# Experiences of caregivers who support a patient who elects voluntarily stopping eating and drinking (VSED) to hasten death

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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

## Background

Voluntarily stopping eating and drinking (VSED) is an ongoing choice to forego food and hydration to hasten death. VSED does not require clinician involvement, but caregiving is necessary as patients become weak and lose concentration as a result of dehydration. This study is the first to explore the experiences of VSED caregivers.

## Aim

The aim of this thesis is to explore the experiences of informal caregivers (family or friends) who supported a patient through VSED, with supporting objectives to evaluate VSED caregiving against theoretical models of end-of-life caregiving and to compare VSED caregivers' experiences with caregivers who have aided patients at the end of life, including other forms of hastened death.

## Methods

The study included interviews with 24 caregivers of 20 individuals who attempted VSED. Inductive and deductive thematic analysis were used to analyse the experiences of VSED caregivers. These experiences are compared with results of two systematic reviews of studies on end-of-life and hastened death caregiving.

## Findings

Caregivers believe that VSED is the best death available to the patient. Caregivers act as advocates and worry that the patient's goals will be challenged by healthcare or legal authorities. Obtaining support from hospice helps legitimise VSED. Through the VSED process, caregivers carry the responsibility for the patient's success as the patient becomes weaker. Finally, caregivers note that there is no social script to guide someone aiding a person who is slowly, deliberately trying to die: caregivers choose what roles to play, such as focusing on physical care or being emotionally present as the patient's spouse or child.

## Conclusion

Caregivers take responsibility for VSED patients' success. Caregivers' interaction with clinicians, community, and legal structures exceeds the scope of available caregiving theories. A socio-ecological model and the theory of bio-power can help illustrate how each layer of society affects VSED caregivers' experience.

# Table of Contents

# List of Tables

# List of Figures

# Chapter 1: Introduction

On a warm evening in August 2016, about 100 elderly New Yorkers crowded a lecture hall at the Society for Ethical Culture on Manhattan's Upper West Side. They had gathered to hear Judith Schwarz, PhD, clinical director of the advocacy group End of Life Choices New York, present an overview of voluntarily stopping eating and drinking (VSED) as a means to hasten death. She addressed the moral and ethical implications of VSED, as well as the practicalities: what support patients need, the typical clinical course, and the imperative of not drinking, as dehydration is what facilitates death.

The audience had questions. How long would it take? Could someone do VSED alone? Emphatically not, Schwarz said. VSED can take two weeks, more if the patient drinks. Patients require physical care as they grow weaker. They need help managing symptoms like dry mouth, and most importantly, they need emotional support and someone to remind them of their goals as they become confused with dehydration. VSED isn't easy and requires great determination, Schwarz said. She had seen many patients give up or have to try more than once.

As the youngest person in the room by 30 years, I sat on the floor as I took notes. The presentation had focused on the VSED process for the patient, but I wondered about the family or friends who served as their caregivers: what must it be like to sit with someone for two weeks whilst they slowly, deliberately tried to die? At home that night, I scoured PubMed and found very little literature on VSED, and none on the experience of informal caregivers. The question was on my mind a few weeks later when I left for the first residential week at Lancaster University's PhD programme in palliative care. Four years later, this thesis serves as an attempt to answer it.

## Aims and focus

The aim of this study was to explore the experiences of U.S. caregivers supporting patients through VSED. To achieve this aim, the study included three objectives.

The first was to explore the experiences, including actions, relationships, emotions, and concerns in a particular social context (Snape & Spencer, 2007), of caregivers in the United States who have supported someone through VSED.

The second objective was to evaluate ways in which VSED caregiving does or does not align with available theoretical models of end-of-life caregiving, specifically Hudson's modified stress coping model (2003). This objective was included to help contextualise VSED caregiving, which has not been previously studied. Using an existing theoretical model provides a lens through which VSED caregiving can be evaluated on its own and also compared more broadly with other caregiving experiences.

The third objective was to compare experiences of VSED caregivers with results of research with caregivers who have aided patients at the end of life, including in other forms of hastened death. Comparing VSED with them can help highlight ways in which caregivers' experiences may be similar or may require different support.

## 1.1 Background of researcher

Undertaking a PhD programme in palliative care unites my professional background as a medical journalist and educator and a longstanding interest in the healthcare individuals receive at end of life. I have spent most of my career synthesising and translating scientific evidence for healthcare professionals. The work led to an understanding that healthcare only evolves and improves when it has rigorous evidence to guide it. Learning to think and work as a social scientist, a process facilitated by the reflexive nature of this thesis research, gives me an opportunity to contribute to that evidence base in a field that holds meaning for me.

## 1.2 Research design

The primary focus of this thesis is a qualitative study, using thematic analysis, of interviews with individuals who were caregivers to someone who undertook VSED to hasten death. Because VSED caregiving has not been studied elsewhere, it is not possible to compare results of this analysis directly with other, similar research. To better understand how VSED caregiving compares with other types of caregiving at the end of life, I conducted two systematic reviews: one on experiences of informal caregivers of patients pursuing other forms of hastened death such as medical aid in dying or euthanasia, and one on informal caregivers of patients at end of life generally. I used Hudson's modified stress coping model (2003) as a lens to identify similarities and differences in how caregivers in these populations and in VSED navigate and interpret caregiving events.

## 1.3 Contribution to Knowledge

Through application of multiple analytic frames, this thesis makes several contributions to the study of caregiving at end of life. First, it is one of the first studies to offer insight into the experiences of VSED caregivers – for example, the sense of responsibility they feel for ensuring the patient's success. Second, the comparison of empirical data with that from the systematic reviews reveals ways in which VSED caregiving is similar to or different from other forms of end-of-life care. Third, by using Hudson's modified stress-coping model with both original data and systematic reviews, this thesis generates recommendations for improving the model, specifically by acknowledging the substantial influence that health professionals have in caregivers' navigation of the end of life experience. Finally, through synthesis and critique of all of these analyses, this thesis applies multiple layers of social theory, specifically the socio-ecological model and theories of bio-power, to situate VSED caregivers' experience in a larger biome of socio-political forces.

### 1.4 Organisation of thesis

The thesis begins with an overview of the clinical, ethical, and legal literature on VSED and situates VSED within the larger context of hastened death in the United States and the American health system's policies for end-of-life care. The introduction concludes with an overview of theories related to end-of-life caregiving, with a focus on Hudson's modified stress-coping model (2003).

In Chapter 3 I outline the philosophical and methodological underpinnings of the thesis as a whole, both the qualitative study of caregivers' experiences supporting patients through VSED and the systematic review of literature on two adjacent populations. It describes the study protocol and the thematic analysis approaches used to examine the data.

Chapter 4 contains two systematic reviews of literature: narrative syntheses of qualitative studies of experiences of caregivers of patients at end of life generally, and caregivers of patients choosing to hasten death. Both syntheses use Hudson's model as a frame for analysis.

Results of the qualitative interview study are presented in Chapters 5 and 6. Chapter 5 presents four themes constructed from inductive, reflexive thematic analysis of the data. Chapter 6 presents findings of a deductive analysis using Hudson's model.

Chapter 7, the Discussion, situates the experience of VSED caregivers in broader context. First, I compare VSED caregivers' experiences with end-of-life and hastened death caregivers' experiences. Second, I apply the socio-ecological model and theories of bio-power as ways of explaining key themes in caregivers' experiences. The thesis concludes with a review of findings, their significance, and implications for practice and future research.

# Chapter 2: Background

In this chapter I outline the medical, legal, and ethical position of VSED as a form of hastened death, as well as the limited descriptive research on VSED available both in the United States and internationally. For context, in this chapter I also outline the various other forms of hastened death such as euthanasia and aid in dying, where they are legal, and by whom they are accessed, with particular focus on the United States, the location of this study. Finally, the chapter introduces a theoretical model for caregiving at the end of life that is used in this thesis as a basis for comparison of caregiving across VSED, other forms of hastened death, and at the end of life generally.

## 2.1 Terminology of hastened death

In this thesis, hastened death describes an act characterised by intention to die and is collaborative in nature. Bostwick and Cohen (2009) distinguish hastened death from suicide in terms of the framing within the social milieu: a death that takes place with "the collaboration and support of others" (p. 4) is hastened death, whilst one that takes place in isolation and without social support is suicide. Nonetheless, terminology across various forms of hastened death varies by jurisdiction and between supporters and opponents. For example, Canada legalised medical assistance in dying, which encompasses administration of a lethal dose of medication by the patient or by a physician or nurse practitioner (Holmes et al., 2018), whereas the Netherlands distinguishes between euthanasia (physician-administered) and physician-assisted suicide (patient-administered) (Jansen-Van Der Weide, Onwuteaka-Philipsen, Van Der Heide, & Van Der Wal, 2009). In this thesis I use aid in dying (AID) as an encompassing term for assisted, hastened death. As Buchbinder notes, no choice of terminology in this field is truly neutral; the choice of AID as a term inherently demarcates a view that hastened death is not suicide (Buchbinder, 2018). Other terminology, such as assisted suicide, is used in this thesis when referring specifically to local terms for hastened death practices outside the United States.

In addition, in this thesis "patient" refers to the individual undertaking VSED, and "caregiver" refers to unpaid friends or family who provide some combination of practical, physical, or social support through the VSED process. Professional caregivers, such as paid health aides, are noted as such. As with AID, these terms carry implied meanings. All VSED cases in this study had at least some involvement with health professionals; patients were therefore at least nominally under the care of a medical professional. The term caregiver here designates an individual who has taken on support functions in assisting the patient with VSED, but it does not negate additional roles most caregivers have as spouses, children, or friends, or their other formal or informal caregiving experiences.

Finally, VSED is a term used in clinical settings to describe a deliberate, planned effort to hasten death (Pope & Anderson, 2011; Pope & West, 2014; Quill, Ganzini, Truog, & Pope, 2018; Wax, An, Kosier, & Quill, 2018). However, research on long-term care residents has noted that elderly individuals without other conditions, such as dementia that might lead to reduced appetite, sometimes choose to limit or stop intake in the months prior to death (Marcus & Berry, 1998). In this thesis VSED denotes the activity of a patient carrying out a personal choice not to eat or drink in order to hasten death, regardless of the level of planning or clinician involvement.

## 2.2 Hastened death in United States and abroad

Individuals in the United States who wish to hasten their death can pursue AID in some cases or choose VSED. AID is available in nine states and the District of Columbia, legalised through ballot measures, legislation, or legal precedent (Death with Dignity). Most states follow the model first established in Oregon in 1997, which allows adults with decision-making capacity and a terminal diagnosis with a physician-determined life expectancy of less than six months to request a lethal prescription. The patient must make two oral requests at least 15 days apart as well as a written, witnessed request. Two physicians must confirm the patient’s diagnosis, prognosis, and capacity, and may refer the patient for psychological assessment. The attending physician also must inform the patient of alternatives such as hospice. All prescriptions are recorded with the state health authority (Oregon Health Authority).

In the United States and Switzerland, the patient must be able to ingest the lethal dose without assistance. Euthanasia, which is a lethal medication administered by a physician to a patient who has provided active consent, is legal in Belgium, Luxembourg, the Netherlands, Canada, and Colombia (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). All of these, except Colombia, also allow what is usually called physician-assisted suicide, in which a physician prescribes medication that the patient takes with the intent of dying (Emanuel et al., 2016). Assisted suicide also is legal in Switzerland (Hurst & Mauron, 2003). Where both options are legal, physician administration is more common (Health Canada, 2019; van der Heide, van Delden, & Onwuteaka-Philipsen, 2017).

In addition, patients in the United States must be judged mentally competent and free of coercion to make the request. This requirement, and the less than six-month life expectancy, eliminate AID as a possibility for patients with dementia because by the time they would be clinically regarded as six months from death, they would be unlikely to be able to request medication. Similarly, patients with Parkinson's or other neurodegenerative diseases may be unable to complete AID if they lack the motor function to take charge of their own ingestion (National Academies of Sciences Engineering and Medicine, 2018).

#### *2.2.1 Demographics of AID*

Since Oregon's Death with Dignity Act was passed in 1997, 2,217 people have requested medication in that state and 1,459 have died from ingestion, accounting for a rate of 45.9 per 10,000 total deaths (Oregon Health Authority, 2019). Cancer is the most common diagnosis (62.5%) followed by neurological or cardiovascular disease (14.9% and 9.5%, respectively) (Oregon Health Authority, 2019). In Oregon, 96% of patients who have died from ingestion are white, with a median age of 72. Three quarters have at least some college education and 20% have an advanced degree. In California, where AID has been available only since 2016, the diagnostic mix and age and education demographics are similar. Notably, in California 88% of patients requesting AID in 2018 were white, although whites comprise less than half the state population (California Department of Public Health, 2019; United States Census Bureau, 2019).

### 2.3 Voluntarily stopping eating and drinking

Voluntarily stopping eating and drinking (VSED) is a "self-initiated effort to accelerate dying" (Wax et al., 2018, p. 441). Distinct from cachexia, which may be a natural stage in the advancement of some diseases, VSED is an ongoing voluntary choice to forego food and hydration. Unlike euthanasia or assisted suicide, VSED does not require lethal medication or a physician's order, although symptom management is recommended and ongoing caregiving is necessary (Quill et al., 2018).

VSED generally is described in three stages: an early stage in which the patient is alert and may experience thirst but can engage with others, a middle stage marked by progressive weakness as renal function fails, and a late stage in which the patient is largely unresponsive until death (Quill et al., 2018; Royal Dutch Medical Association, 2014; Wax et al., 2018) (Table 2.1.). Symptoms related to VSED include thirst and difficult urination, particularly in the first few days. Patients rarely express intolerable hunger because the body begins metabolising fats through ketosis (Wax et al., 2018). As dehydration continues, patients become weaker and may experience delirium. Patients become sleepier over time and may lapse into a coma several days before death. Depending on the patient's underlying health and how strictly they limit fluid intake, patients typically die within two weeks of initiating VSED (Ganzini et al., 2003; Royal Dutch Medical Association, 2014). Death is described as peaceful (Ganzini et al., 2003; Ivanovic, Buche, & Fringer, 2014) and thought to be caused by cardiac arrest as sodium and potassium transport in heart cells is disrupted (Royal Dutch Medical Association, 2014).

**Table 2.1.** Stages of VSED

| **Stage** | **Early** | **Middle** | **Late** |
|---|---|---|---|
| Duration | 1-4 days | Variable | 1-4 days |
| Patient status | Alert | Weakening, more sleep | Largely unresponsive, coma |
| Symptoms | Thirst, hunger (minor), difficult urination | Thirst, weakness, delirium | Unconsciousness, pain, delirium |
| Management | Oral care, treatment for anxiety | Oral care; treatment for anxiety, delirium or pain; help with transfers | Turning repositioning, palliative sedation or pain management |

Clinical recommendations for symptom management during VSED include oral swabs, mist sprays, lotion, and room humidification to ease dry mouth and other symptoms of dehydration as even small sips of water adding up to 50ml/day or more or use of ice chips can slow dehydration and prolong dying (Royal Dutch Medical Association, 2014; Shacter, 2017; Wax et al., 2018). As patients become weaker, they require assistance with toileting and hygiene, and eventually need help turning as they become bed bound. Because thirst can lead to anxiety, clinical guidance includes having benzodiazepines available, as well as antipsychotics if required for severe delirium (Wax et al., 2018). Other palliative measures, including palliative sedation, may be required for patients with severe ongoing agitation (Schwarz, 2007). Hospice support is recommended if possible, although some hospices may resist becoming involved with attempts to deliberately hasten death and others may require the patient to have already initiated VSED (Wax et al., 2018).

For clinicians who receive a request for information about or support for VSED, Wax et al (2018) suggest beginning with a clinical evaluation to determine the nature of the patient's current or anticipated suffering, with treatment or specialty referral to address symptoms if necessary. Wax et al note that patient inquiries about VSED should be addressed promptly, particularly for patients with conditions causing cognitive decline who may have a short window in which to initiate VSED. Assessment also should include potential for coercion, as well as screening for psychiatric conditions such as depression or eating disorders that may be treatable. Patients should complete appropriate advance directives such as do-not-resuscitate orders and enrol in hospice before or shortly after initiating VSED if possible.

Wax et al note that VSED requires "significant social support" (2018, p. 443) and suggest that patients and caregivers need a clear plan for managing requests for food or water if the patient becomes delirious. Patients and caregivers should plan in advance how to manage these situations, generally by reminding them of their goals and explaining that they can have fluids if they wish, but that doing so will work against their goals (Schwarz, 2007; Wax et al., 2018). In addition, some patients change their mind whilst conscious (Schwarz, 2016; Wax et al., 2018) and halt the process, and caregivers must be prepared for either outcome.

### *2.3.1. Who chooses VSED?*

Few studies have looked specifically at the incidence of VSED. Among 571 Japanese hospice and palliative physicians, 32% had experience with a patient choosing VSED (Shinjo et al., 2019). A recent survey of Swiss nursing home directors estimated that 1.7% of nursing home residents die by VSED (Stangle, Schnepp, Buche, & Fringer, 2020). Dutch studies have produced estimates of 0.4% to 1.75 of annual deaths (Royal Dutch Medical Association, 2014), and in a survey of Dutch family physicians, 46% reported having cared for a person who elected VSED (Bolt, Hagens, Willems, & Onwuteaka-Philipsen, 2015). The only US data are from a 2001 survey mailed to Oregon hospice nurses (Ganzini et al., 2003). Among respondents, 41% reported having cared for a patient who attempted or completed VSED. Among the 102 cases reported in that survey, patients' average age was 74; 54% were women; 48% were married; and 48% were widowed, divorced, or unmarried. Cancer was the most frequent diagnosis (60%), followed by neurologic (23%) or cardiovascular disease (16%). In the Dutch study, physicians could choose more than one diagnosis per patient and reported that 39% of patients had a somatic illness other than cancer, 27% had cancer, 12% had early dementia, and 24% had no severe physical or psychological disease (Bolt et al., 2015). Thus, whilst in the Oregon VSED survey patient characteristics mirrored those seeking AID in the United States, a quarter of Dutch patients pursuing VSED had no terminal condition according to their physicians.

Nurses reported readiness to die, current or feared poor quality of life, viewing continued existence as pointless, desire to die at home, and desire to control the circumstances of death as common reasons for choosing VSED (Ganzini et al., 2003). Somatic issues, such as pain, fatigue, or dyspnoea, or fear of them were also common, however, in a similar survey of Dutch physicians, somatic motives were listed most often, followed by existential concerns or fears of dependence (Bolt et al., 2015; Royal Dutch Medical Association, 2014). Both studies were based on clinician perception of patients' reasoning. A German study of palliative care patients expressing a wish to hasten death (not VSED-specific) found it to be "an extreme coping strategy to maintain control against anticipated agony" (Pestinger et al., 2015, p. 711), with agony encompassing loss of ability, physical deterioration, and dying over a period of months. A Swiss study identified the wish "to spare others from the burden of oneself" as a frequent meaning of patients' statements of wishes to die, as well as a wish to "not have to wait until death arrives" (Ohnsorge, Gudat, & Rehmann-Sutter, 2014, p7).

### *2.3.2 Legal and ethical aspects of VSED*

VSED has been described as "not illegal" in the United States (Quill et al., 2018). It is not specifically described in law, and little relevant legal precedent has been set, either related to patients undertaking it or clinicians aiding patients in their VSED effort (Quill et al., 2018). Legal scholars (Pope & Anderson, 2011) place refusal to eat and drink within the context of legally protected self-determination, for which precedent was set in a 1914 legal case in which a patient underwent a surgical procedure without consent ("Schloendorff v Society of New York Hospitals," 1914): "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a [physician] who performs [an intervention] without his patient's consent…is liable in damages." This and other case law, and the constitutional right to privacy, protect patients' rights to refuse medical treatment, including discontinuing life-sustaining medical treatment such as artificial nutrition and hydration (Pope & West, 2014).

More ambiguous is whether natural nutrition and hydration are medical treatment. Pope cites two cases in which US courts have ruled that feeding in a care setting constituted medical treatment (Pope & West, 2014). However, in long-term care settings in the United States, administrators may view provision of food and drink as part of basic care, such as toileting or bathing, rather than medical care. Federal guidance requires that facilities' "actual food and nutrition services meet each resident's daily nutritional and dietary needs and choices" (Centers for Medicare & Medicaid Services, 2017), and administrators may fear being charged with abuse or neglect (Centers for Medicare & Medicaid Services, 2017; Pope & Anderson, 2011). Pope and Anderson (2011) argue that although regulations are intended to guard against patients not receiving wanted nutrition and hydration, federal rules also allow long-term care residents to refuse treatment. Court rulings in Australia and Canada similarly have ruled that competent adults may not be compelled to eat or drink (Pope & West, 2014).

