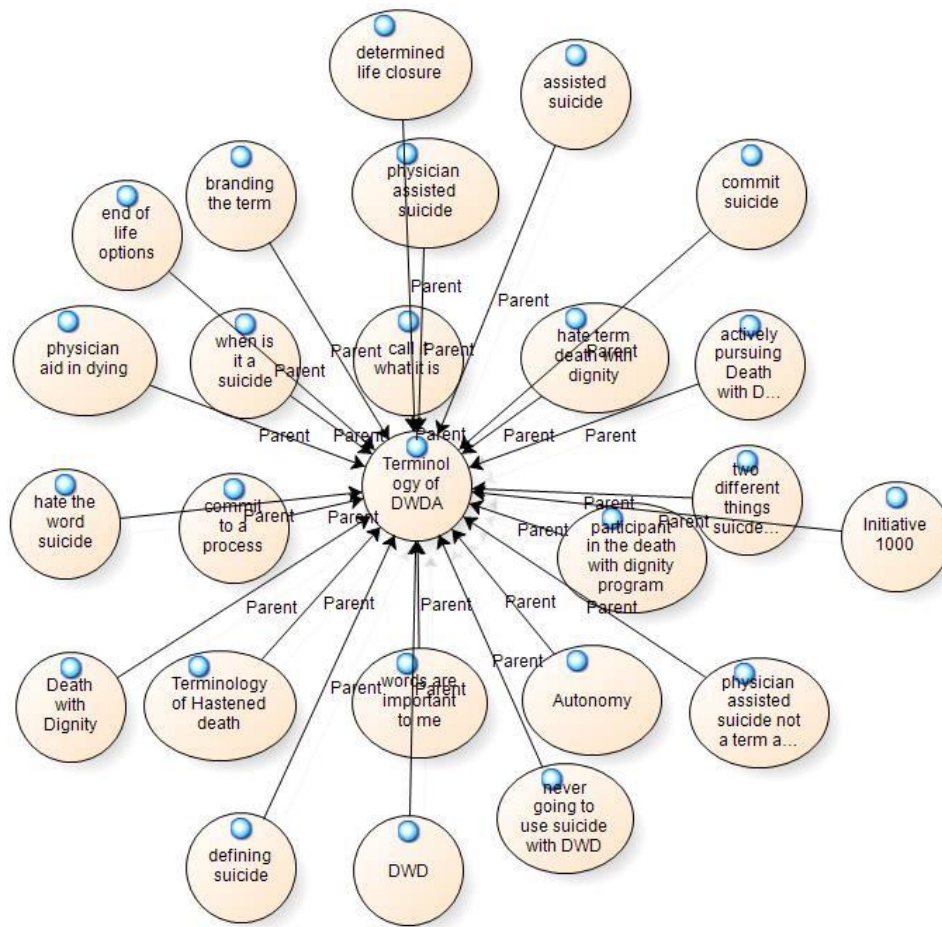| Suicide Assessment	Cultural Issues	Barriers/obstacles
training does not address eol	access to medical care Indian Nations	barrier to pain management rural barrier
create safe place to discuss	system not seen as supportive	need to keep it secret when rural
no training	high suicide rate-high drug diversion	DWDA cost
problems with follow up	limited health care access for Latino	DWDA regulation taxing
limited resources	language barrier/literacy barrier	DWDA access to medications-scarcity of meds
suicidal do not send signals	distance to travel to get and or receive care	DWDA - literacy barrier
screening for risk of guns	autonomy not valued in all communities	DWDA access to participating provider
not chaplains' role	undocumented - any care is good care	

Home vs Institutional Care	Team Issues	Challenges
we can spend hours in home	DWD impact on team	denial of death
Pal Sedation not in home	staff training	have to face my own stuff
It's totally different at home	support by team members	managing symptoms and quality of life
with us it's the end of the road	team members who refuse to participate	not being able to talk about death with dignity
pts have to talk about dying at home		understanding nuances of clinical training
Patient in control in the home		prognostication issues

more open communication in the home	232	assessing depression and mental competence
Up close &personal		do diligence
when pts have hospice they don't want DWD		isolation as professional

Additional Categories

Professional identity	Socioeconomic priorities
Purpose for participating	Story - personal
Response to initial question	Things happen when we aren't there
Shift in policy/beliefs/sea change	

Appendix 12. Example of Coding Tree from NVivo10

Appendix 13. Example of how themes were identified

Stages of Coding		Process of Coding into theme	
Familiarisation with data		Researcher completed interviews, and transcribed all data from recordings. Recordings were then reviewed against transcription.	
Coding – Used Nvivo10 to code and categorise	**"DWDA stories"** identified as one initial category Initially coded across entire dataset	**Examples of Codes:** *I'm not allowed to know* *Like attending your own wake* *Staying within organisational guidelines but still helping patient* *Having a prescription is like a security blanket* *Standarising practice is hard* *Not abandon patient* *There is a fine line between policy and wanting to support a patient* *Pretending that we can't always manage pain...is naive*	**Example of Codes:** Barriers/Lack of access to: DWD – *can't afford, can't get medicine* *Can't get to a doctor* *Don't have money for gas* *Easier to get access to a gun or save up pain medications* Cultural differences – *need to do anything you can do to keep someone alive* *Don't trust the system*
Searching for themes	Identified some categories within each professional group – established new categories in Nvivo10	*Separated codes into professional groups:* **Physicians**: *sense of responsibility, personal/professional conflicts; ... the responsibility of signing that and getting someone the prescription like that, that is a heavy-duty thing, that is a really big deal.* **Nurses** *– choice is theirs, conflict with personal values, organisational restrictions; can't think of one hospice*	Across professional groups DWDA barriers/access/organisational issues identified *team members very supportive*

		team member who would bow out of a DWD or not be engaged **Social Workers –** *I love it, but conflict between professional/personal ethics and organisational policy* **Chaplains –** *I might have done the same thing in his circumstance*	
Reviewing themes	New categories: professional roles and differences Nurses, social workers, chaplains – Intimacy of care in home; *we can spend hours in a home* Physician – *less involved in home visits*	Review of subthemes and relationships between them – power identified as impacting barriers to access
Defining and naming two of the initial themes and sub-themes	**Relationship of hospice with medical aid in dying** Variation among professional groups. Professionals have a different sense of power and responsibility with patients pursuing medical aid in dying	**Social Justice (cost, access, barriers, cultural differences)**
Writing up Themes	**Final analysis**	

Adapted from Braun & Clarke (2013)