Beyond legal issues, patients considering VSED, their family or caregivers, and their clinicians may have ethical or moral concerns about the process, specifically whether it is a form of suicide, whether suicide is always morally wrong, and whether clinicians who oppose suicide have an obligation to support a patient who has elected VSED (Quill et al., 2018; Schwarz, 2007; Wax et al., 2018). Proponents of the permissibility of VSED note that suicide may be rational if patients are choosing a deliberate death by a known means — a harm — over perceived greater harm, such as prolonged suffering from illness that will also end in death (Bernat, Gert, & Mogielnicki, 1993). VSED also is perceived as less likely than AID to be a coerced choice: "VSED requires a sustained determination of the patient's own will despite substantial discomforts such as thirst and hunger. Furthermore, decisions to undertake VSED can be reversed by the patient, at least in the early phases. Among other 'last resort' decisions, VSED raises the fewest concerns that the choice is voluntary" (Quill et al., 2018, p. 125).

In a legal review of VSED, Pope and Anderson (Pope & Anderson, 2011) outline four distinctions between VSED and AID that might make VSED less objectionable to clinicians or others who will not support active measures to hasten death:

- Refusal of medical treatment is legal, and hand feeding has been legally established in the United States as a medical treatment.
- Laws related to suicide frame it as "active interventions such as the introduction of a lethal agent," (p. 420) whereas VSED is passive: it is an omission rather than an act.
- Unlike AID, which involves a request from the patient for the doctor to provide the patient with a harm, VSED is a request not to have unwanted things done to the patient, such as having food or liquid forcibly introduced. "The doctor cannot owe the patient any duty to maintain his life where that life can only be sustained by intrusive medical care to which the patient will not consent." (p. 421)
- VSED has no exterior cause of death: rather than ingesting a fatal, physician-supplied substance, the patient instead allows the natural biological process of excreting liquid to continue without taking in liquid to counteract it. The patient's own biology, not a clinician's steps to reduce suffering, causes the death.

Quill et al (2018) note two opposing viewpoints on the role of clinicians in VSED. One is that suicide is immoral and any effort to facilitate it, such as by managing symptoms of VSED, is morally and possibly legally wrong. The other is that suffering, whether from symptoms related to VSED or other causes, should be met with palliative care if desired. Jansen and Sulmasy (2002) suggest a third position in between, that it could be permissible for a physician to support a patient’s choice to refuse treatment, including nutrition and hydration, in the face of terminal suffering, but that the physician should not suggest it as an option lest the patient be influenced to choose it.

## 2.4 End-of-life care in the United States

Directly or indirectly, many aspects of healthcare and caregiving for Americans at the end of life are shaped by national health policy, chiefly Medicare. Medicare is a national programme that pays for health services for adults ages 65 or older or individuals with disability (Department of Health and Human  Services). Medicare pays for hospice care for individuals who are expected to have six or fewer months to live, based on determination by their primary care physician and a hospice physician. Individuals who seek hospice care must forgo curative treatment for the primary condition related to their terminal diagnosis, accepting hospice care instead (Department of Health and Human  Services). Hospice care in the United States is primarily home-based. Patients receive equipment and supplies, such as a hospital bed, and visits from nurses, social workers, counsellors and others as needed. Hospice supplies medication to manage symptoms and hospice staff typically train family or other informal caregivers on basic aspects of care. Inpatient or residential hospice is rare, and Medicare benefits do not include payment for inpatient hospice care beyond brief respite stays or when necessary for symptom management.

Informal caregivers have 24-hour phone access to hospice staff, who can answer questions or order medication but do not provide extensive in-person care (Kolata, 2019). About 30 percent of natural deaths in the United States occur in the home (Cross & Warraich, 2019), and nearly half of Medicare beneficiaries are enrolled at hospice at the time of death (National Hospice and Palliative Care Organization, 2019).

## 2.5 Caregiving in hastened death

No studies have addressed the experiences of caregivers assisting a patient with VSED. A few studies have described the role of caregivers in the context of other forms of hastened death, specifically AID. Ganzini, Goy, Dobscha, & Prigerson (2009) surveyed 95 family members of patients who requested aid in dying, including 36 who died after ingestion, and compared mental health outcomes with family members of individuals who died in other ways. The team found no differences in depression, grief, or mental health service use, and families of patients who requested AID reported more preparedness and acceptance of death than comparison families.

In an ethnographic study of AID in Vermont, Buchbinder, Ojo, Knio, & Brassfield (2018) interviewed 19 caregivers of 11 patients who pursued AID and noted that caregivers played both instrumental and emotional roles focused around preparation, ingestion, waiting for death, and the time after death. These align closely with Gamondi's study of Swiss families in which a patient pursued assisted suicide (Gamondi, Pott, Preston, & Payne, 2018). Gamondi et al (2018) added two earlier stages of caregiver involvement – during the patient's contemplation of assisted suicide as an option and the patient's attempt to gain acceptance for the act from family and relevant professionals.

In contrast to the social isolation of suicide, Buchbinder et al (2018) noted that patients pursuing AID did so with substantial practical and emotional support from caregivers on the day of death: fulfilling the patient's last wishes, being present, offering encouragement and support, and taking charge of the logistics of preparing medication and supporting ingestion. In the brief duration of AID, caregivers "reported suppressing their own anticipatory grief and emotional response to attend to the needs of the dying person" (p. 6). Buchbinder et al (2018) point out the dichotomy that the highly independent decision of pursuing AID, often to avoid future dependency, is itself socially dependent. It can also be a form of caretaking in which the patient relieves friends and family of the need to provide future care.

## 2.6 Theories of caregiving at end of life

Several authors have proposed theoretical models of the experience of caregiving at the end of life or in the context of serious illness. Swanson's (1991) middle-range theory of caregiving draws on themes identified in three phenomenological nursing studies of mothers and women who miscarried. It defines five caring processes (all quotes p. 162):

- Knowing: "Striving to understand an event as it has meaning in the life of the other"
- Being with: "Being emotionally present to the other"
- Doing for: "Doing for the other as he/should would do for the self if it were at all possible"
- Enabling: "Facilitating the other's passage through life transitions and unfamiliar events"

- Maintaining belief: “Sustaining faith in the other’s capacity to get through an event or transition and face a future of fulfilment"

Subsequently, Andershed and Ternestedt (1999) used Swanson’s themes as a frame for analysing involvement of relatives in care for the dying. They grouped findings from interviews of six spouses of patients with late-stage cancer into the first three of Swanson’s themes only. Themes of enabling and maintaining belief, however, seem consistent with studies of caregiving in hastened death. Gamondi’s (2018) study of Swiss families supporting patients through assisted suicide highlights the family’s role in sharing the patient’s values about assisted suicide, advocating for the patient in acquiring necessary documents, and supporting the patient’s decision and timeline even amid their own ambivalence. Such actions appear to exceed knowing or doing for and fit better within enabling (both logistically and through expressed support) and maintaining belief in the patient’s ability to achieve his or her desired death.

Waldrop et al propose a model of caregiving in which an individual acquires the caregiver role at the onset of the patient’s illness and start of care (Waldrop, Kramer, Skretny, Milch, & Finn, 2005). As the caregiver manages care at home, they receive information about the illness, observe physical and cognitive decline, and observe the patient’s personality change and role loss. These interrelated experiences contribute to the caregiver’s comprehension of the patient’s terminality, which leads to a transition to end-stage caregiving, characterised by near-acute care, upholding patients’ wishes, and making practical decisions about the end of life, death, and financial and other practical matters. For the caregiver, these roles and tasks take place in the context of a stress-process model that accounts for the patient’s illness, the requirements of caregiving, other stressors such as work or financial strain, and personal or external resources for coping. These factors influence outcomes of distress or meaning making.

Hudson’s model (2003) for family caregivers in the context of palliative care is rooted in Lazarus and Folkman’s stress-coping model (Folkman, 1984), further revised by Folkman (Folkman, 1997). The revised model traces how caregivers appraise and respond to events in caregiving. Their emotional response to the outcome may be positive emotions or feelings of distress, or they may engage in meaning-based coping such as revising goals for the situation, reappraising the situation in a positive light, or finding meaning through spiritual beliefs. Such coping approaches can lead to positive emotion and can inform how the individual caregiver copes with subsequent events. Hudson’s model is the basis of several analyses in this thesis and is described in detail in Chapter 3.

## 2.7 Conclusion

VSED is a means of hastening death that is little studied and does not appear to be subject to the extensive regulations that surround aid in dying. It is marked by an ongoing act of will not to imbibe fluids on the part of the patient and by support from caregivers during the 10 to 14 days it may take to dehydrate to the point of death. These unique circumstances suggest that caregivers’ experience in supporting a patient through VSED may be similar in some ways to other caregivers at end of life, but also may be similar to caregivers supporting a patient through other forms of hastened death. Several theories, including Hudson’s modified stress coping model, have been proposed to make sense of caregiver experience.

In the next chapter I present an overview of the methodology and methods used to answer the research question, “What is the experience of US caregivers supporting patients through VSED?” Subsequent chapters present a systematic review of the available literature on caregivers’ experience at end of life and in other forms of hastened death as a frame of reference, followed by analysis of original data from interviews with VSED caregivers.

# Chapter 3: Methodology and Methods

## 3.1 Overview

In the previous chapter, the phenomenon of VSED was introduced. In this chapter I present the philosophical and methodological foundations for the empirical research into the experience of caregivers of a patient undertaking VSED.

Specifically, I address the primary research question, “What is the experience of US caregivers supporting patients through VSED?” and the secondary question, “How does the experience of VSED caregivers compare with the experiences of caregivers at end of life and in AID?”

## 3.2 Ontology and epistemology

Effective research is structured on a cohesive, consistent line from ontology (what can be known) to epistemology (how it can be known), the research question, and methods (the tools used to obtain and assess the information) (Bryman, 2016). This study is bounded in constructionism and interpretivism (Figure 3.1.). Constructionist ontology views reality as emergent, “in a continuous state of construction and reconstruction,” in which social actors continually work to understand and define structures and cultures around them, frequently through interaction (Bryman, 2016, p. 30). It is closely tied to interpretivist epistemology, which proposes that knowledge is produced by interpreting one’s surroundings, rather than simply observing universal mechanisms in action (Ormston, Spencer, Barnard, & Snape, 2003). Individuals singly and collectively take in and interpret their social world and construct meaning from it. As such, the ontology of constructionism and an interpretivist epistemology are an appropriate and consistent foundation for formulating inquiry into a social phenomenon that exists largely outside cultural, legal, or governmental structures: VSED legally is defined less by law than by the lack of laws specific to it (Quill et al., 2018), and less by medical guidelines than by the goals and plans created by patient and caregiver. Drawing from a foundation of constructionism and interpretivism, the methods used in this study assume that individual caregivers helping patients achieve a desired death will interact with the patient, family members, clinicians, and the larger community and will form their own interpretation of the caregiving process and those interactions.

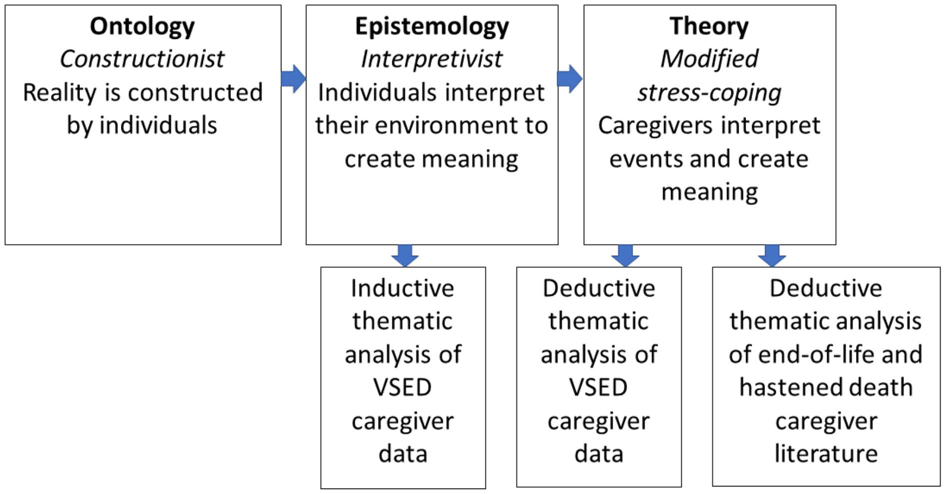

**Figure 3.1.** Philosophical and theoretical underpinnings

Constructionism and interpretivism have particular implications as underpinnings for qualitative research: they assume that the subject of study is participants' own interpretations and creations of meaning in their environment, which calls for a primarily inductive method of inquiry (Ormston et al., 2003). Because reality and meaning are constructed, the researcher herself actively participates in interpreting events and co-creating meaning with the participants. Whilst those interpretations may be entirely inductive, they also draw on the researcher's own previous experience, bias, and exposure to theory (Mason & Dale, 2011; Ormston et al., 2003). For example, caregivers often have difficulty recognising and acknowledging their own needs, including their health, when caring for someone at the end of life (Martín, Olano-Lizarraga, & Saracíbar-Razquin, 2016). A standard prompt in the interview guide for this study was, "How were you feeling [during a period of caregiving]?" By asking the question, the researcher invited the study participant to reinterpret his or her memories of caregiving and the meaning ascribed to them. The researcher and participant together created a new interpretation of that event, which the researcher subsequently compared and analysed with others to arrive at broader themes of meaning.

## 3.3 Theoretical framing

Hudson's modified stress-coping model (2003) provides a framework for understanding the experience of VSED caregivers and is used in various analyses in this thesis. Hudson's model is constructionist in nature: it assumes that caregivers have an inner emotional life and life experiences that may shape their perspective on caregiving events and outcomes (Figure 3.2.).

Hudson's model can be used to describe the overall arc of a caregiving experience as well as individual events within it. Key components of the model include:

- Appraisal: the caregiver's initial assessment of the environment (or an event) and whether it falls within or beyond the caregiver's resources. Events falling beyond the caregiver's resources may further be appraised as challenges, threats, or harms.
- Coping: the caregiver's thoughts, feelings, and actions in response to appraisal, marked by emotional or problem-focused orientation, often complementary.
- Event outcomes: the caregiver's appraisal of whether the event's results are consistent with their goals.
- Emotional outcome: the caregiver's reaction to the event outcome. In Hudson's model, it can include positive emotion or distress, but also different types of meaning-based reframing, such as setting revised goals, that can inform future appraisal and coping.
- Influencing factors: experiences, relationships, skills, expectations, and socio-demographic factors that may affect how a caregiver appraises, reacts to, and interprets events in caregiving.

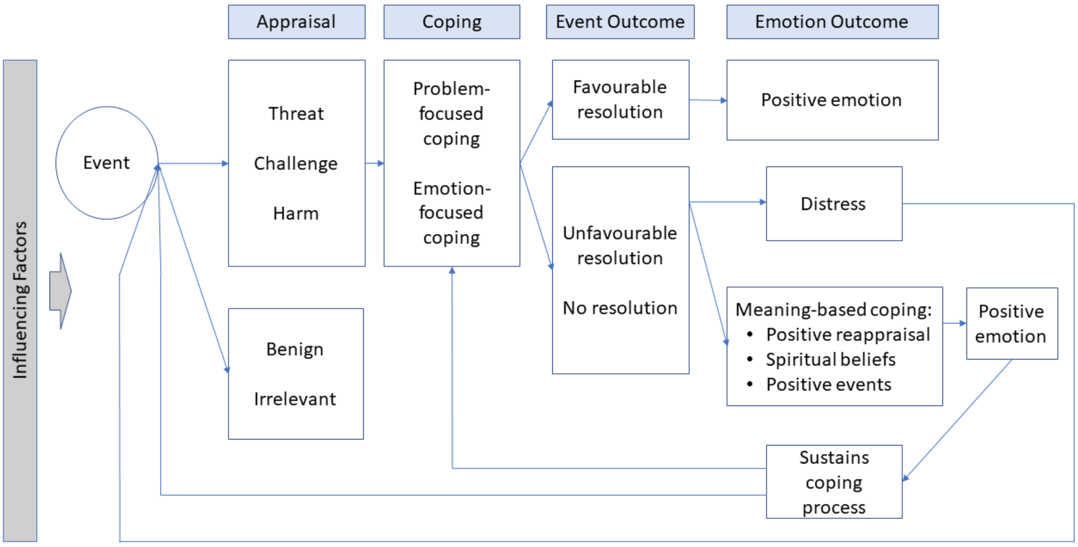

**Figure 3.2.** Adapted from Hudson's modified stress-coping model

## 3.4 Methodology: Reflexive thematic analysis

Thematic analysis provides both structure and adaptability, making it an ideal methodology for a study of a previously unexplored topic. As noted by Braun and Clarke (2019a, 2019b), reflexive thematic analysis is not one approach but rather a set of approaches to identify themes in qualitative data. A core component is the researcher's role in knowledge production, consistent with constructionism (Braun & Clarke, 2019a). The approaches can be deductive or inductive, depending on analytic need, but reflexivity is dependent on deep reflection and engagement with the data, willingness to acknowledge the subjectivity of the researcher, and transparency about ways in which theory influences analysis (Braun & Clarke, 2019a). These properties particularly suit this study, in which the subject matter has not been previously analysed, suggesting an inductive approach. However, potentially relevant theory and data from adjacent populations (end-of-life and hastened death caregivers) are available, creating the possibility of using theory-driven, deductive approaches to compare the new data with other studies. Hybrid inductive-deductive thematic analysis has been used by others (Fereday & Muir-Cochrane, 2006; Roberts, Dowell, & Nie, 2019; Swain, 2018) as a means of capturing both participant-generated concepts (inductive) and concepts rooted in theory (deductive), although not always in specifically reflexive thematic analysis. However, Braun and Clarke's recent publications (2019a, 2019c) suggest strongly that inductive and deductive thematic analysis can be complementary.

Thematic analysis's flexibility and consistency were important factors in choosing a methodology for this thesis. I considered constructivist grounded theory (Charmaz, 2014) for the empirical study but wanted to make extensive use of Hudson's model as a consistent framing mechanism to compare VSED data against adjacent caregiver literature (described in section 3.7.2, below). Phenomenological analysis also would have offered in-depth exploration of caregiver experience, but because this is the first study of VSED caregiving I wanted the flexibility to explore breadth and diversity in caregiver experiences as well as external social and political forces that might influence caregiver experience. To hold open all these possibilities, not knowing how this exploratory study would resolve, reflexive thematic analysis offered the best fit for purpose.

## 3.5 Reflexivity

Because the researcher plays an active role in shaping the meaning of the topic under study, robust research demands reflexivity: an awareness of one's self and position in society and relative to study participants, and beliefs and experiences that may influence interpretation (Braun & Clarke, 2013; Hennink, 2010); recognition of pre-existing theoretical influences that may affect data collection or interpretation; and awareness of the wider social context in which the research is taking place (Green, 2018; Hennink, 2010).

A longstanding general interest in healthcare choices at the end of life led me to pursue a PhD in palliative care. In particular, I have been influenced by critiques that patients in the US health system may find themselves on a "conveyor belt" of increasingly invasive care that emphasises longevity over quality of life (Gawande, 2014; Zitter, 2017). As a non-clinician, I have been interested in how individuals can make their end of life wishes known and what steps they can take to ensure they are honoured.

In 2017 I began volunteering with End of Life Choices New York as a community educator, speaking at senior centres about advance care planning. I learned about VSED through the group's other community education efforts. AID is illegal in New York, and End of Life Choice's medical director includes VSED as an option for individuals who contact the organisation looking for ways to control the circumstances of their death. Before and throughout my research, I have repeatedly interrogated my views on VSED.

My motivation for studying VSED caregiving was driven by awareness that VSED happens with some frequency in the United States (Ganzini et al., 2003) but has not been widely studied (Ivanovic et al., 2014). As a former medical journalist, I have long noted that improvement in medical care cannot happen without an evidence base. Therefore, a study made sense as a way to contribute to good care for those who choose VSED and their caregivers. Using qualitative methods to explore caregivers' experiences is an incremental step following on the limited available research on VSED – surveys of healthcare professionals' impressions of patient experience. Allowing caregivers to reflect on first-hand experience would bring new insights to the field.

My involvement with an organisation that provides education about hastened death, and simply my interest in the topic, did provide social currency that may have helped with recruitment or put participants at ease. In interviews, acknowledging familiarity with key books, articles, or speakers on VSED may have reassured participants that I held similar values, although I did not discuss my views during interactions with participants. During interviews, I tried to reflect on whether such interactions affected the nature of the discussion and used the interview guide prompts to ensure that I asked each participant about the same topics. After each interview, I used a reflexivity journal to record factors that improved or disrupted the flow of information, new ideas or variations, and my overall impressions of the interview. I referred to these memos during analysis as a check against bias that may have occurred during interviews (Appendix A: Sample memo).

## 3.6 Recruitment and data collection

In the remainder of the chapter I describe the processes for recruiting participants and gathering and analysing data for the study on the experiences of VSED caregivers.

### *3.6.1 Recruitment*

Participants—people in the United States who had been a primary, nonprofessional caregiver to someone who had undertaken VSED—were recruited through my contacts with clinicians, researchers, end-of-life rights advocates, and journalists. I sent these contacts an email with a description of the study and a request for help in passing study information along to caregivers who might be interested. Other recruitment channels included Lancaster University Faculty of Health and Medicine Research Ethics Committee-approved social media descriptions of the study and an approved study flyer that was posted at the Harvard University bioethics conference in April 2019. Some caregivers forwarded study details to friends, neighbours, or relatives who also had experience as VSED caregivers.

As the size and diversity of the VSED caregiver population is unknown, I sought approval for an initial sample of up to 20 participants. Braun and Clarke (2013) suggest 10 to 20 interviews as a target for medium-sized studies using thematic analysis, depending on the breadth and depth of the topic. The goal for recruiting participants and completing interviews was not saturation but rather the acquisition of enough rich data to support construction of robust themes (Braun & Clarke, 2019a).

Caregivers who wished to participate in the study were invited to respond to me directly by email, minimising the burden for intermediaries (Appendix B: Invitation Email). Caregivers were then sent further study details (Appendix C: Participant Information Sheet), including regionally specific bereavement resources and a consent form, and invited to participate in a 90-minute interview. Participants were reminded that they had the opportunity to ask questions, withdraw from the interview at any time, or withdraw their data from the study up until the point of data synthesis. Participant eligibility was determined based on inclusion and exclusion criteria outlined in Table 3.1.

**Table 3.1.** Inclusion and exclusion criteria for participation

| Inclusion criteria | Exclusion criteria |
|---|---|
| Directly assisted a patient through the VSED process | Patient elected aid in dying, euthanasia, or palliative sedation |
| Adult age 18+ | Caregiver of patient currently undergoing VSED |
| Caregiver of patient who attempted but did not complete VSED | Clinician serving in a formal capacity; long term care facility staff |
| Friend, family, or unpaid caregiver | Cessation of eating and drinking did not appear to be an act of will but rather part of the dying process |
| VSED was intentional | Did not speak English |

### 3.6.2 Informed consent

Informed consent is a process that ensures that participants understand the nature of a study and their rights as participants. Potential participants should have enough information and time to ask questions and decide whether to participate and should understand that participation is voluntary and that withdrawal or refusal have no negative consequences. Essential information includes any potential harms or benefits of participation and how their identity and data will be protected (Hennink, 2010). All potential participants received a full description of the research project, its purpose, and the interview process, along with contact information for the researcher. Participants had further opportunities to withdraw from the research during the interview and for up to one month thereafter. All participants received two copies of the consent form – one for their own records and one to sign. Participants also were asked whether and how they could be contacted with follow-up questions (Appendix D: Consent form).

### 3.6.3 Interview and data procedures

In-depth interviews are a method of gathering in-depth data from a single participant. Typically they are loosely structured in a way that allows the participant to share what they find important and the interviewer to adjust questions in response (Braun & Clarke, 2013). Semi-structured interviews, therefore, are opportunities for both parties to co-create meaning (Hennink, 2010), consistent with constructionist ontology. For this study, in-depth, semi-structured interviews were conducted using an interview guide (Appendix E) influenced by other studies on hastened death caregiving (Gamondi et al., 2018) as well as published narratives on VSED (Menzel, 2016) and two VSED caregivers who gave input during the proposal development process. Those caregivers recommended allowing adequate time for participants to describe the patient pursuing VSED, their personality, and the circumstances leading to the decision to initiate VSED. Subsequent sections of the interview guide followed a roughly linear process of planning and preparation; choosing a start date; early, middle, and late stage VSED; death; and events after death. Each section included prompts to elicit what was happening, the caregiver’s particular role, and the caregiver’s reactions and experiences. Beyond these prompts, interviews could adapt to fit topics participants found important to share, such as familial history with dementia or dynamics among family members.

Interviews were conducted by phone, videoconference, or when possible in person. Because participants were scattered throughout the United States and recruitment was unpredictable, face-to-face interviews were only possible within a day’s drive of my location. Three interviews were face-to-face in participants’ homes, following university lone-worker policy of leaving logistics details with a colleague, to be opened only if I failed to check in after the interview was expected to end; it was not necessary to act on that contingency. Remote interviews were conducted using web-based conference software that enabled recording and downloading an audio file directly to the secure cloud server. Among the remote participants, approximately half chose a video option. Audio and video interviews were not discernibly different in the duration of the interview, quality of rapport achieved, or the nature of information shared, consistent with other studies comparing in-person and phone interviews (Cachia, 2011; Drabble, Trocki, Salcedo, Walker, & Korcha, 2016). Interviews ranged from 49 to 105 minutes. Participants were invited to share any follow-up thoughts by email; such texts were added to the end of interview transcripts for four participants who sent emails after their interview.

Some participants filled out, scanned, and returned consent forms in advance of the interview or filled them out in person. For others, I began the interview session by asking about any questions about the study, asking permission to record, beginning recording, and then obtaining consent by reading each item of the consent form aloud and asking for verbal confirmation of each item. Per the study protocol, I documented their assent on a consent sheet and documented that the process had been completed verbally. Interviews concluded with gathering standard demographic information about participants and patients. All consent forms were scanned and uploaded to a secure server, with copies removed from any portable storage devices. Demographic information was entered into a standard, anonymous record on the secure server. All paper documents were shredded following completion of the data collection phase. All interviews were digitally audio recorded, with files stored on a secure server and files on recording devices deleted.

Immediately following each interview, I drafted a reflexivity journal entry summarising the aspects of VSED experience that appeared to be most important to the participant. I included my observations about how the participant’s experience appeared to be similar to or different from others, and whether it sparked any new insights or generated concepts not present in other interviews. Whenever possible, I tried to note my own emotional responses to the interview as well, such as a tendency to relate to participants who were only children dealing with the death of a parent – a situation I expect to find myself in someday. I transcribed all audio files verbatim, noting pauses, gestures, or emotion (laughter, crying). Transcribing interviews I had conducted helped familiarise me further with their content. Transcription of earlier interviews often overlapped on the same days as conducting new interviews, contributing to immersion in the data.

### *3.6.4 Research ethics and risk of harm*

The research protocol was approved by the Lancaster University Faculty of Health & Medicine Research Ethics Committee (FHMREC) in November 2018 (FHMREC #18020). In February 2019, FHMREC approved an amendment to increase the number of potential participants from 20 to 25 because recruitment was more successful than anticipated. The ethics application, and all participant materials, acknowledged that the subject matter for interviews was emotionally intense. The participant informed consent form included the stipulation that the researcher would inform appropriate parties if it was thought that the participant posed a risk of harm to him or herself or others. No participant evinced a risk of harm during the interviews. Rather, many participants were eager to talk about their experience and expressed interest in seeing any publications based on the research.

The research protocol also noted the risk posed to the researcher obtaining end-of-life narratives. The volume and intensity of data were emotionally taxing at times, both because of the singular focus on narratives of dying but also because the interviews could be emotional for participants. I found it challenging as a researcher to ask others to go through such an emotionally taxing experience for the sake of science. Throughout the data gathering and analysis process I met regularly with a skilled mental health professional who has an interest in end-of-life issues. I raised the issue of feeling overwhelmed by the intensity of the narratives to my supervisors and confirmation panel examiners, all of whom were quick to offer support and extra supervision sessions to talk through the process. Based on my experience I have suggested that future Autumn Academy sessions of Lancaster University's blended learning PhD programme offer training on conducting emotionally sensitive research.

## 3.7 Data analysis

Analysis of data on VSED caregiver experience took place in sequential inductive and deductive approaches. This approach differs from other hybrid inductive-deductive thematic analysis described in the literature, such as the simultaneous use of a priori deductive codes and a posteriori inductive codes described by Swain (2018). My approach is rooted in the recognition that the VSED caregiver interviews represented thick, rich data on a previously unstudied topic. I determined that if I performed deductive coding based on the stress-coping model first, immersion in the material through that lens might inhibit my ability to identify concepts that fall outside the model. For example, feeling a sense of responsibility for the patient's success was an aspect of experience expressed by many caregivers, but it doesn't necessarily fall neatly into emotional outcome, mutuality, or other a priori codes derived from Hudson. Having conducted and transcribed the interviews, I also knew the data were simply too layered for conducting inductive and deductive coding simultaneously as suggested by Swain (2018). For example, a caregiver described going to the patient's doctor to obtain help with VSED. The office visit itself is an event with appraisal, coping, and emotional and event outcomes as outlined by Hudson. But it also contained concepts about interaction with healthcare providers, the desire for permission to do VSED, fears about what the process would be like, and the caregiver's role as advocate, all potentially important given that these experiences have never been studied before. Therefore, I purposely completed inductive coding on each transcript before undertaking subsequent, deductive coding based on Hudson (2003).

### *3.7.1 Inductive analysis*

Inductive reflexive thematic analysis was used to identify codes and construct themes from original data about VSED caregiver experience, presented in Chapter 5. Although Braun and Clarke's reflexive thematic analysis is closely associated with inductive approaches, recent papers have noted that it can be "a mix of semantic and latent, inductive and deductive" approaches (2019a, p. 4). They clarify that deductive thematic analysis should not be merely lumping data by interview question but rather “using existing theory as a lens through which to code and interpret the data” (Braun & Clarke, 2019c, p. 13).

Inductive analysis followed the six-stage process outlined by Braun and Clarke (2006) for thematic analysis:

- familiarising oneself with the data, including transcription, reading the data, and making note of initial ideas
- generating initial codes by identifying interesting aspects of the data in a systematic way across the entire data set
- beginning to build themes by gathering codes that seem related and their data into potential themes
- reviewing themes by testing whether a potential theme is consistent with the data underlying it and creating a map of the analysis
- defining and naming themes to create a cohesive story about what each theme contains
- producing the report, in which themes are illustrated with robust examples and tied back to the research questions and broader literature

As Braun and Clarke note, this process is iterative rather than linear. All coding was completed using NVivo 12.0 qualitative analysis software (QSR International). Inductive analysis identified events, activities, beliefs, and roles that were important to participants describing their experience as VSED caregivers. After all transcripts had been coded, text associated with each code in NVivo were analysed, with subcodes created to capture further detail. For example, the initial code “other hastened death” was parsed to reflect caregivers’ beliefs that AID would have been a faster, preferable way to die or that VSED was a more natural ending to life. Inductive codes and subcodes were analysed and clustered into related concepts (Appendix F: Code Tree). These were then reviewed and tested for coherence across subsets of participants (such as those who cared for a patient with dementia, spouses vs children, and caregivers who did or did not have a healthcare background). Themes constructed from inductive codes are presented in Chapter 5.

### 3.7.2 Deductive analysis

Deductive thematic analysis based on the theory-driven elements of Hudson's modified stress-coping model were applied to the VSED caregiver data, with analysis presented in Chapter 6. The same theory-based codes also drive the deductive thematic analysis that is the basis for the narrative synthesis of two sets of published studies about caregivers' experiences at end of life and in hastened death (Chapter 4).

In the systematic reviews, deductive analysis preceded analysis with inductive codes because the primary focus of the systematic reviews was to establish Hudson's model as a common lens for analysis across populations. The use of the same deductive-plus-inductive, Hudson-derived code set for thematic analysis across two sets of literature and original data provides a basis for comparison of the three, which is presented at the beginning of the discussion chapter (Chapter 7). Results of this comparison, along with results of the inductive analysis, are the foundation for building a theoretical model of VSED caregiver experience in the second half of the discussion chapter.

Deductive analysis followed a modified version of Braun and Clarke's process described above. Deductive coding took place in two rounds: one to characterise events in the VSED process using codes based on Hudson's model, and a second round to code individual factors identified by Hudson that influence caregiving experience, such as particular skills or expectations (See Section 3.3 and Figure 3.2, above). Subsequently, as in the inductive coding process, each of the Hudson-derived deductive codes were assessed individually to identify subcodes. Caregivers' descriptions of events occurred organically in interviews. For example, the deductive appraisal code "threat" could apply to internal events, such as the patient asking for water, or to external events such as a hospice declining to provide service.

Each stage of Hudson's model (appraisal, coping, event outcome, emotion outcome, influencing factors) was treated as its own theory-based theme, with codes and subcodes in each theme synthesised to present a cohesive picture of that aspect of caregiver experience. Braun and Clarke distinguish between themes that generate "patterns of shared meaning" from those that act as domain summaries, e.g. summarising participants' responses to a particular interview question (Braun & Clarke, 2019a, p. 5). The deductive, stress-coping model-derived themes presented in Chapter 6 are the former – they reflect meaning generated by the caregivers but also the interpretive lens of the researcher who must decide whether an event is a challenge or a threat, for example.

Finally, the deductive and inductive themes for each stage of Hudson's model that were constructed for the two systematic reviews and the VSED caregiver dataset were considered side by side, allowing identification of commonalities and differences. For example, concepts from codes about what caregivers perceived as a threat to the patient, what constituted favourable or unfavourable resolution, and caregivers' perception of patient suffering all contributed to the insight, noted in the discussion chapter (Chapter 7), that VSED and hastened death caregivers both regard planned death as better than suffering for the patient for whom they care.

The two approaches to analysing VSED caregiver experiences are complementary, each offering different insights. The inductive approach led to construction of broad themes that address aspects of relationships between the caregiver and the patient, broader society, and VSED as a phenomenon. The deductive, theory-driven analysis shows how caregivers negotiate specific events in the VSED process and the experience as a whole. Comparing VSED caregivers' navigation of events with the experiences of other end-of-life caregivers, the focus of the systematic review, helps illuminate how VSED is unique and how some caregiving experiences may be universal. This analysis, through the lens of Hudson, is the focus of the first part of Chapter 7. Layering these analyses, in turn, allows a more nuanced assessment of the VSED caregiver experience in broader society, something neither analysis could fully generate on its own. The second half of the discussion chapter addresses the theoretical implications of the combined analysis.

## 3.8 Quality

At each stage of analysis, data and methods were checked against Braun and Clarke's checklist for good thematic analysis (2006), which include giving equal attention to each data item, and ensuring that themes are generated from thorough analysis rather than singular vivid examples. A summary of the checklist and work for this thesis are provided in Table 3.2.

**Table 3.2.** Checklist for thematic analysis

| Phase | Criteria | Notes |
|---|---|---|
| Transcription | The data have been transcribed to an appropriate level of detail and checked for accuracy. | I transcribed all recordings myself and reviewed sections of each recording against the final text to check for missing data. |

| | | |
|---|---|---|
| Coding | • Each data item has been given equal attention in the coding process.<br>• Themes have not been generated by a few vivid examples; coding has been thorough.<br>• All relevant extracts for each theme have been collated<br>• Themes have been checked against each other and the original data set.<br>• Themes are internally coherent, consistent, and distinctive. | Initial inductive codes were lumped (e.g. “interaction with healthcare providers”) and then data within each code were analysed and split to identify important variation (e.g. positive, ambivalent or negative reactions to VSED, receiving or being denied care). In constructing each theme, I examined the data associated with each contributing code to look for exemplars but also outliers that could necessitate revising the theme. I checked for consistency across caregiver type (e.g. spouse, child, neighbour) and reason for VSED (e.g. dementia). |
| Analysis | • Data have been analysed rather than paraphrased.<br>• Data extracts match analytic claims.<br>• Analysis tells a well-organised story about the topic.<br>• There is a balance between analytic and illustrative extracts. | Themes were organised to match the general chronology of the VSED caregiver experience, both inductively and using the Hudson model. Data examples were selected after each theme was described, and important exceptions were included. |
| Overall | Enough time is allowed for thorough analysis. | Coding and analysis took roughly eight months. |
| Written report | • Assumptions about thematic analysis are clearly explained.<br>• The final work reflects the described method.<br>• Language is epistemologically consistent.<br>• The researcher is active in construction of themes. | Each section of the thesis has been compared back with this chapter for consistency in language, method, and epistemology. |

## 3.9 Conclusion

The research design and analysis in this thesis are based in constructionist ontology and interpretivism. They suppose that caregivers of patients undertaking VSED create their own meanings about events and interactions in the world around them, and that these are informed by the caregivers’ own knowledge and experience. These principles have been applied elsewhere in studies of caregivers and are represented in Hudson’s model, which serves as the theoretical anchor of this research. The combination of stress-coping model and thematic analysis form the basis for systematic reviews of literature on adjacent caregiving populations (end of life and hastened death) and original data on VSED caregivers.

Thematic analysis offers a rigorous but adaptable method for examining data from a previously unstudied population. The stress-coping model provides a common lens through which VSED, end-of-life, and hastened death caregiving can be examined side by side. Together, these two approaches to analysis provide a more nuanced view of VSED caregiver experience than either alone.

The next chapter presents narrative synthesis of systematic reviews of end-of-life and hastened death caregivers' experiences, which will be used in the discussion chapter to contextualise results of the VSED caregiver study. Following the systematic reviews, Chapters 5 and 6 present the inductive and deductive analysis of VSED caregiver experience.

# Chapter 4: Systematic literature review

## 4.1 Focus of review

In this chapter, systematic analysis of two populations – caregivers of people at end of life and caregivers of people undertaking other forms of hastened death – are presented as adjacent comparators for the experiences of caregivers of patients undertaking VSED. End-of-life caregiving frequently is managed by friends and family, with an estimated 900,000 older adults receiving care from 2.3 million caregivers in the United States in 2011 (Ornstein, Kelley, Bollens-Lund, & Wolff, 2017). Caregivers face challenges in managing patients' needs and household tasks, financial strain, and their own stress, anxiety, and exhaustion, among others, over the course of weeks or months (Funk et al., 2010). Whilst many aspects of caregiving can be applied to any serious or chronic illness scenario, end-of-life caregiving also carries potential for rewards in terms of meaningfulness and opportunities for closeness with the patient before death (Hudson, 2003).

Multiple systematic reviews have examined the experiences and needs of end-of-life caregivers (Andershed, 2006; Bee, Barnes, & Luker, 2009; Broady, 2017; Fringer, Hechinger, & Schnepp, 2018; Funk et al., 2010; Morgan, Ann Williams, Trussardi, & Gott, 2016; Stajduhar, Funk, & Outcalt, 2013; Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2014; Yoo, Lee, & Chang, 2008). Few have used theoretical frameworks as an analytic structure. Broady (2017) used personal construct psychology as the basis for a framework analysis, and Morgan et al (2016) conducted a feminist quality appraisal of gender in family caregiving.

To date, one published systematic review has evaluated the experience of caregivers specifically in the context of hastened death (Gamondi, Fusi-Schmidhauser, Oriani, Payne, & Preston, 2019). Studies describe caregiving roles such as helping the patient navigate the medical and legal hurdles to obtaining a lethal prescription, assisting with preparation of the medication, bearing witness to the death, and orchestrating the completion of patients' wishes before, during, and after death (Back et al., 2002; Buchbinder, 2018; Buchbinder et al., 2018; Gamondi, et al., 2019; Gamondi, et al., 2015; Gamondi et al., 2018; Starks et al., 2007).

This review is different as it uses Hudson's (2003) conceptual model of family caregiving for palliative care, which is based on Folkman's (1997) stress-coping model and seeks to draw a comparison of experience during hastened and non-hastened death.

The focus of this review is to synthesise themes found in qualitative studies of end-of-life caregiving and hastened death caregiving using the structure of Hudson's model to identify events, coping responses, and personal factors common within and across each type of caregiving. Applying the model to each body of literature individually facilitates development of a rich synthesis of caregiving in end-of-life and hastened death contexts separately and provides a rubric for comparing them. Further, themes identified inductively in either set of studies can provide insight into the strengths and limitations of the model itself.

Finally, synthesis of the end-of-life and hastened death caregiving studies provides two points of comparison for the research on which this thesis is focused: caregiving for individuals electing VSED.

## 4.2 Methods

This review is rooted in constructionism and supposes that study participants, and researchers, build meaning and shape reality through their interactions with the world and with others. These created meanings are reflected in Hudson's (2003) conceptual model of family caregiving for people receiving palliative care, in which caregivers identify, appraise, and respond to events based on their own strengths or challenges. This review applies deductive themes drawn from Hudson as well as inductive analysis to produce a narrative synthesis of the two literatures.

Narrative synthesis can integrate diverse data against a framework or theory (Popay et al., 2006) and is useful for exploring heterogeneity across multiple studies (Booth, Sutton, & Papaioannou, 2016). This review follows Popay's (2006) recommended steps:

- developing a theory (in this review, Hudson's model is the theory)
- developing a preliminary synthesis
- exploring relationships in the data
- assessing the robustness of the synthesis

### *Review question and literature search*

The initial review question supports the thesis research question, "What are the experiences of caregivers supporting a patient who has elected to hasten death by voluntarily stopping eating and drinking (VSED)?" Because no studies have explored caregiver experience with VSED directly, the systematic review provides a basis for exploring ways in which VSED caregivers' needs (examined through my empirical research) may be similar to or different from those of caregivers in other end of life contexts.

The revised review question is: “What are the experiences of family and friends providing care at home for a person at the end of life or in the context of the patient’s hastened death?” Specifically, the question can be broken out into clearly defined population, exposure, context, outcome, and study design (PECOS) criteria (Booth et al., 2016; Centre for Reviews and Dissemination, 2009) (Table 4.1.).

**Table 4.1.** PECOS criteria

| | |
|---|---|
| **Population** | Family members or caregivers of adult patients with life-limiting illness, through the point of death |
| **Exposure** | Caring for an adult patient who is dying (life expectancy <3-6 months) or who chooses hastened death (aid in dying, assisted suicide, euthanasia) |
| **Context** | Caregiving in the home |
| **Outcome** | Caregivers’ emotional, practical, and philosophical experiences with caring for loved ones at end of life, either because of illness or related to deliberately hastened death |
| **Study design** | Qualitative, including interviews, focus groups, phenomenology, ethnography |

The review question further may be broken down into a series of objectives that align with Popay’s steps as follows:

- What are the experiences of caregivers of patients at the end of life? (preliminary synthesis)
- What are the experiences of caregivers of patients electing hastened death? (preliminary synthesis)
- In what ways are caregivers’ experiences similar or different at end of life vs hastened death? (exploring relationships in the data)
- In what ways does the qualitative literature on end-of-life and hastened death caregiving support or refute Hudson’s model of caregiving experience? (assessing the robustness of the synthesis)

The review began October 10, 2018 with two sets of searches of Medline, CINAHL, Web of Science and PsycInfo — one for general end-of-life caregiving and one for hastened death. The findings informed the deductive analysis of the interview data. More recent papers are introduced in the discussion chapter. The Boolean search terms are described in Table 4.2.

**Table 4.2.** Key search terms

| | **End of life** | **Hastened death** |
|---|---|---|
| **Population** | (Terminal* OR end-of-life* OR life-limiting OR cancer OR palliative OR hospice) AND (famil* OR caregiv*) | (Terminal* OR end-of-life* OR life-limiting OR cancer OR palliative OR hospice) AND (famil* OR caregiv*) |
| **Exposure (for hastened death searches only)** | N/A | [[(aid* OR assist*) AND (dying OR suicide)] OR [hasten* death] OR euthanasia OR [wish AND (hasten death OR die)] |
| **Context** | Home | Home |
| **Outcome** | Belief* OR experienc* OR emotion* OR support* OR need* | Belief* OR experienc* OR emotion* OR support* OR need* |
| **Study design** | Qualitative | Qualitative |

For parity between the two sets of data, the searches were limited to studies published in or after 1998, the year medical aid in dying was legalised in Oregon, the first U.S. jurisdiction to explicitly allow it. Reference lists of included papers and relevant systematic reviews identified in the search process were searched for additional citations.

## 4.3 Selection criteria

Predefined inclusion and exclusion criteria (Table 4.3.) guided title and abstract review of the initial results of each search. In addition, full-text searching omitted studies in which caregivers' experiences could not be separated from those of patients or professionals, or studies in which current and former caregivers' experiences were interwoven.

**Table 4.3.** Inclusion and exclusion criteria

| **Inclusion criteria** | **Exclusion criteria** |
|---|---|
| Research published in peer-reviewed journals | Ethical or legal reviews |
| Published in English | Not about caregiver experience |
| Hospice or palliative care; life expectancy <6 months | Case reports, personal essays |
| Patient has died, caregiver is bereaved | Animal studies |

| | |
|---|---|
| | Patients under age 18 |
| | Quantitative |

All studies selected for inclusion were reviewed using the RATS (Relevance, Appropriateness, Transparency, Soundness) Quality/Appropriateness Appraisal Tool (Clark, 2003) (Appendix G) to identify studies with limitations such as unspecified recruitment or analysis methods that could warrant concern about the validity of the findings. Included studies were analysed using NVivo qualitative data analysis software.

### 4.4 Analytic approach

Using Popay's (2006) narrative synthesis approach, participant narratives and author analysis from the results and discussion sections in all studies in both searches were coded first using a priori codes aligned with elements of Hudson's model (such as appraisal, coping, and event outcome; Appendix H: A Priori Codes), and subsequently using inductive codes representing concepts not found in the model. A strength of narrative synthesis is its flexibility for blending studies with diverse methodologies, using a range of analytic techniques depending on the requirements of the data (Popay, 2006).

Each code was analysed separately in each data set, employing subcodes where needed to clarify multiple concepts (for example, a favourable resolution could mean getting needed services or the patient having a peaceful death). The two pools of studies were then synthesised individually within each theme of Hudson's model as well as emergent themes outside the model. The two synthesised data sets then were analysed side by side to identify commonalities or differences. Where particularly illustrative, quotes are included.

### 4.5 Results

A search using the end-of-life caregiving term set (Table 4.2.) yielded 9,429 studies for review, with 5,390 remaining after duplicates were removed. Two reviewers scanned the first 10 percent of titles independently and conferred to refine the inclusion and exclusion criteria (Table 4.3.) and repeated the process for abstract review and full-text review. After title review, 744 studies remained for abstract review. Studies were limited to those capturing experiences of bereaved caregivers, and only those who had cared for a patient through a death at home. Following abstract review, 128 studies remained for full-text review, with 32 studies included. Finally, the first reviewer reviewed citations from relevant systematic reviews and included papers to search for possible overlooked studies, identifying two more and bringing the total to 34 (Figure 4.1.).

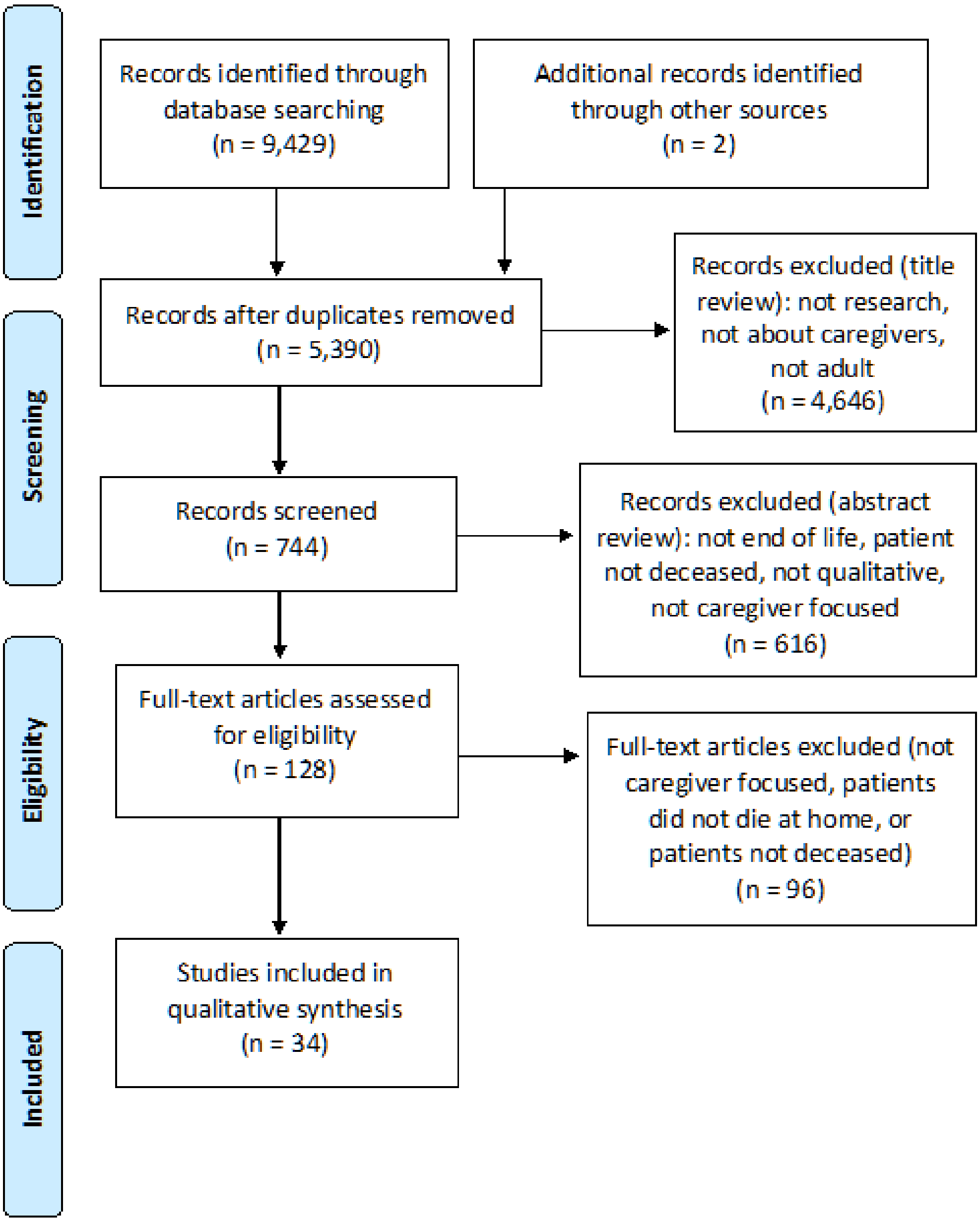

**Figure 4.1.** PRISMA flow diagram: end-of-life caregiving

Searches using the hastened death term set yielded 1,410 studies for review, with 1,117 remaining after duplicates were removed. Following the same review and refinement process, 106 studies remained for abstract review and 13 studies remained for full-text review. Full-text review yielded seven studies for inclusion. Hand-searching of references from those studies yielded four more, for a total of 11 (Figure 4.2.).

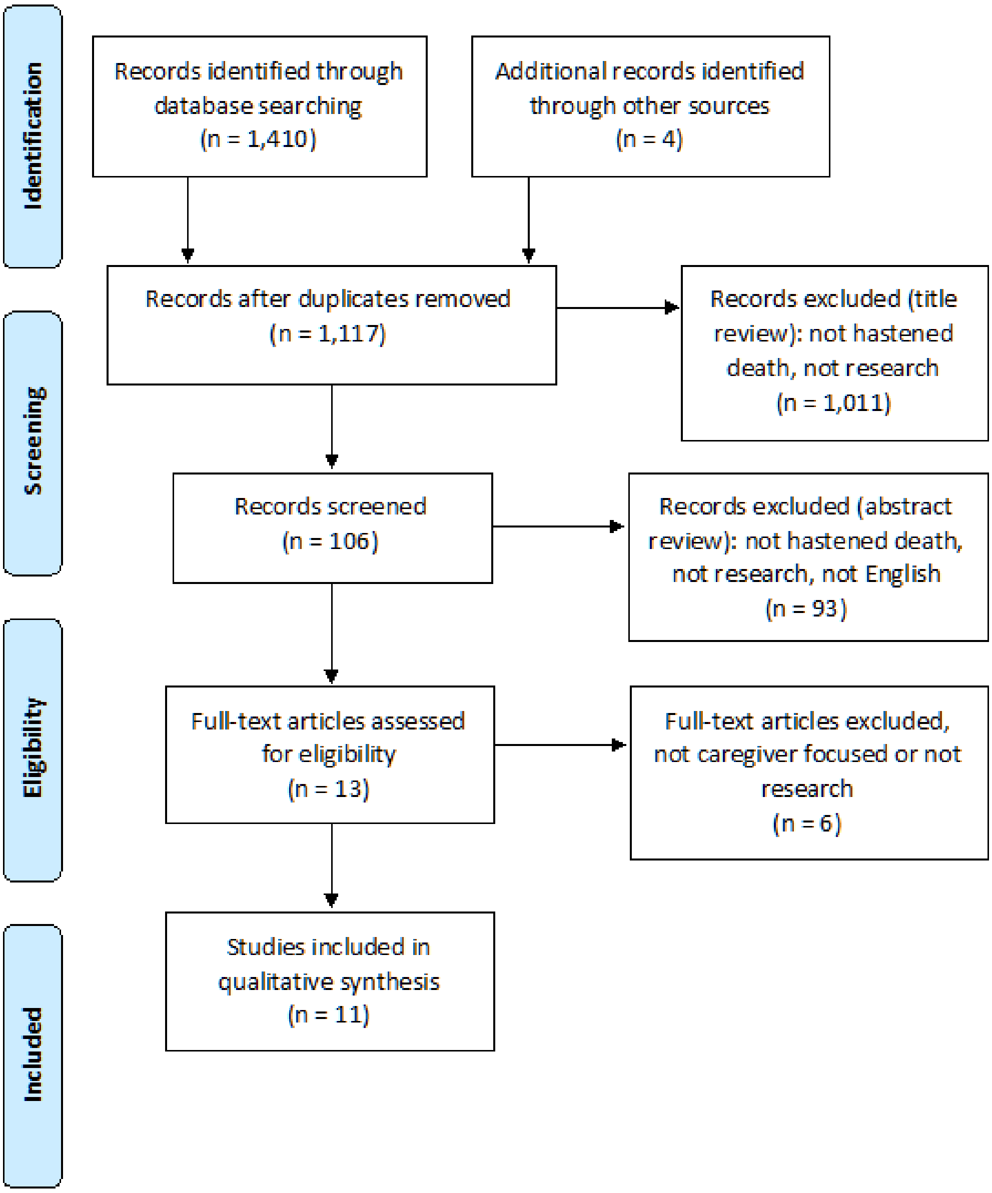

**Figure 4.2.** PRISMA flow diagram: hastened death caregiving

### 4.5.1 Overview of included studies

Of the 34 end-of-life caregiving studies, six were from Australia, seven from Canada, five from the United States, six from the United Kingdom, 8 from elsewhere in Europe, one from Japan, and one from New Zealand. Among the 11 hastened death studies, five were from the United States, three from the Netherlands, two from Switzerland, and one from Canada. Across both sets, cancer was a frequent cause of patient death, along with motor neuron diseases (MND). Characteristics of papers in both sets are presented in Appendices I and J. Paper numbers in the appendices are used to identify papers in the analyses that follow.

In Hudson's model, the process of appraisal, coping, and resolution begins with identification of an event. Caregiving at the end of life was commonly described as an overarching event across both types of caregiving. However, for end-of-life caregivers, events focused on changes in caregiving needs, whereas in hastened death, events primarily followed a predictable pattern of planning, preparation, orchestrating the death, and tying up loose ends. The results of the synthesis are presented in the context of Hudson's model from appraisal through outcome, followed by influencing factors, and lastly by inductive themes not represented within the model (Figure 4.3). Tables summarise findings by code for each part of the model below.

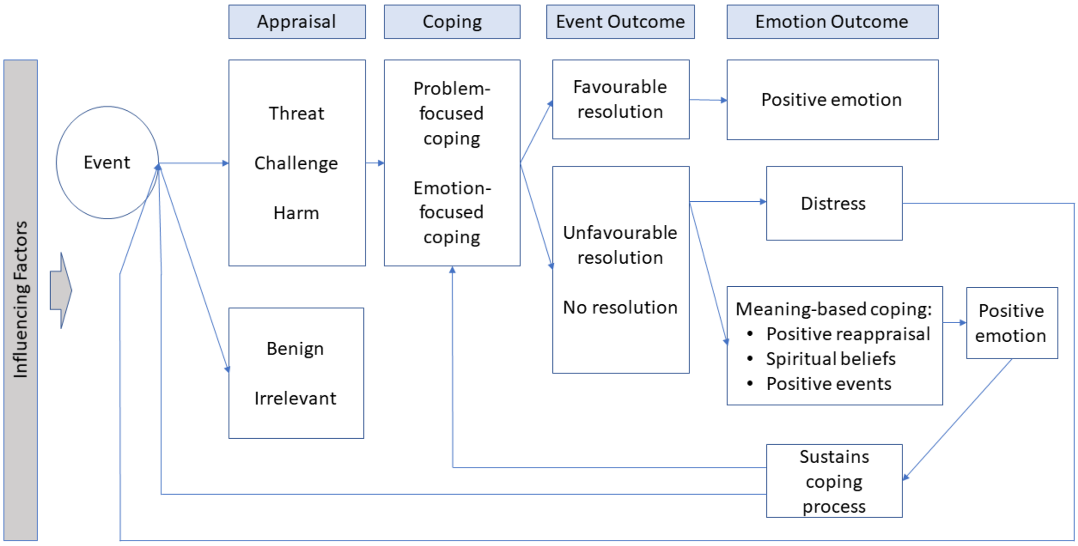

**Figure 4.3.** Adapted from Hudson's modified stress-coping model

### *4.5.2 Appraisal (Hudson)*

Appraisal is the caregiver's initial assessment of the environment (or an event) and whether it falls within or beyond the caregiver's resources. In reports on studies on caregiving, researchers rarely describe events appraised as irrelevant in final study analysis. End-of-life caregiving events appraised as benign include those in which the patient appeared content and comfortable, such as having guests or being bathed. For both sets of caregivers, challenging events were those that tested caregivers' capacity but were important to carrying out their commitment to caring for the patient. For end-of-life caregivers coping with escalating care needs despite fatigue was challenging; hastened death caregivers were challenged by reconciling their own ambivalence to aid in dying.

Among end-of-life caregivers, events perceived as threats primarily concerned the patient's well-being and could be internal (the caregiver's own preparedness and resources) or external (unavailability of hospice or other support). However, caregivers also perceived threats to themselves, such as the toll of fatigue or conflicts from other family members with differing views of care goals, or threats to the family, such as exposure to the patient's deterioration. Hastened death caregivers primarily identified threats as things that jeopardised the patient's ability to achieve their desired death: uncooperative physicians, incomplete ingestion of lethal medication, or a difficult or prolonged dying process. For hastened death caregivers, the possibility of legal consequences following the death and the potential for social stigma, particularly in Switzerland, were threats to their own well-being before, during, and after the death.

End-of-life caregivers identified multiple sources of harm, including disease progression, insufficient professional care, and the potential that being honest about prognosis would be detrimental for the patient. In hastened death studies in Canada and the United States, events appraised as harms were those in which health professionals caused the patient to suffer more than necessary by making hastened death more difficult.

**Table 4.4.** Appraisal

| **Appraisal** | **End of life** | **Hastened death** |
|---|---|---|
| Benign | The patient is content and comfortable (1,6,10,17,24) | The patient receives services that facilitate their goal of hastened death. The death is peaceful (37,38,43) |

| | | |
|---|---|---|
| Challenge | Coping with escalating number and intensity of caregiving tasks, patient’s decline, disruption in routine; demands consistent with caregiver’s sense of duty and commitment, but achievable (1,4,12,14,17,19,20,25-27,29-31,34) | Planning and preparation, reconciling one’s own beliefs to help the patient (36-40,42,45) |
| Threat | Events that could affect the patient’s well-being, either internal (carer’s own preparedness and resources) or external (availability of services); events that affect carer’s effectiveness, such as fatigue. Realisation of potential for death (2,3,7,10,11,15,17-19, 21-23,27,29,32,33)<br>*“And then you weren’t really sleeping because every few seconds you’re waking up and going ‘is she still breathing, is she still there?’” (Totman et al., p. 500)* | Patient denied access to hastened death; risk of incomplete ingestion, difficult or prolonged death, legal repercussions after death, social stigma (36,38-40,42-45)<br>*“He started taking it and apparently it tastes awful, and so started gagging a little bit, and wanted to stop halfway. And we had discussed before, once you start it, you have to do the whole thing. So then we gave him alcohol. Ah, it was terrible...”* (Buchbinder et al., p. 5) |
| Harm | Disease progression, insufficient professional help, potential to harm patient by being honest about prognosis (2,3,7,10,11,15,17-19,21-23,27,29,32,33 | Burden of secrecy about cause of death (Switzerland), inadequate support from providers resulting in more difficult death (U.S., Canada) (39,40,42,45) |

### *4.5.3 Coping (Hudson)*

Coping includes the caregiver's thoughts, feelings, and actions in response to appraisal. In both sets of studies, the logistical demands of caregiving require frequent problem-focused coping, but the overarching activity of caregiving appears motivated by emotion and concern for the patient. Anticipatory grief is common among end-of-life caregiving studies but rarely discussed in hastened death studies. Rather, hastened death caregivers described setting their own feelings aside for the finite time left to focus on patient needs.

**Table 4.5**. Coping

| **Coping** | **End of life** | **Hastened death** |
|---|---|---|
| Problem-focused | Solving logistical problems, learning new skills, keeping household running, arranging help, focusing on patient wishes, serving as gatekeeper (1,2,5,7-10,12,13,15, 17,18,20,22-24, 26, 27, 29, 30, 34)<br>*"So I remember us sitting down and then dividing the tasks, like, father doing the shopping, and my sister would do this, and I'd do that...." (Strang & Koop, p.110)* | Planning and conducting logistics such as physician appointments or filling prescriptions, planning events before, during, and after death, finding solutions for protracted or complicated dying (36-40,42,45) |
| Emotion-focused | Caregiving as an opportunity to show love, be rewarded with closeness; frustration, sadness, or anticipatory grieving (2,6,7,10,11,13,14,16,17,19, 23,26,27,29- 32, 34)<br>*"So you know it was just a sadness* | Overall focus on fulfilling patient's desire to avoid prolonged suffering; where hastened death was illegal or quasi-legal, moral distress in trying to reconcile patients' request for support with own ambivalence or discomfort; in Switzerland, carrying |

| | | |
|---|---|---|
| | *that we couldn't use the time to talk, to really, that I couldn't help her prepare for her death."*<br>*(Sinding, p.158)* | the burden of secrecy after death (39,40,45)<br>*"My brother was used to say: "you do not have to be selfish, you do not have to think only for yourselves… if I want to do this thing is because I do not have solutions and I can't bear it anymore." Ehm…he was saying that we were selfish because we wanted to keep him alive… at all costs. Even in these conditions… so inhumane." (Gamondi et al. 2015, p149)* |

### 4.5.4 Event outcome (Hudson)

Event outcomes are the caregiver's appraisal of whether the event's results are consistent with their goals. Caregivers in both groups frame their views on death in terms of the patient's wishes – such as avoiding suffering – regardless of their own feelings. In end-of-life studies, positive events are those that involve the patient's status, whereas events can be viewed as unfavourable if they have negative consequences for either the patient or caregiver. In most studies, hastened death caregivers tend to view events in terms of the patient's goals rather than their own needs.

**Table 4.6.** Event outcome

| **Event outcome** | **End of life** | **Hastened death** |
|---|---|---|
| Favourable resolution | The caregiver has the skills and resources to solve a problem; death brings an end to suffering or is consistent with patient wishes; the caregiver has guidance or professional help in dealing with post-death tasks (7,10-12,14,17,18,22,25,27,29) | Healthcare providers help plan for or carry out the death; the caregiver finds the hastened death to be peaceful or joyful; loved ones have a chance for closure; the patient avoids unwanted suffering (35-39,41,42,45) |

| | | |
|---|---|---|
| | *'I feel maybe it's hard to say but I knew the end would come and really it was a release not only for me but for X, I knew it was because it was very hard to watch him.' (Hasson et al. 2010, p. 733)* | *''We all toasted with the bourbon. Yep. And I mean, I haven't been around many dying people so I don't have experience with how that often goes, but this was joyful and peaceful, and it's exactly what he wanted.'' (Buchbinder et al. p. 5)* |
| Unfavourable resolution | Professional help is unavailable or inadequate; the illness causes family tension; caregiving demands are unrelenting; the death is unexpected, and the caregiver feels unprepared (2-5,8,9,18,19,21-24,26,27,29,31) | Healthcare providers are unwilling to discuss hastened death; the patient cannot achieve hastened death and suffers; in Switzerland, the caregiver experiences ongoing distress about breaking social norms to assist in hastened death (35-40,42,45) |
| No resolution | Caregiver lives in state of constant vigilance; caregiver cannot process or mourn the patient's death (7,14,23,31,32) | |

### 4.5.5 Emotion outcome (Hudson)

Emotion outcome is the caregiver's reaction to the event outcome. In Hudson's model, it can include positive emotion or distress, but also different types of meaning-based reframing, such as revising goals, that can inform future appraisal and coping. Being reconciled to the patient's death and helping the patient avoid unnecessary suffering were tied to positive emotional outcomes or the ability to reframe events positively for both types of caregivers. End-of-life caregivers who were unprepared for the death found caregiving more distressing, and the patient's suffering also caused distress for both groups. The gruelling nature of long-term caregiving also was distressing for end-of-life caregivers, particularly when circumstances led to a feeling of letting the patient or family down. For some hastened death caregivers, the intentionality of the death led to distress. Thus, for both sets of caregivers, a feeling of violating family or cultural expectations about dying and caregiving led to distress.

**Table 4.7.** Emotion outcome

| **Emotion outcome** | **End of life** | **Hastened death** |
|---|---|---|
| Positive emotion | Satisfaction with overall caregiving; patient’s serenity with own condition (17,18,21,27,29,30) | Events that align with patient’s wishes (36,37) |
| Distress | Patient decline, conflict between exhaustion and increasing patient needs, social isolation, breaking a promise to the patient, family conflict (2-4,6,10,11,14,17-24,27,29,31,32)<br>*“There’s a point where you’ve done, you’ve gone overboard. You hear the 110% effort stuff; well I think it’s probably 180% effort…. You just, you become a basket case.” (Sinding, p.157)* | Complicated dying, moral distress about patient choice to die (36,38-40,42,43,45)<br>*‘‘The ‘I-killed-my-mom thing’ is big, still. Because it’s the truth—how do I come to some resolution around that?” (Starks et al., p117)* |
| Positive reappraisal | Caring provides opportunity for growth, respect, closeness, or strengthening family ties; death allows patient to escape suffering; escalating need for care results in more clinical resources (1,4-8,10-12,16,18,20,23,25-27,29,32-34)<br>*“I think it’s one of the—I mean it’s so wonderful that you can give someone yourself. I mean that’s a real thing to do. And that they’ll let you.” (Sinding, p. 157)* | Clinicians who would not facilitate hastened death but were supportive in other ways; in retrospect, hastened death seen as right choice (36,38,39,42,45) |
| Revised goals | Reducing hopes for patient’s future, deciding to encourage the patient to “let go” to avoid further suffering, admitting patient needs institution-based care | Putting own grief or ambivalence on hold to focus on patient’s wishes, reconciling to idea of hastened death as better |

| | | |
|---|---|---|
| | (2,4,6,7,8,11,12,14,15,17,18,20,24,27,31-33)<br>*'I had to realize that this person was no [longer] capable mentally or physically, and I had to take over the role of [parent] just like you do, first it was like a 6-year-old and then a 5-year-old.' (Clukey 2008, p312)* | option than disease trajectory or unassisted suicide (36,38,39) |
| Spiritual beliefs | Taking comfort in a larger force to supply strength or determine patient's fate, taking comfort in an afterlife (2,7,10,14,27,30,32) | Spiritual or ritual elements, during or after death, add to closure (37,39,45) |
| Positive events | Events that eased suffering, allowed for closure, or provided humour (1,6,7,10,22,26) | In U.S. and Canadian studies, deaths were described as joyful, sacred, or peaceful, with patients' wishes achieved. (37,38,42,43,45) |

### *4.5.6 Influencing factors (Hudson)*

Hudson lists 18 variables that can influence caregivers' experience (see Appendix H for definitions). Although each is distinct and based on other research or conceptual models, they can be broadly clustered as:

- Ability (preparedness, mastery, competence, self-efficacy)
- Structure (social support, information, respite)
- Satisfaction (rewards, meaningfulness, mutuality, choice, and commitment)
- Outlook (anxiety, depression, and psychological distress; positive emotion; optimism)
- Personal (cultural factors; caregiver burden and health; patient's disease status, level of dependency, and duration of illness; caregiver age, gender, socio-economic status)

Caregiver age, gender, and socio-economic status were excluded from this analysis because they could not be teased apart in a synthesis of multiple published works.

End-of-life caregiving studies had ability-related codes more often than hastened death studies, possibly because the duration of caregiving facilitated learning new skills or gaining confidence in abilities. Hastened death caregiving, by contrast, was a finite process with few steps repeated and little precedent. End-of-life caregivers frequently described exhaustion and mentioned the value of respite, but hastened death caregivers did not, perhaps because of the shorter timeframe or a choice to defer their own needs until after the death.

Many influencing factors could be positive or negative. Social isolation and lack of information were stressful for both types of caregivers. Meeting the patient's wishes was related to satisfaction in both groups, whilst being unable to meet expectations for care was stressful. Hastened death caregivers, particularly in the United States and Canada, often described preparing for the death as communal, whilst those in Switzerland were more likely to describe fear of stigma if the cause of death were widely known.

**Table 4.8.** Influencing factors

| **Influencing factors** | **End of life** | **Hastened death** |
|---|---|---|
| Ability (preparedness, mastery, competence, self-efficacy) | Knowing what to expect, being prepared for patient's death, feeling able to learn skills to meet new demands, taking pride in ability to care, having relevant previous experience (1-4,6-12,14-26,28-30,32-34)<br>*"[Home palliative care physician] sat me down at one point, I think the last visit before she died…. He told me what I might expect and… That was invaluable." (Mohammed et al., p. 1232)* | Because caregivers had not facilitated hastened deaths before, few reported ability-related factors; not knowing how to manage a difficult hastened death was stressful (37,45)<br>*"I guess the only thing I wish is I think it would have been easier if we could have had more knowledge as far as how to do it; it would have been a whole ton smoother. And it ended up feeling fairly desperate. ...I don't remember it as being anything negative, I just remember it as being exhausting." (Starks et al., p. 117)* |

|  |  |  |
|---|---|---|
| Support (social support, information, respite) | Lack of support from friends and family and lack of information about what to expect in caregiving were closely related to caregiver isolation and exhaustion; caregivers acknowledged the importance of respite, but more often in retrospect after death. (1,34,6-16,18-23,25,26,28-33)<br>*"In retrospect . . . my sister should have been trained, or somebody, to actually watch me for two weeks . . . you need to watch that caregiver and make sure she's getting sleep and actually has her wits about her." (Mangan et al., p. 252)* | Experience varied by jurisdiction: Swiss caregivers and U.S. caregivers where AID was illegal reported feeling isolated by potential social stigma. Where hastened death was legal, some caregivers found support from family and friends. Swiss caregivers appeared to have adequate information about hastened death, but U.S. caregivers did not always have information on how to handle difficult deaths. Respite was not mentioned in hastened death studies. (36,37,39-41,45)<br>*"The impossibility to tell "look, he has died of assisted suicide…" it was tremendous, it was sad." (Gamondi et al., 2015, p. 150)* |
| Satisfaction (rewards, meaningfulness, mutuality, choice and commitment) | Enhancing: fulfilling sense of duty, showing love, meeting patient's wishes, personal growth, being close with patient<br>Challenging: feeling inadequate when unable to meet all patient needs, needing to respect patient's perspective (1,2,3,6-19,21-25,27,29-34)<br>*"I thought to myself, yeah,* | Enhancing: being able to help patient enact wishes, being present for aided death, helping avoid suffering, taking place in sacred or celebratory event, engaging in communal act of planning and conducting death (37,38,40,42,45)<br>*"When I got down there that morning this whole circle of her closest people had done a ritual around this killing drug, this beautiful* |

| | | |
|---|---|---|
| | *you've [wife] done things like that for me, it's my turn to help you out and look after you and support you." (Totman et al., p. 503)* | *ritual around it. . .. They were all in a circle with a candle lit and they were emptying the capsules together and they were being playful and just the most beautiful energy, loving and making jokes and everything. . .. They prepared it in a very sacred and light way." (Buchbinder 2018, p. 8)* |
| Outlook (anxiety, depression, and psychological distress; positive emotion; optimism) | Enhancing: satisfaction with performing well, feeling appreciated, closure<br>Challenging: Impending loss of patient, relentless burden of caregiving, gradual loss of closeness with patient, not wanting to harm patient's optimism<br>(1,4,5,9-11,16,18,20,21, 24,25,27,30,32-34) | Setting aside anticipatory grief to focus on patient, seeing patients achieve wish of peaceful death and release from suffering (37,38,42) |
| Personal (cultural factors; caregiver burden and health; patient's disease status, level of dependency, and duration of illness; caregiver age, gender, socio-economic status) | Exhaustion from caregiving, balancing caregiving and other life responsibilities, sense of duty to patient, patient's acceptance or denial of condition<br>(1-14,18-33) | Understanding patient's current suffering, likely trajectory and the inevitability of death, shared expectation that hastened death would be more comfortable, lack of clarity about when hastened death would be appropriate (36-40,42,44,45) |

### 4.5.7 Inductive themes: other factors

Beyond the themes outlined in Hudson's model, other internal and external factors appear to affect caregivers' experiences. Healthcare professionals are not listed as an influencing factor in Hudson's model, but their role is a frequent theme in caregiving studies, either as sources of support and information or representing failures of the health system to adequately respond to patient and caregiver needs.

**Table 4.9.** Healthcare professionals

| | **End of life** | **Hastened death** |
|---|---|---|
| Healthcare professionals | Enhancing: providing instruction and information, handling tasks beyond caregiver's skill, acknowledging caregiver effort, providing regular social interaction or respite<br>Challenging: lack of care coordination or continuity, lack of empathy, lack of specialised knowledge or services, lack of clarity about available services, focus only on patient, disappearance of services after death<br>(2,3,4-8,9-15,18-22,24,25,28-30,32,33) | Enhancing: providing information about what to expect in death<br>Challenging: lack of comfort in discussing or supporting patient's desire for hastened death (36,3-40,42,43,45) |

The structure of healthcare, nationally or locally, affect whether home care services or hospice are available, whether specialised care for conditions such as MND are available, and whether patients and caregivers can readily find out about services for which they are eligible. Costs of medication and equipment also can add to caregivers' burden. Whether hastened death was legal and whether information and support were available affected caregivers' moral distress and preparedness to facilitate a comfortable death. Hastened death caregivers felt challenged or distressed when healthcare professionals were unwilling to discuss or support the patient's goals for death.

Internally, caregivers reported different fundamental motivations for providing care. In addition to cultural norms and a desire for closeness at the end of the patient's life, some end of life caregivers also expressed distrust of the healthcare system, particularly hospitals, as motivation to care for the patient at home. Whilst some caregivers saw the hospital as a fallback solution if the patient's needs became too great, others saw the potential of sending the patient to the hospital as a sign that they had failed at caregiving.

Finally, grief affects caregiving at the end of life. Anticipatory grief was common among end-of-life caregivers. On the one hand, coming to terms with the patient's impending death was associated with easier resolution of grief after death. On the other hand, the weight of anticipatory grief could lead caregivers in both groups to shut down their emotions or to seek distraction in the form of tasks. In this respect, grief might affect whether caregivers take a problem- or emotion-focused approach, or both, to events.

**Table 4.10.** Other factors

| Other factors | End of life | Hastened death |
|---|---|---|
| Structure of healthcare delivery | Availability, or not, of specialised services or at-home care support, cost of care, social policies supporting family caregiving (8,15,18,21,26,32) | Legality, or not, of hastened death (36,37,39,40,45) |
| Grief | Variable acceptance of impending death, anticipatory grief (2,5,6,10,11,13,15,18-20,23,31) | Acceptance of hastened death as better than suffering or prolonged dying (39) |

## 4.6 Discussion

This theory-centred review uses Hudson's caregiving model (2003) as a structure for synthesising results of studies that evaluated caregivers' experiences in caring for patients at home at end of life and in the context of the patient's wish for hastened death. Whilst many of the themes identified the analysis fit consistently with the Hudson model, inductively identified codes and relationships across concepts suggest opportunities to refine the model:

1. **The role of healthcare professionals**. Healthcare professionals play a major role in caregivers' experience at end of life and in hastened death. Professionals provide knowledge, teach skills, take decision making pressure off caregivers' shoulders, offer support and validation, and can be a gateway to resources. When healthcare professionals are unavailable, don't fulfil promises to take measures to relieve patient suffering, or don't support caregivers' assessment that the care is too much to handle, caregivers often report feeling isolated. Meta-analyses of caregiver studies noted that across many studies, caregivers expected health professionals to take responsibility to developing a trusting, supportive relationship with families (Andershed et al 2006, Funk et al 2010). For some end-of-life caregivers, the regular presence of hospice staff is a welcome, regular break in caregiving, and its loss is felt after the patient's death. In hastened death contexts, professionals' legal ability or personal willingness to discuss the patient's wishes and options, and provide practical support, contributed to caregivers' reduced moral distress and satisfaction that the patient's wishes could be achieved. The role of professionals is not called out in Hudson's model but might fall into either social support or information.
2. **Healthcare policy**. Whilst some caregivers reported having their needs anticipated well and addressed, others reported isolation, stress, and in some cases financial strain as the patients' needs outstripped the support structures available. For example, family caregivers of patients with MND in Australia reported difficulty accessing community palliative care services or support adequate to the increasing demands of the disease (Bentley, 2016). These structural issues are relevant for both end-of-life and hastened death caregivers. They are distinct from the availability or attitude of individual health professionals and may be more relevant in countries with limited or inequitable healthcare infrastructure as opposed to national health coverage. Ventura et al. (2014) categorised unmet needs in studies of palliative care patients receiving services at home, including transportation, equipment, caregiving support, and respite, in addition to adequate communication and information from professionals.
3. **Certainty of death**. Acceptance and anticipation of patient's death appears related to having less grief before and after death. In hastened death studies, caregivers are actively working toward the patient's goal of a peaceful death, whereas some end-of-life caregivers are unprepared or surprised by the death. Hudson's caregiving model is not end-of-life specific, but grief may be a relevant factor for caregivers when death is likely. Broady's (2017) scoping review of caregiver literature notes

that anticipatory grief may encompass awareness of both the patient's impending death and the change in identity, away from caregiver, that will follow.

Further, the side-by-side analyses reveal similarities and differences between caregivers' experiences in both settings. Across studies, caregivers commonly sought closeness with the patient and reported satisfaction at having done their best to care for the patient in a critical time. Hastened death caregivers were more consistently reconciled to the patient's death and generally believed that death was preferable to anticipated suffering. Some but not all end of life caregivers reached this conclusion. However, the deliberate nature of hastened death may mean that patients choose likeminded caregivers more deliberately than in situations where caregiving may not be expected to lead to death. Hastened death caregivers reported exhaustion and burden less often than end-of-life caregivers, possibly because their scope of preparing for hastened death is finite.

## 4.7 Strengths and limitations

This review is the first to apply Hudson's model as a lens for synthesising literature on the experience of caregivers at end of life. As such, the review also evaluates the limits of Hudson's model and identifies potential refinements, such as the role of healthcare professionals as an influencing factor, that could strengthen it.

A major limitation of synthesising qualitative studies against such a model is that they may use other analytic models that may emphasise different aspects of caregiving. Further, because each study represents data synthesised from participants by the authors, salient aspects of Hudson's model, such as the appraisal of benign caregiving events, may have fallen out of the earlier published work in favour of events that better aligned with the authors' own theoretical underpinnings. Applying Hudson's model against a full set of original data, the purpose of the larger thesis, may better illuminate its strengths and weaknesses.

## 4.8 Relevance to future research

This synthesis contributes to original research on VSED caregiving in several ways:

- It provides an initial assessment of the completeness of Hudson's caregiving model and themes that may strengthen the model for use in analysing VSED caregiving data.
- It maps where various aspects of end-of-life and hastened death caregiving overlap and diverge, which in turn provides a basis for comparison with VSED caregiving.

## 4.9 Conclusion

Hudson’s model is an effective lens for interpreting caregivers’ experiences at end of life and in hastened death, although modifications such as the inclusion of professional caregivers could strengthen it. In both contexts, caregivers are motivated by the desire to ease patient suffering and may put their own needs or feelings aside to focus on that priority. Hastened death caregivers’ expectation of impending death, and the relatively short duration of caregiving may result in less caregiver burden and less difficult grief relative to end-of-life caregivers. Acceptance of the patient’s condition, social support, and support from healthcare professionals all appear to improve caregiver experience.

The experiences of these two types of caregivers can reasonably be considered adjacent to or overlapping with VSED caregivers’ experiences. As demonstrated in the analyses in Chapters 5 and 6, VSED caregivers undertake physical care and assume responsibility for patients’ comfort in the last days of life, similar to end-of-life caregivers. Like other hastened death caregivers, they are resolved to helping the patient achieve death on the patient’s terms. Chapter 6 assesses VSED caregivers’ experiences using Hudson’s model. Chapter 7 begins with a comparison of all three types of caregiving based on the findings of Chapters 4 to 6.

# Chapter 5: Findings on caregivers' experiences supporting patients through VSED

In the following two chapters I present the findings of original research on the experiences of caregivers assisting someone with VSED. In Chapter 5 I present the results of inductive thematic analysis of the experience of caregivers supporting patients through VSED. Chapter 6 reports the results of deductive analysis of VSED caregivers' experiences through the lens of Hudson's model, which was also used as the framework for the systematic review of caregiver experience at end of life and in other forms of hastened death (Chapter 4).

## 5.1 Participants, patients, and types of VSED

This study incorporates the experiences of 24 caregivers of 20 patients who undertook VSED, with 19 resulting deaths. The median time from initiation of VSED until death was 10 days, with a range of 2 to 28 days. One patient halted her VSED effort after three weeks and remains alive. In four cases, two caregivers were interviewed about the same patient. VSED attempts took place in 10 states between 2009 and 2018, with a median of five years between the death and the interview for this study. All participants vividly recalled the events and emotions associated with the VSED caregiving process.

Patient and caregiver characteristics are described in Table 5.1. All caregivers were white and had at least some college education; half had advanced degrees. Eight caregivers were not religious; others were Catholic, Jewish, protestant, or Buddhist. Caregivers had a median age of 61 (range 26-86) at time of VSED; patients had a median age at death of 80 (range 43-94). Patients were evenly divided among men and women, but more caregivers were women.

**Table 5.1.** Participants

| Participant | Age of participant at VSED | Time since VSED | Gender | Relationship to patient | Patient condition |
|---|---|---|---|---|---|
| Alex | 57 | <5 years | M | son | dementia |
| Amanda<br>Teresa | 27<br>65 | <5 years | F<br>F | daughter<br>wife | dementia |
| Amy<br>Jim | 26<br>68 | <10 years | F<br>M | daughter<br>husband | CADASIL |
| Andrea | 78 | <5 years | F | neighbour/friend | Parkinson's, bipolar |
| Brian | 75 | <1 year | M | neighbour/friend | achalasia, Parkinson's |
| Dawn | 46 | <10 years | F | daughter | COPD, abdominal aortic aneurysm |
| Edith<br>Scott | 86<br>56 | <5 years | F<br>M | wife<br>son | dementia |

| | | | | | |
|---|---|---|---|---|---|
| Fran | 66 | <10 years | F | wife | dementia |
| Joanne | 75 | <5 years | F | wife | dementia |
| Lauren | 37 | <1 year | F | daughter | spinal fracture |
| Linda | 67 | <10 years | F | daughter | old age |
| Patsy | 55 | <10 years | F | daughter | COPD |
| Paul | 50 | <5 years | M | son | cardiovascular |
| Robin | 53 | <10 years | F | partner | multiple myeloma |
| Ruth | 77 | <10 years | F | wife | dementia |
| Sam<br>Sharon | 62<br>60 | 10 years | M<br>F | son-in-law<br>daughter | oral cancer |
| Sarah | 74 | <10 years | F | mother | progressive neuromuscular disease |
| Ted | 73 | <5 years | M | husband | MND |
| Vicky | 54 | <5 years | F | daughter | COPD |
| Zoe | 44 | <1 year | F | daughter | multiple myeloma |

Patients undertaking VSED fell into three broad categories, each requiring different engagement from caregivers:

**Progressive illness.** Some patients had metastatic cancer, MND, or progressive neuromuscular conditions such as Parkinson's disease. For some, death was expected in a matter of months; for others, their condition's course would lead to months or years of increasing disability before death. Patients and caregivers asked the patient's physician and hospice in advance for support for VSED and established a plan for caregiving. Caregivers felt that patients had time to settle their affairs and say goodbye to friends and family before or shortly after starting.

*Exemplar:* Wanda, 73, was a gerontological social worker diagnosed with MND. She told her husband, Ted, that she would initiate VSED when she could no longer toilet herself. A year beforehand, Ted and Wanda met with her physicians and the local residential hospice to make preparations. In the year before she died, she attended family milestone events and said goodbye to all but her immediate family. She set a start date for after her birthday. Wanda stopped eating at home; three days later she entered hospice and stopped drinking. Ted coordinated family visits and was at her side when she died.

**Early dementia**. Some patients had a diagnosis of early dementia. All patients and caregivers in this category had experience with an older relative who had died with dementia. Patients wished to avoid living for years without being able to engage intellectually or emotionally and wished to spare their families the burden of caring for them in that state. Together, patients and caregivers set markers that would signal that the patient's quality of life was deteriorating, with a goal of initiating VSED whilst the patient retained the intellectual ability and will to follow through. Caregivers took on the logistics of planning and preparing, and sometimes were active in helping the patient recognise that it was time to start.

*Exemplar*: Joanne, 75, and Dale, 71, had noticed Dale's cognitive changes and attended a presentation about end of life options for dementia by the state end-of-life advocacy organisation. Dale decided he would prefer VSED to any scenario of living through dementia. Together they discussed VSED with his doctor, who agreed to provide support. Joanne hired aides from a local health cooperative to provide round-the-clock physical care and medication management. When Dale's impairment increased, he started VSED, choosing a start date in early December so he could die before Christmas to spare the family the pain of associating his death with the holiday. The adult children flew in to spend time with Dale a week into the process; he died on day 10.

**Done with living**. Some patients had a change in health status that reduced their independence and had little prospect for improvement, but they were not necessarily close to death. Most had one or more chronic health conditions; one had recently become quadriplegic following an accident. Several had outlived spouses and peers. Some made a stated, deliberate choice to stop eating and drinking in order to die; others told clinicians and family they wanted no further medical interventions and stopped eating and drinking as well. Caregivers ascertained patients' wish to die and took steps to make the process comfortable, calling physicians to obtain hospice support or asking nursing home staff not to bring unwanted food to the patient.

*Exemplar*: Patsy's mother, 83, had become fully dependent on supplemental oxygen after years with COPD. Small in stature, she was unable to lift the portable oxygen cannister and realised she had become house-bound. She announced to her family that she had stopped eating and drinking. Patsy, 55, lived abroad but flew home the next day. Patsy and her siblings knew their mother's iron will and said they would support her choice. They called her doctor, who determined that she was making a mentally sound decision and ordered hospice care. Patsy stayed with her mother for six days until her death, with hospice aides providing overnight care. Children and grandchildren were able to visit and say goodbye.

## 5.2 Caregivers' experiences

Following Braun and Clarke's (2013) guidance on reflexive thematic analysis, inductive coding of interview transcripts initially generated more than 100 codes related to caregivers' experiences with VSED. Subsequent rounds of analysis collated these codes into potential themes representing concrete aspects of caregiver experience (Appendix F). In a final round of analysis, these potential themes were clustered together as subthemes to four eventual major themes of VSED caregiving experience shown in Table 5.2.

**Table 5.2.** Themes

| Theme | Supporting subthemes |
|---|---|
| VSED is the best death available to the patient | People have the right to choose how to die |
| | AID is unavailable |
| | VSED is different than suicide |
| | VSED is the best death available |
| | VSED was peaceful |
| | VSED can be a gift to caregiver |
| Risk and legitimacy | Will healthcare providers support VSED? |
| | Is VSED legal? |
| | Will family or community challenge VSED? |
| Carrying responsibility for the patient's success | Project managing the death |
| | Feeling responsible for the patient's success |
| | Being vigilant for threats |
| There is no script | Anticipatory grief |
| | Choosing what roles to play |
| | The chance for closure is a gift |
| | There is no script |
| | Putting self on hold |

### *5.2.1 VSED is the best death available to the patient*

Caregivers contrasted VSED with other trajectories of living and dying available to the patient and concluded that VSED was the best death available to the patient. For patients with serious illness or dementia whose remaining life course, probable suffering, and death could be predicted, caregivers saw VSED as an alternative that offered a peaceful option distinct from suicide. For caregivers of people done with living, the choice of VSED was interpreted as an understandable choice rather than suffering from debility or loss of independence.

Across groups, caregivers expressed support for the right of individuals to choose their death, either in general principle or in response to the patient's particular situation. One caregiver, Paul, was an exception. Based on his deeply held Catholic faith, he questioned how anyone could rationally choose to not want to live. For most caregivers, a stated belief in the right of individuals to choose their death was a prerequisite for their own ability to come to terms with the patient's choice, support the patient, and evaluate for themselves the options the patient might consider. Dawn, a nurse, found she felt prepared when her father declined medical treatment for ongoing health issues and decided to die:

> "I myself believe in helping people who are terminal move on with dignity and pain-free and peacefully, but not everybody can do that. … I'm very accepting of what he did and how he chose to end his life. It was very much in sync with his personality. … He was going to die sometime in the near future anyway, it was a given. He just hastened it a little and went on his terms." –Dawn

In all dementia cases, the patient and caregiver had investigated the options and knew that AID was not legally available, rendering VSED the best available means to meet the patient's wishes. Most caregivers said the patients would have preferred a faster option if one had been available, but the legality of how to die was important.

> "We didn't talk much about this but she knew it was not an option, to give her medication to make her die. She wasn't terminal by any stretch of the imagination. So I don't think it was the ideal for her, but she was glad to have an exit strategy. She was glad it went well; she was happy along the way. She really wanted to be dead." –Alex

Only one caregiver for the done-with-living group mentioned discussing AID with the patient, who would have preferred the swifter option but lived in a state where it was unavailable. Another later helped a spouse with AID in a state where it was legal and found VSED and AID to be similar. For the most part, caregivers of patients who were done with living did not discuss VSED in terms of AID or suicide but simply as a way to avoid future suffering in life and have a good chance for a peaceful death.

In three cases with progressive illness, patients and caregivers had discussed hastening death by other means, such as moving to Oregon to qualify for AID or through suicide or means described in the book *Final Exit* (Humphry, 1991). Others, particularly those working with palliative doctors or with a doctor in the family, did not mention considering other means.

The variation in awareness of AID or other hastened death suggests that patients and caregivers arrive at VSED through different paths. For some it is an outgrowth of extensive research to find an alternative to suffering or an unacceptable death when AID is not available. For patients done with living, however, VSED appears to be chosen more organically as the patient refuses food and drink as part of refusing to live longer. For these patients and their caregivers, the ability to avoid unwanted suffering in the remainder of life, control the initiation of the dying process, and choose a predictable, peaceful death make VSED preferable to the patient's other options for living or dying.

Caregivers of patients with dementia and progressive illness consistently said that the alternative death expected by the patient through disease progression was “horrible”, “unacceptable”, or “pretty sad”, with low quality of life or heavy symptom burden. Most viewed VSED in retrospect, by contrast, as “peaceful”, “a very good death”, “a completely perfect situation”, and “painless”, although some thought the patient should not have to go through such a protracted process. Most caregivers of patients who were done with living said they could empathise with the patient’s choice and found meaning in the patient being able to enact control in their life at the end, particularly when poor health had limited their independence.

Some caregivers distinguished between VSED and suicide, usually noting that healthcare providers, clergy, family, or neighbours might object to the patient’s choice of VSED and see it as a form of suicide, in contrast to the caregiver’s own views. For most caregivers, suicide had negative connotations. One caregiver found the distinction less clear but also not meaningful to the patient:

> “Along the way she said, "You know, Alex, this is suicide. I know I'm healthy. I'm trying to make myself die in a way that's acceptable." So naming that, using her word, also was controversial I think in our family and the community.” –Alex

On the other hand, Paul’s recognition that his mother was attempting to die caused a struggle between his duties as a devout Catholic, a son, and his mother’s healthcare power of attorney.

> “I was disappointed that my mother chose to go down this path and she didn't have to. … At the same time, the Catholic faith tradition is big on your conscience rights. So I was trying to respect her decisions to points where I could go to. I certainly wouldn't help her commit suicide or stop eating or drinking. But also as the power of attorney my job was to make the choices she wanted to make. So I wouldn't help her with this but I didn't try to forcefully intercede even though at the end I kind of suspected what was going on.” –Paul

Caregivers believed that VSED addressed the patient’s desire to control the time and circumstances of their death in the face of an undesirable health trajectory. Some caregivers also acknowledged that VSED was a gift from the patient to the caregiver: by choosing to die sooner, patients spared caregivers years of intensive caregiving or worry about the patient’s health, or years spent knowing that the patient was living in circumstances he or she would have found intolerable when fully capacitated.

> "I didn't have to make the decision to go to a nursing home. I didn't have to move home to take care of her. I didn't have to interview nurses. I didn't have to shower my mom. I didn't have to carry her anywhere or change her diapers. That is huge. If you could give that to your kid, that gift is so incredibly big. It doesn't mean that it's a fun death or that it was easy or I didn't care or that I wouldn't want more time with her. But I'm absolutely certain that she got what she wanted, and absolutely certain that she gave me what she wanted me to have. [cry]" –Amy

What makes VSED the best available death for the patient, in caregivers' views, is a combination of internal and external factors such as the patient's probable future suffering or quality of life and respect for the patient's lifelong desire for control. Caregivers' views are predicated on a belief that people have the right to choose to die, in general. VSED appeals to many caregivers for being distinct from and a more legally and socially acceptable option than suicide, consistent with patients' need for control, and more bearable than the suffering likely if the patient continues to live.

### 5.2.2 Risk and legitimacy

Once committed to supporting the patient's choice to pursue VSED, caregivers often found themselves acting as patients' agents to line up whatever medical, social, or other support seemed necessary to achieve a successful VSED. Whilst caregivers understood and supported patients' goals, they were aware that friends, family, healthcare providers, and the larger community might not. Consequently, many caregivers expressed some awareness of risk that external parties might object to VSED or try to stop it. To mediate that risk, caregivers sought markers that the patient's choice was legitimate.

Nearly all patients and caregivers actively sought hospice support for VSED to improve patients' comfort and get help with symptoms that might arise. Enrolling in hospice required first obtaining physician referral. Whilst patients with a cancer diagnosis had been enrolled in hospice prior to initiating VSED, most patients and caregivers found themselves asking for hospice support at a time when the patient might not be considered eligible based on the Medicare criteria that patients should be within six months of death. They also were aware of the risk that the physician might not support the patient's choice and decline to provide medical care or referral. Therefore, patients and caregivers interested in VSED faced uncertainty about whether individual clinicians or healthcare institutions would agree medically or morally to support the patient's choice. The local, Catholic-run hospice in Fran's town refused to care for her husband once they learned of his plans for VSED. On the other hand, Sarah's son, who had a progressive neurological condition that left him unable to move, was able to secure support from an inpatient palliative and hospice unit although he was not actively dying.

> “I talked to the doctor who is kind of the gatekeeper for hospice care and we got a meeting [to request support for VSED]. I'll be serious, she met us in the doorway with her arms crossed. She was like, ‘I don't think you guys know what you're talking about.’ By the time we ended our visit with her, she was literally saying, ‘All I need you to do is go across the street and get a blood test and I will find something to indicate that you deserve to be on palliative care through hospice.’” –Robin

Physician support for and engagement with VSED ranged from house calls and symptom management when hospice was unavailable to basic hospice referral to agreeing to deprescribe the patient’s existing medication for chronic conditions. Jim sought support from his wife’s neurologist when she decided to begin VSED. The neurologist refused to refer her to hospice, stating that she was not ill enough. Through his wife’s primary care physician and his own ties within the community, Jim was able to obtain hospice support.

Ultimately, 85% of patients were enrolled in hospice care, although the level of support ranged from providing a hospital bed to full inpatient care. Several patients lived in areas where the only hospices were Catholic-run institutions that declined to support VSED. For caregivers, hospice provided not only symptom management and an information resource, but legitimacy – not only in the community but for other clinicians as well as hired aides.

> “Hospice came to visit, and I was actually surprised and relieved when they accepted her. They said she was not their typical hospice candidate. And once they talked to her they felt, I guess, better about her and admitted her to their program. And once that happened I felt like the nurses, the social worker kind of shifted her tone. She was suddenly supportive of my mom's choices that she didn't seem before she was admitted to hospice.” –Lauren

Several caregivers were conscious of the potential that others in the community may view VSED as a form of suicide or elder abuse and could try to intervene. Some pointed to the experience of Phyllis Shacter, whose book about her husband’s death through VSED includes an incident in which Adult Protective Services visited the home because of an anonymous report of elder abuse.

> “There was a little bit of, I mean I didn't like want to tell the neighbour, I didn't want someone to feel like, ‘Well, you can't do that! Stop!’ And we had hospice around, so

> that lent some legitimacy to it. I can only imagine if there was someone who didn't have hospice who just was at home with their loved one waiting for them to die, how that, I bet that would be really hard." –Amy

Perception of legal risk varied depending on the condition prompting patients to pursue VSED. Patients with dementia in Washington state worked with lawyers to fill out extensive paperwork stating their understanding of their illness and absolving family, caregivers, and clinicians of any responsibility for death. Washington has a longstanding AID law and was the first to develop a dementia-specific advance directive. Such measures were less common in other parts of the country or for other patients pursuing VSED.

Caregivers' choice of who to tell about VSED varied by individual circumstance, driven by patient and caregiver perception of potential stigma and support. Some waited until after the patient's death before telling anyone outside the family what had happened. Teresa and Amanda described a party-like atmosphere whilst caring for Daniel, who had early dementia, with friends visiting and dropping off meals for the caregivers. Alex's mother, also with early dementia, told some friends about her plans and created a stir.

> "Everybody that she talked to, she talked about this. I was actually at one point doing some damage control because I started getting some phone calls from family members, from others who were calling in alarm saying, 'Your mom's trying to kill herself! Are you trying to kill her? What is your role in this? How can you let her do this?'" –Alex

Perception of risk of social stigma appeared to be more common for caregivers caring for patients who did not outwardly appear to be plausibly near death, particularly patients early in dementia whose symptoms might not be noticed in casual conversation. Caregivers of patients who were more physically ill or who were elderly and frail less often mentioned anticipating or managing external reactions beyond normal grief.

Caregivers' thoughts about external reactions to VSED suggest that on some level caregivers carry an awareness about who in society can die without censure: the visibly ill, the frail and old. As patients' intent on VSED flouted those conventions by pursuing death on their own terms, some caregivers who had taken on responsibility for planning and coordinating the VSED perceived more threats and barriers from the community, the medical establishment, and the law.

> “We didn't give him water, and I believe that was the right choice because that's what he wanted, but in the legal court of law, I don't believe that would stand up. And if Adult Protective Services was there when he was asking for water and we were saying no, I believe we could have got in big trouble for it.” –Amanda

The power of those institutions to facilitate or impede VSED can be seen in several cases. A quarter of VSED cases took place in a nonhospice institutional setting, such as assisted living or a nursing home, where at least some level of institutionally provided care was available for patients. In independent living, patients and caregivers had autonomy in making care decisions to facilitate VSED, asking for help only if needed. In two nursing home-sited cases, patients were elderly and “done with living” and their choice to stop eating did not appear to alarm staff. Paul, for example, perceived that nursing home staff felt his mother’s refusal of food was part of the dying process rather than an act of will. However, one case in a continuing care community illustrates the tension between individual choice and institutional power. In an assisted living unit of a facility that offered a continuum of care, a woman with Parkinson’s, Maureen, recruited a neighbour, Andrea, to orchestrate Maureen’s VSED attempt. At Maureen’s direction, Andrea organised neighbours to read to Maureen and hired aides to sit with her overnight. However, Maureen’s medications were administered by facility nurses. Andrea noted that the nursing staff expressed disapproval of Maureen’s goals and administered anxiety medication sparingly despite Andrea’s requests for more aggressive symptom management. Facility managers also refused to allow Maureen to hire a death doula to sit with her or offer guidance on the VSED process. Confused and agitated as dehydration progressed, Maureen asked for water. The overnight aides, unfamiliar with VSED, gave it to her. Hospice had agreed to help, but only after Maureen ceased eating and drinking entirely. Andrea, as a neighbour, had no authority to ask for changes to treatment. Without sufficient medical and psychosocial support, Maureen continued to drink enough to slow the pace of dehydration until after several weeks she gave up on her effort. She is still living.

> “She wanted a death with dignity. That was the term she used and I wanted that to happen for her. I didn't have much control over the medical end of her care. ... And I felt like, toward the end when these women were coming who weren't trained at all and who were giving her water, that things had just spiralled out of control, and that was really frustrating and hard for me.” –Andrea

In their role as orchestrators of VSED, some caregivers perceived the possibility of external threats to patients' success in the form of individuals or institutions challenging the patients' right to die on their own terms. Counter-measures included secrecy and legal documentation, but hospice admission was desirable not only for practical support in VSED but because hospice conveyed that the patient was viewed by formal healthcare institutions as dying, offering a sense of legitimacy.

### 5.2.3 Carrying responsibility for the patient's success

VSED is characterised by a gradual decline in patients' physical function and mental clarity during dehydration. Most patients undertaking VSED become entirely dependent on caregivers as VSED proceeds, and some are dependent on caregivers' help for logistics well before VSED begins. One of caregivers' most important tasks is reminding patients of their goals and the consequences of drinking. Many caregivers noted that as patients' capacity decreased, the caregivers took on the full weight of responsibility for ensuring that patients succeeded in VSED.

Caregivers consistently listed independence as among patients' dominant personality traits, but at some point in the VSED process patients handed off responsibility for the outcome to caregivers. In dementia, handoffs of power and responsibility occurred early because of patients' growing cognitive impairment. Patients with dementia were able to state and follow through on their desire to hasten death through VSED but lacked the executive function to help with planning or preparation. Dementia caregivers' role began once patients had stated their intent to pursue VSED. They looked for information and support, made appointments with doctors, and often worked with the patients to set milestones about when to start.

> "I kind of fought it each step of the way because I didn't want to let him go. I did but I didn't. And it was so hard the whole time going, 'Are you sure this is what you want? You don't have to do this. But we're here.' And he kept saying, 'I have the best team possible. I have my wife, I have my daughter, and I have [death midwife].' And he totally trusted the three of us to help him do the path that he wanted. –Teresa

In particular, caregivers assisting patients with cognitive decline were closely involved in determining when to start VSED. Patients with progressive illness or those who were done with living tended to set their own start dates based on their assessment of quality of life. Caregivers of patients with cognitive decline, on the other hand, were acutely aware that there was a window of opportunity: a time when quality of life had diminished enough to motivate the patient to start VSED but the patient still retained the cognitive capacity and will to choose not to drink. The patient’s decreasing capacity became a threat against success of VSED.

> “I think the markers were the most difficult part. ... It puts it in this really grey area in that a person is asking you to do something, they've made a contract about how they want things to go, but things are always changing as they lose parts of their memory. So we had a list of 20 [markers]. One of the basic ones was driving. … He had an older dog and one of his biggest goals in life was to make sure that Snoopy went before him, and then Snoopy died like six months before him. … We would have meetings every month with the death midwife. We got to one meeting where my dad was like, "It's time," and we were all like "yeah, it's time to start." –Amanda

In dementia scenarios, caregivers juggled their commitment to helping the patient achieve the goal of using VSED to avoid an unwanted future death, their grief about losing the patient, and their own assessment of the patient’s diminishing capacity to exert the independent will required for VSED. Some dementia patients had an abrupt change of function that made timing straightforward, whilst other caregivers wrestled with when to suggest to the patient that it was time to start. Some caregivers looked for consensus among family that the time was right.

> “Mom took me aside at one point. She had a bit of a breakdown and cried. She was saying how she didn't want to be the person who chose the when this would happen, but she knew that the time was soon. She was, I think, looking for permission to let go, and that was really tricky because the evidence of dad's dementia was there. It was essentially her getting to the point where she was saying ‘ok.’ She has to let go, because if she doesn't let go, then it won't be dad's choice.” –Scott

The sense of responsibility for choosing a start date is unique to dementia caregivers; by contrast, patients with progressive illness or who were “done with living” played a more active role in setting their own VSED start, often related to a deterioration in health status. Some patients who were “done with living” simply started VSED without preparation. In these cases caregivers often were taken by surprise by the decision but empathised with patients’ perceptions of diminished quality of life and quickly started making logistical arrangements to support the process.

Whether or not they helped identify a start date, caregivers across groups played an active role in ensuring the patient's success. Caregivers worked with patients or took the lead in reaching out to physicians for direct support and/or referral to hospice. Through these channels, patients had access to medication considered to be best practice for symptom relief, typically lorazepam for anxiety and morphine for pain or discomfort in the later stages of dying (Quill et al., 2018). Hospice often also provided a hospital bed for home care and could answer caregivers' questions about the dying process. Several caregivers noted that the arrival of the comfort pack – medications kept in the home to treat breakthrough symptoms – provided peace of mind.

Some of caregivers' roles during VSED were improvised based on what they or the patient imagined might happen during VSED, as few had any guidance about what to expect about the nature of VSED itself. Caregivers were vigilant against threats to the patient's success, often arising directly from the patient's deteriorating condition. As dehydration progressed, patients became physically weaker, increasing the chance that they could fall and injure themselves seriously enough to require medical attention. Caregivers assumed that emergency clinicians would not understand VSED and would hydrate the patient, or that a fracture would result in inpatient care in a rehabilitation setting that would not support VSED.

> "For the first few days until she really became totally bedridden, we had a commode next to the bed but Brenda wanted to go to the bathroom. So I'd be sleeping and I'd wake up finding her halfway out of bed, heading for the bathroom. … So my fear was if she falls and breaks her hip, then the whole plan is derailed and she'll have to go to the hospital and then how will they treat her in terms of nutrition and fluids. … So I was very vigilant I guess during that whole period, which is exhausting." –Jim

Caregivers took steps to minimise patients' exposure to food or drink that might prove tempting. Many avoided cooking in the house and some arranged to have friends bring meals that could be eaten when the patient was asleep. Others asked nursing home staff not to bring meals the patient didn't want.

> "It was maybe the second day. Dale was up and kind of agitated. So he went to the kitchen and opened the cupboard and took down a box of crackers that he always kept up there. … And this is when I thought, 'This is it. I can't say, "You can't have those crackers, Dale."' So I just said, 'Remember, Dale, we talked about this and you were planning you weren't going to be having anything to eat.' And he looked at

> those crackers, and he put them back in the box, and put the box back in the cupboard, and closed it up. So, he wasn't denied the crackers but he needed to be reminded.” –Joanne

Thirst was a bigger challenge than hunger. Even a few millilitres of liquid can slow the VSED process (Quill et al., 2018), and patients were far more likely to complain of thirst than hunger, particularly as advanced dehydration fogged their executive function. Across the cases, caregivers arrived at a consistent practical and ethical approach to patients’ request for fluids. When a patient expressed thirst and asked for something to drink, caregiver responses generally included:

- A reminder that not drinking was the patient’s choice and part of reaching their goal of dying
- Reassurance that the caregiver would give them something to drink if they really wanted it
- Acknowledgment that any fluids would slow down the dying process
- An offer for alternative relief, such as a glycerine swab or spraying mist into the patient’s mouth

For most patients, most of the time, these measures were adequate. But in a few cases, the tension over how to manage the patient’s short-term demand for water and long-term goals caused distress. Ted’s wife, Wanda, gulped enough water in the shower to clear her confusion and was dismayed to realise what she had done. She asked her palliative physician for palliative sedation to prevent her from being tempted further. Ted was relieved. He knew how unhappy she would be if VSED failed but also was aware that if she asked for water, he would have to give it to her. Her choice of sedation relieved him of managing the conflict of whether to honour Wanda’s immediate or global wishes. Amanda’s father, whose dementia symptoms were compounded by alcohol withdrawal, asked for water repeatedly for days, and each request required the caregivers and hired aides to find ways to reason with him or offer alternative relief.

By contrast, Linda and her father didn’t understand the relationship between dehydration and speed of death when he decided he was “done with living”. He continued to eat minimally and drink a few ounces of water every day for three weeks. In retrospect, Linda was grateful for the time she had with her father at the end of his life but wished she had known how to help him achieve his goal of dying.

> “I had never had any experience with VSED up to this point, so I just said to him, ‘I will give you whatever you want. If you don't want to eat, you don't have to eat. If you don't want to drink, you don't have to drink.’ … He did a couple times during the process say, ‘You know, I just wish I could get this over with.’ And if I had known enough to say to him at the time, ‘If you stop drinking this will be over with much more quickly.’’’ –Linda

Many caregivers anticipated that patients would require round-the-clock care that would exceed the caregiver’s stamina and skill. Most caregivers in the study had at least some external help, ranging from a hospice bathing aide to hired nurses working in shifts. Caregivers varied in what tasks they felt were important to perform themselves. Some took on primary responsibility for the patient’s care and realised only later that it was overwhelming. Some wanted to assume responsibility for negotiating the patient’s thirst or administering medication. Others were happy to hand off all physical care and symptom management. Unsure of how long VSED would last, some caregivers viewed coverage from aides in part as a form of self care for themselves, the better to be able to fully support the patient.

> “I didn't want the [aides] to feel they had to take responsibility to administer [medication]. … However, the caregivers had said to me that I had to take care of myself. And they insisted that I get out of the house a bit every day, even on the first couple of days. And of course the fact that they were here at night meant I could go to bed and sleep. Neighbours were bringing me food so there was no cooking. So I was well cared-for, but it was important for me and to Dale, as we had talked about it ahead of time, that I not get exhausted and sick. And so that was what I was trying to be able to do, trying to take care of myself and just be with Dale as much as I possibly could.” –Joanne

Hospice staff’s guidance and aides’ clinical skills and comfort with VSED, or lack thereof, played a role in many caregivers’ confidence in being able to help the patient die comfortably. Caregivers who had clinical experience of their own typically reported less anxiety about the process itself. Andrea felt that inexperienced aides’ discomfort with VSED led to Maureen being given enough water to derail VSED. Lauren hired aides from an agency suggested by hospice but found them unskilled in even basic care, leaving Lauren to manage both the physical and emotional aspects of her mother dying.

> "I knew I needed to move her, I knew I needed to change her diaper, I knew I wanted to sit there with her and talk to her while I could, which wasn't very long. I knew I wanted to hold her hand. I did those things. … At one point, and it was probably the day before she died, I was changing her diaper and she looked up at me and said, 'What are we doing?' [cry] And it was like she didn't remember anything, she didn't know what we were doing, she didn't know what was going on. And I was floored. I just didn't know what was going to happen. So I held it together for a minute and kind of went back to the bathroom and sat on the floor and sobbed." –Lauren

Some patients remained alert until nearly the time of death, but many became weaker and sleepier over time, eventually losing the strength to get out of bed. Caregivers' vigilance shifted from the risk of falls to the risk of bedsores, which might also require medical attention and pose a risk to the success of VSED. As death became more imminent, many caregivers reported spending time focused on encouraging patients, now unconscious, to let go.

> "And so we just sat down next to his bed and grabbed his hand, and I basically was like, 'You can go. You're loved. You're supported, we love you, we're here.' And almost like what I imagine you would tell someone who was giving birth, but the other way. Telling him he could go, we were safe, it was going to be ok." –Amanda

Having concurred that VSED was the best death available to the patient, caregivers took upon themselves whatever was necessary to ensure patients' success as VSED commenced. Beyond logistics and physical and emotional support, many caregivers eventually found themselves embodying, and speaking for, the patient's will. Patients handed over power to caregivers, entrusting them with their death. Caregivers bore this responsibility willingly, and actively navigated between their own feelings and their commitment to help the patient.

### *5.2.4 There is no script*

VSED was a new experience for most caregivers. Many had not previously cared for someone dying, much less someone actively choosing to die. The relative certainty of death created a sense of finitude, but some caregivers were unsure how to facilitate meaning for the patient or create it for themselves. Combined with the improvised plans caregivers made to support what they thought the patient would need, the unique circumstances of VSED left some caregivers feeling that there was no script for the VSED process.

Caregivers and patients entered the VSED process with the certainty that if all went to plan, the patient would die within a matter of days to weeks. The finite timeframe led to two sets of dual realities for caregivers. First, caregivers simultaneously carried their hopes for the patient's successful death and their own anticipatory sense of loss. Second, caregivers perceived that time as both long and short: too long for one person to manage the entirety of care without becoming exhausted in most cases, but a very finite time in which to say goodbye or seek closure. The patient's health and cognition, availability of aides, and caregivers' preparedness all shaped how caregivers perceived that time and chose to spend it.

Choosing how to spend one's own time and energy during VSED had a practical dimension related to ensuring the patient's success, as described above. Whilst many caregivers at least occasionally administered medication or helped turn the patient, only a few chose to play an active, primary role in the patient's physical care; three were caring for patients who were "done with living", and two of those caregivers had nursing backgrounds. Some caregivers' choices to focus on emotional needs might have been influenced by site of care: some patients were able to gain admission to inpatient hospice care, and two were in nursing homes. Managing physical care also may have been more feasible for patients being "done with living" because they were cognitively present.

Many caregivers knew they lacked the skill or endurance to attend to the patient's physical needs during VSED. But even some caregivers with clinical expertise chose to forgo giving physical care in order to focus on being emotionally present with the patient. This emotional focus appeared to have two purposes. First, emotional support was something many caregivers felt they could provide uniquely to the patient as a spouse or child. Second, some caregivers consciously chose the emotional path as a gift to themselves, to make the most of the last days with the patient.

Robin set out to be the primary caregiver for her partner, Willie, who had multiple myeloma. She quickly found herself overwhelmed by the complexity of managing his care and coping with impending loss. After first trying to care for him in her home, she was able to secure a bed for him at a local residential hospice.

> "I probably had 8-9 days of tracking, 'Shit, when's the last time we gave you morphine? Do you want an ice chip? Do you not want an ice chip? Do you want a washcloth?' I mean, 20 days of that, I couldn't have done it. Thank god I didn't have to. … The idea that there were real live nurses [at the hospice] who were helping was just a huge load off my mind. I could do my emotional work which was enormous

> without trying to figure out who can bathe Willie. Because that's one of the things I couldn't do. I couldn't really deal with his changing body.” –Robin

Caregivers took on the role of closure facilitator or gatekeeper, inviting close friends and family to visit and say goodbye per the patient’s wishes. Some caregivers focused on what seemed important to the patient, whether it was drafting an obituary or communicating plans about financial assets. Others focused on offering support and reassurance.

> “On what we call Bourbon Day, all his daughters were there. There was just an awareness that this is the last time we're going to do this. It made it really special to sit there and drink bourbon and watch football. Which, I hate football. But you know, it's what he wanted to do, and that seemed to me to be the most important thing. Your life gets really small. It gets to breathing and holding a hand and mostly meeting people where they are.” –Zoe

Caregivers understood that the patient’s goal was to die through VSED, but many pushed their own feelings about loss aside to focus on helping the patient succeed. Some caregivers, either intuitively or at the patient’s request, avoided sharing their grief so as not to distract the patient or weaken their resolve. The intensity of caring for and being present with a patient through the early and middle stages of VSED meant that some caregivers confronted the emotional weight of the patient’s impending death more toward the end of the VSED process.

> “That span of time was difficult because I was the one trying to make the family all coherent, trying to do everything I could do for her, trying to get quality time, trying to bring food into the house so the family could eat, running around like crazy. It was sort of like I had to bury all the feelings I was having until later.” –Ted

> “The other thing that caused me a lot of anxiety was wondering how it would all resolve. Maybe the 5th day, the 6th day, the doctor turned to me and said, ‘There's no turning back now. If Tim changes his mind now and we take him to the emergency room, there's nothing they can do.’ So up to that point, I didn't know what was going to happen. The fear of the unknown, of how it would resolve, was almost unbearable for me. And the thought of him being in a dementia facility and me having to watch him decline in a dementia facility felt worse to me than his choice.” –Fran

Some patients welcomed the opportunity to spend time with family and offer reassurance that death was welcome. Some caregivers and patients had plans for passing the time with favourite music and movies, and several caregivers mentioned spending time identifying family photos with the patient or passing along mementos. But two weeks is a long time in which to make every moment meaningful. Starting VSED could be anticlimactic after an emotional build-up of preparation. Some caregivers found themselves checking email as the patient slept.

> “One of the things that's true is nothing happens for days. It's just boredom. You sort of feel fine, you're tired. ‘When's something going to happen?’ she'd say. So [daughter] calls one day and Gladys goes ‘Still here!’ [laugh]" –Sam

However, some patients with cognitive decline were unable to focus or were agitated in the early days of VSED, leaving some caregivers frustrated because hoped-for closure was no longer feasible. Other caregivers perceived that patients were withdrawing into themselves, either because of their illness or to focus on the dying process, leaving the caregiver unsure how to insert their own needs for closure into the time available. Brenda, who was losing physical and executive function because of a genetic neurodegenerative condition, received care at home from her husband, Jim, and daughter, Amy. Brenda’s condition had diminished her ability to focus or communicate, and her family perceived her as past the point of wanting or needing closure. In turn, they tried to balance caregiving with finding their own meaning in the time before she died.

> “It’s often hard to know when your loved one is dying. And that's how you end up having a lousy death, because you're never ready to say goodbye. So to know that Brenda was dying, that was, wow, strange as it may sound, that was a gift. Because it allowed us to get out, well, for me, things that she had given me over the years. Notes, or a book she'd given me … and just to say, ‘Haven't we had a great life? And thank you.’" –Jim

> “Everything just felt weird and comical. Like what are we doing? How do you navigate this? Because it was so long and drawn out, I think, and intentional. I don't think you often have that space and time to be like, ‘this is what is marching down the pike’ and you want to make the most of this last time together, but also she's in a coma most of the time or totally checked out. It was like a weird time warp with no script and none of the regular rules applied. When do we eat, when do we not eat, when do we open the shades, what do we buy? Even the books I was reading, like

> am I ruining these books forever? Are these going to be the books that I read my mom on her deathbed, do I want to do that?” –Amy

Caregivers often have time to plan for VSED and want to spend the time in meaningful ways such as giving physical care or reminiscing. The duration and round-the-clock requirements of VSED exceed the endurance of a single caregiver, and many hired professional aides. Being able to choose what role to play was important to caregivers, but in some cases the course of VSED or the patient’s capacity meant caregivers couldn’t achieve desired closure. The lack of social scripts for VSED meant caregivers' roles, like many other parts of the process, were improvised.

## 5.3 Conclusion

The four themes presented above demonstrate caregivers’ commitment to helping patients complete VSED despite uncertainty, possible risk, and their own grief. In VSED, caregiving goes well beyond acts of physical care or expressions of emotional support but is an immersive, consuming process to which caregivers commit entirely. As patients’ capacity fades and their dependence increases, caregivers assume responsibility for their success. Despite lack of experience in caregiving, and particularly VSED, many VSED caregivers anticipate the magnitude of the task and take steps to ensure that the process not only is successful for the patient but one the caregivers themselves can endure and find meaning in. Chapter 6 analyses the data through the lens of Hudson’s modified stress-coping model of end-of-life caregiving (2003), focusing on how caregivers appraise, cope with, and assess the outcomes of the VSED process overall and individual events within it.

# Chapter 6: Findings applying the modified stress-coping model

As described in Chapter 5, VSED caregiving shares some characteristics of general caregiving at end of life. It often takes place in the home with family members or friends coordinating care, often with support from hospice and some level of medical supervision. VSED also is a form of hastened death in which patients and caregivers usually share an explicit understanding that the patient is taking actions to control the time and means of their death. Such intentionality may frame VSED caregivers' experience of the process.

In this chapter, Hudson's modified stress-coping model (Hudson, 2003) serves as a frame through which to analyse the experiences of VSED caregivers. A comparison of VSED caregiving with end-of-life and AID caregiving, which were analysed in Chapter 4, follows in the discussion (Chapter 7). For this analysis, data from interviews with 24 VSED caregivers (described in Chapter 5) underwent deductive thematic analysis following Braun and Clarke's approach (2006) and using a priori codes based on Hudson's model. These codes are the same used in the systematic review.

## 6.1 The Modified stress-coping model in VSED

### 6.1.1 Appraisal

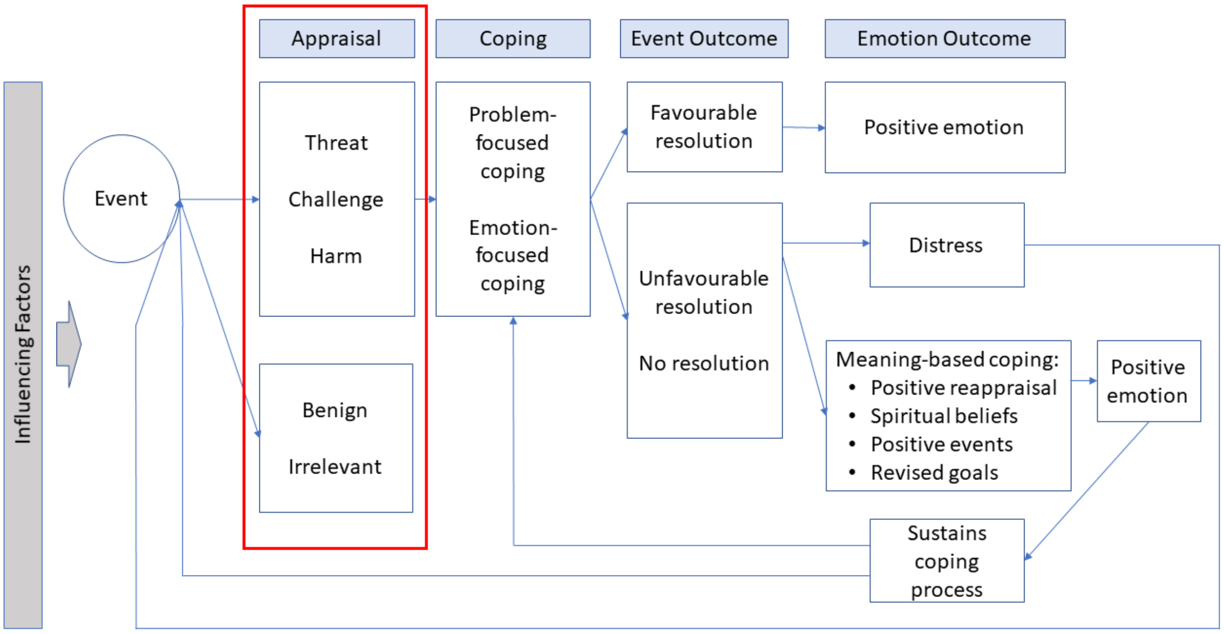

**Figure 6.1.** Appraisal in the modified stress-coping model

In Hudson's modified stress-coping model, caregivers appraise events – either the overarching event of caregiving or specific situations such as a doctor appointment or the patient asking for water. Caregivers may note benign or irrelevant events in passing, but other events may be seen as challenges to their abilities; threats to themselves, the patient, or the goals of either; or direct harms to either. For VSED caregivers, most events were appraised in terms of whether they would help the patient achieve death on their terms, firstly, and how they related to achieving a successful VSED in support of the first goal. The caregiver's own emotions and needs were both independent of the patient's process and tied directly to the caregiver's ability to help the patient succeed; therefore the caregiver's own situation informed their appraisal. Learning about and planning for VSED were usually appraised as benign, as most caregivers saw VSED as a solution to a problem or as a logical extension of the patient's lifelong independence. The exception was Paul, who regarded his mother's intent to die as a harm. Likewise, caregivers tended to view death, which was usually regarded as peaceful, as benign. Challenges that were surmountable included learning enough to make VSED successful and finding competent aides.

> "We had the conversations with the nurses, we had the conversations with the hospice people one by one. And nobody was unprepared for what was going on. It really was a question of 'here's what she wants, here's what we're going to do, if you have objections then we need to find somebody else,' and nobody objected." –Brian

Prior to learning about VSED, potential suicide by the patient was appraised as a threat for some caregivers. In a small number of cases, caregivers felt that untreated or undiagnosed mental health issues may have influenced the patient's decision to choose VSED or undermined its success, and these were appraised as threats or harms. Maureen, for example, had discontinued all medication before starting VSED, including those used to treat bipolar disorder. Andrea, her lead caregiver, felt Maureen might have endured thirst better if they had been maintained. Paul felt his mother's choice to die was influenced by undiagnosed depression. Once the process began, caregivers appraised things that threatened the success of VSED as threats. External threats included a neighbour calling Adult Protective Services or a physician refusing to support the patient. Internal threats included the patient's worsening dementia or unrelenting thirst derailing the VSED process. For some caregivers, particularly those in the progressive illness and dementia groups, the priority of focusing on VSED caregiving logistics threatened their ability to be present as family members processing the death of their relative.

When realised, threats could become harms: healthcare professionals who opposed or undermined VSED, or a lack of support leading the caregiver to feel overwhelmed or isolated. Finally, some caregivers appraised VSED itself as a harm because the dying process takes longer than AID would.

> “She asked if I would give her a pill, and I said I can't do that. That would have made it so much easier for her, but I didn't feel I could live with that. She also looked into moving to Oregon but you have to have six months' residency in Oregon. …. So she chose this way to do it. She had no choice. And I think it's just terrible that somebody who knows they're going to die in a very unpleasant manner can't just end their life. It's sad.” –Ted

Maureen’s failed attempt at VSED in assisted living illustrates how threats can play out as harms, particularly in an environment where the designated caregiver had limited ability to take charge of actual care.

> “When she began to get more and more cognitively impaired in that last week or so, she would just desperately ask for water. And they would give it to her. So her body began to try to recover at that point, of course. … The other was the nursing staff, because when she was getting really dehydrated she should have been medicated. She was also getting very anxious and agitated and irritable … When she needed an anti-anxiety drug, she didn't get it. So I think those two things probably contributed to the failure of it.” –Andrea

Maureen and Andrea’s appraisal of the institutional environment as a harm illustrates how appraisals are unique to each caregiver. Dawn supported her father through VSED in a nursing home where his decision to refuse food and water met no formal resistance. She appraised his move into long-term care as benign, or challenging only in that the staff continued to offer him food.

### *6.1.2 Coping*

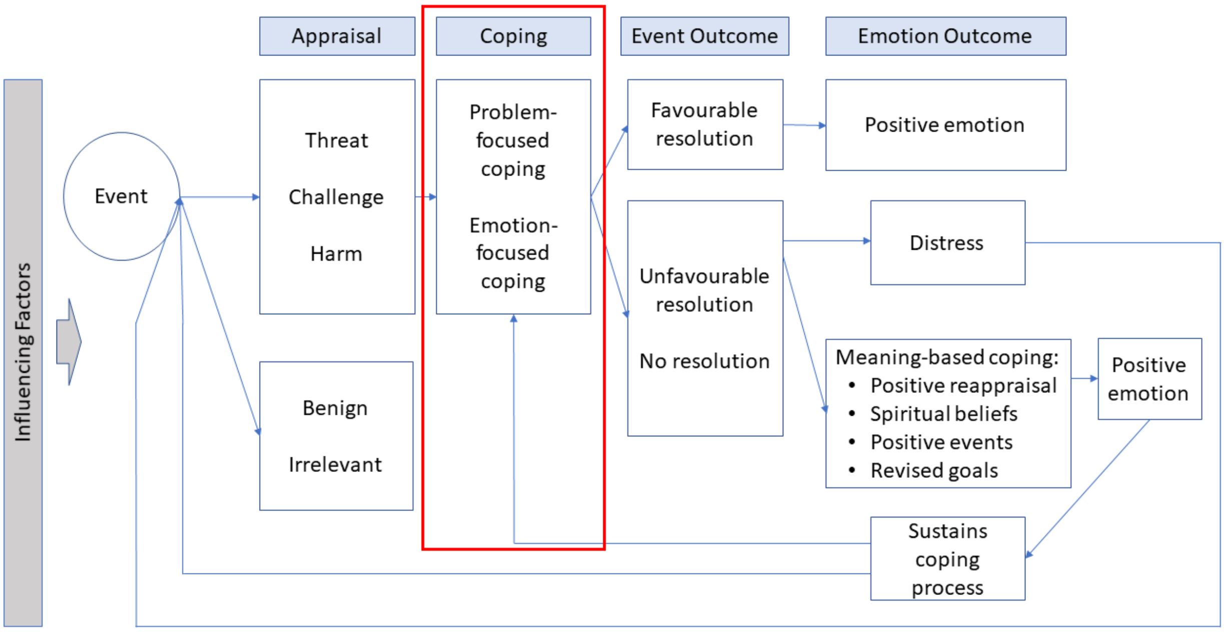

**Figure 6.2.** Coping in the modified stress-coping model

In the modified stress-coping model, caregivers may respond to appraised challenges, threats, or harms with a problem-solving response, an emotion-focused response, or both. A patient's request for water prompted both a problem-focused strategy to distract or soothe them and an emotion-focused response of anxiety that this would be the moment when the VSED would derail. Globally, caregivers assumed project-management duties for the entirety of the VSED whilst coping with their own, often simultaneous, feelings of anticipatory grief, love, commitment to the patient, and gratitude to be able to help. Many VSED caregivers put their own feelings on hold to some extent through the process.

> "I think I said to him, 'Steven, you're all I have. You can't do this.' And he said, 'I know, mom, I know, but it's becoming very difficult for me.' And I think he gave it a lot of thought. And I finally, after seeing his suffering, because I was taking care of him I knew how difficult his life was and how painful his life was, I said to him, finally, 'Steven, I will support you in whatever you want to do. And if you want to talk to the doctor about palliative care, I will support you and I will help you.'" –Sarah

As noted by Hudson (2003), problem- and emotion-focused responses often operate in tandem. Problem-focused responses aim to act on the environment or self, whilst emotion-focused responses aim to change the caregiver's relationship to the environment or the meaning of the event.

### *6.1.3 Event Outcome*

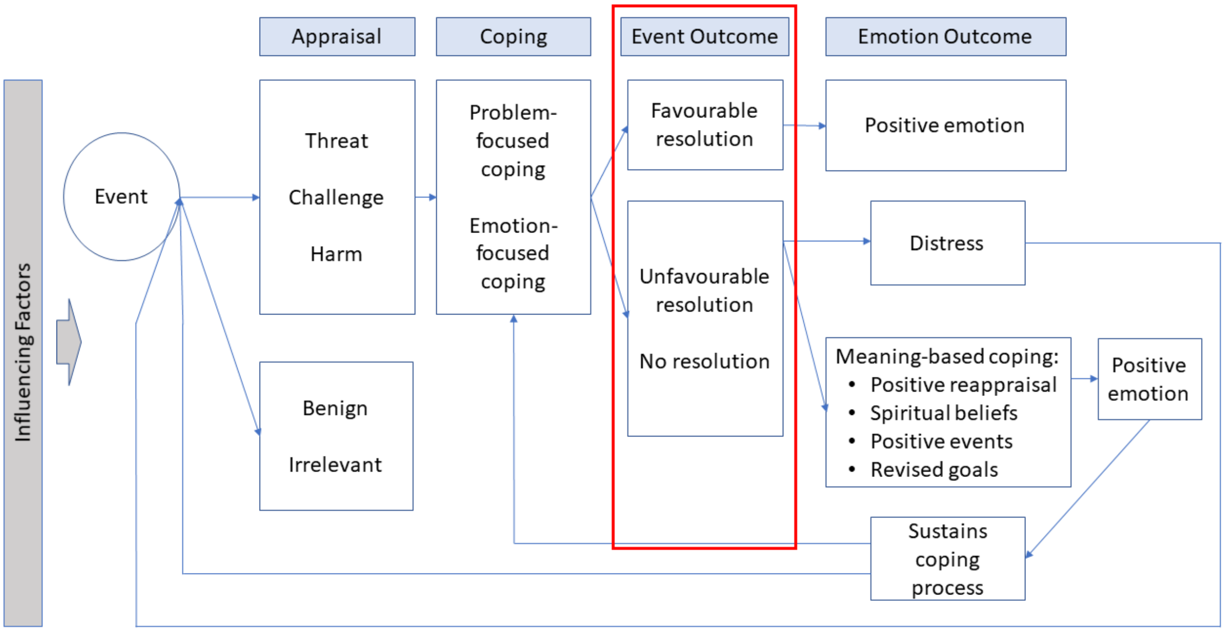

**Figure 6.3.** Event outcome in modified stress-coping model

Following the caregiver's coping strategy or strategies, events in the modified stress-coping model may reach a favourable or unfavourable resolution; others remain unresolved. Events with favourable ends, consistent with patient or caregiver goals, are considered concluded in the model (Hudson, 2003), whereas unfavourable or unresolved events lead to further coping responses. Caregivers' goals were for the patient to get their wish of dying on their terms and for the patient to have a comfortable death. Caregivers also prioritised having family nearby and time for closure. Less directly, caregivers wanted to make it through the VSED process being able to support the patient. The VSED process and death were regarded as favourable when they met those goals.

> "She died as she wished, and comfortably. No pain, and not lingering. I would say four days when you're pretty much out of it is a pretty comfortable way to go. And to be admired. God knows we all would wish for that kind of passing I think." –Brian

Events that ran contrary to those goals, such as failures of expected healthcare support and the caregiver's exhaustion or isolation, were unfavourable, whilst other events left the caregiver stranded with no outcome. The health system simply wasn't available, there was no script on how to spend the time in VSED, or the caregiver felt unable to spend time on their own feelings.

In cases in which the patient fit the “done with living” category, choosing VSED in some cases followed a scenario in which the patient declined to engage in treatments that might have extended or improved their lives. After recovering from sepsis, Dawn’s father chose not to receive further transfusions to treat anaemia from a health problem that caused internal bleeding. Paul’s mother refused to undertake physical therapy that could have helped her regain mobility after a dislocated hip. Lauren’s mother declined extended rehabilitation following an accident that resulted in quadriplegia. These patients subsequently undertook VSED to shorten their lives. Whilst some caregivers viewed these precipitating health events as part of the patient’s life course, for others like Paul, the event remained unresolved because the patient had viable options to live on and did not choose them. How caregivers perceived those initial changes in patients’ health status – as benign, threat, or harm – helped inform whether they later perceived the patient’s death as a favourable or unfavourable outcome.

### 6.1.4 Emotion Outcome

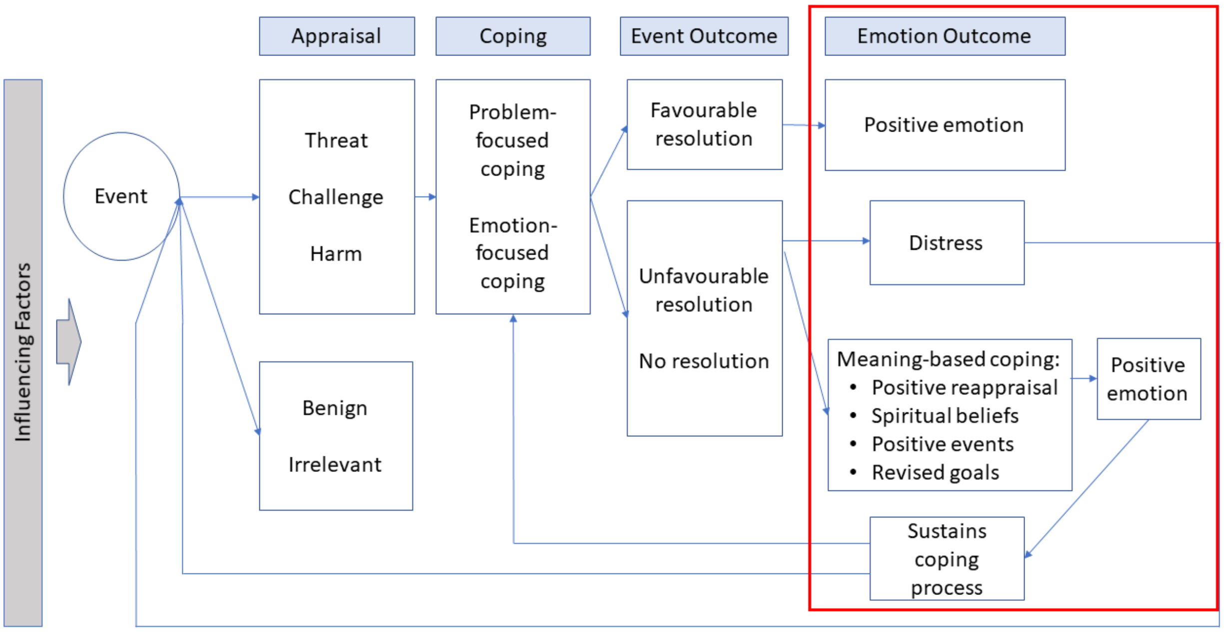

**Figure 6.4.** Emotion outcome in modified stress-coping model

Whilst events with favourable resolutions lead to positive emotion and the end of the event process, events with unfavourable or no resolution prompt distress or coping that can inform subsequent reappraisal and new coping strategies. According to Hudson and Folkman, ongoing negative psychological states and stress motivate caregivers to find ways to reshape an event as positive to find relief (Hudson, 2003).

Caregivers felt positively about having support and the patient achieving a peaceful, desired death that is not suicide. For themselves, they were grateful to spend time with the patient and have the family nearby; some were relieved not to have years of caregiving ahead. Specific positive events, such as the patient being redirected from drinking, thus increasing the probability of success, could shape caregivers' feelings as VSED progressed. Having the family witness a positive death sometimes was an unexpected but welcome positive event within the VSED trajectory.

Having adopted the patient's goal for a hastened, peaceful death, caregivers felt distress when unfavourable event outcomes threatened that prospect. In tandem, some caregivers felt distress when the VSED process unfolded in a way that did not allow opportunity for their own goal for closure.

> "I had it in my head that we'd look at some of his family pictures and he could talk about some of his stuff. But he was just too agitated to relax enough to do that. So my thought that we would have time for goodbyes and stuff really did not happen. I mean, we each said our goodbye to him but it was not as I pictured like it would be. I regret that maybe I should have done some of that a lot earlier but I thought we would have the 10 days, 12 days to reminisce more than we did." –Teresa

VSED frequently required caregivers to reappraise their hopes for the patient and their future or set revised goals. If the caregiver appraised the patient's poor future health prospects as a threat or harm, the choice to die intentionally might initially be an unfavourable outcome. However, some caregivers saw VSED as a positive alternative to dementia or suffering ahead, and as a way for the patient to have control. The patient's own clarity about the choice helped caregivers reconcile their own feelings. For some, VSED remained a second-best choice to AID that was unavailable. Ruth accepted her husband's choice to hasten death and appraised VSED as the most positive available choice when suicide was undesirable and AID unattainable:

> "Probably a year or two before he decided to stop eating and drinking he had talked about wanting to end his life. I think he just did not want to put the family through the final stages of Alzheimer's. ... He talked about drowning himself in the bathtub and using a gun, but both of those would involve me. And then we ran across a book about voluntarily stop eating and drinking, which we had no idea was a legal way to do it. So we talked about that. His son had talked about maybe him being able to move to Oregon [where AID is legal]. But it was pretty evident that he would not

> pass the test. He was not cognitively good enough to sign the papers so we didn't. We gave up on that." –Ruth

The VSED process as a whole can be considered one in which caregivers embraced revised goals and reappraised events. Because patients no longer had the option of a long, healthy life, caregivers like Ruth were able to adjust their goal to the patient having a peaceful death on their own terms. As VSED unfolded, some caregivers found themselves revising goals further – from performing all the caregiving to redistributing the burden, or from creating closure together with the patient to finding ways to achieve it alone when the patient lacked the ability to participate.

Spiritual beliefs did not appear to shape caregivers' emotional framing of the VSED experience in most cases. Some mentioned taking part in faith rituals such as last rites or a final family religious observance as meaningful moments during VSED. Paul, a Catholic deacon, wrestled with his own faith-informed beliefs about suicide and the need to respect the choices that his mother, also a lifelong Catholic, was making.

### 6.1.5 Influencing factors

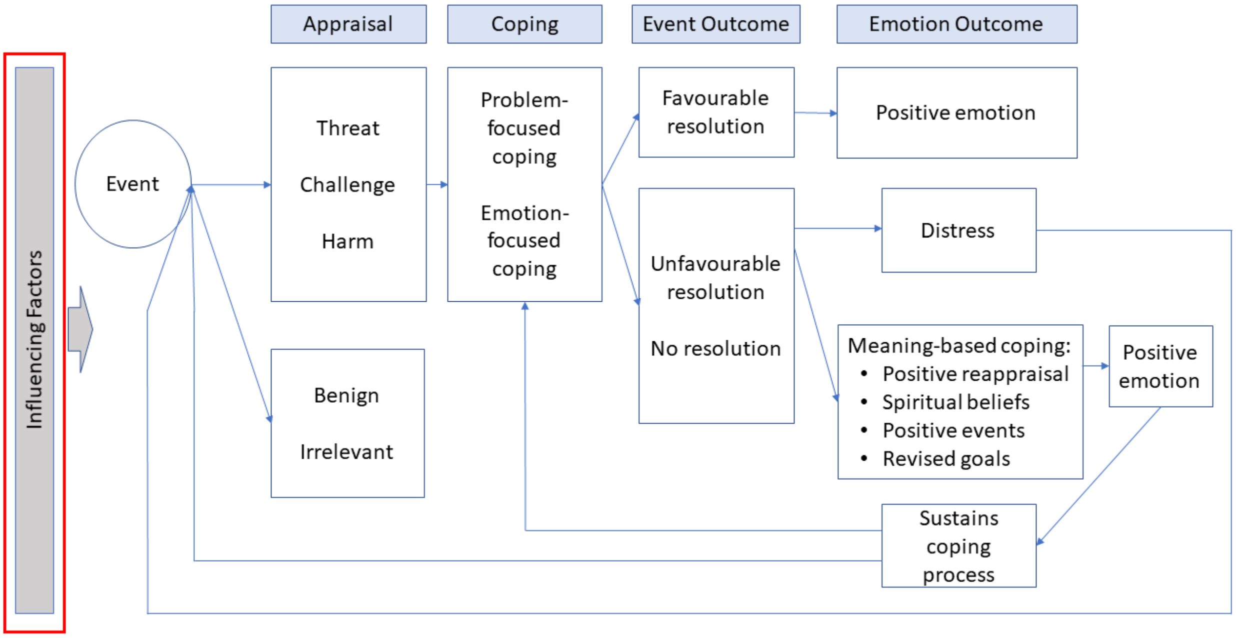

**Figure 6.5.** Influencing factors in the modified stress-coping model

Hudson's modified stress-coping model (Hudson, 2003) identifies internal and external factors that can influence caregivers' experiences at end of life. See Appendix H for definitions. Hudson identified 18 potential influencing factors, such as competence or respite. As in Chapter 4, here they are clustered for more streamlined discussion.

**Ability (competence, mastery, preparedness, self-efficacy):** Factors like mastery and self-efficacy relate to the caregiver's perception that they can take on the role of caregiver. Seven caregivers were current or former healthcare professionals, which gave them some insight into the patient's desire for hastened death rather than future limited quality of life, familiarity with VSED as a plausible way to die, or confidence in their ability to help the patient have a good death. Caregivers who felt confident as advocates or project managers brought these traits to VSED. However, only one caregiver had direct previous VSED experience; several noted that there is no roadmap for how to carry out VSED. Caregivers of patients with dementia in particular noted that they took on almost total responsibility for preparing for VSED because the patient was unable to contribute strategically; these caregivers needed to assess not only the patient's potential needs but their own foreseen skills and limitations during VSED.

> "I was a medical advocate, I was a daughter, I was a wife. I was well-educated. I had been a consultant. I knew how to ask questions. I knew how to assess situations. Most people will not have those skills." –Fran

**Support (information, respite, social support):** External sources provided practical or emotional support that directly affected caregivers' experiences and perceptions: lawyers, doctors, hospice staff or death midwives or doulas provided validation, information, and/or care support. Other caregivers, aides, family and friends provided patient care, emotional support to the primary caregiver, or respite.

> "So the self-care piece for me was an interesting one to really kind of excavate because I was very focused on Willie. And I also had to find the people who were broad-minded enough to think, 'These people are not crazy. These folks are allowed to make these decisions.' And that was really important for me because I'm a really communal woman, I'm a really tribal woman. So I needed to pull in what I needed in order that I could support Willie and honour his wishes but also not go down the tubes." –Robin

However, with each interaction with possible sources of support, there was potential that the caregiver would anticipate or experience rejection or isolation. A healthcare provider could decline to help or provide information, family members could object or decline to help, and members of social circles could be uncomfortable with VSED or even call authorities.

**Satisfaction (choice and commitment, meaningfulness, mutuality, rewards):** Caregivers placed a high value on being able to help the patient achieve their desired death. Giving permission to die and providing care were ways of showing love or demonstrating belief in people's rights to have a good death. For family caregivers, the VSED period offered closeness and closure; some caregivers were able to spend time planning memorials or obituaries with patients, and some patients handed off familial roles or traditions. Whilst caregiving was not easy physically or emotionally for many caregivers, the effort was worthwhile.

> "I really felt my role was to help Brenda in this last phase of her life do what she wanted to do. And that that was the most loving and caring thing I could do." –Jim

**Outlook (anxiety, depression, and psychological distress; optimism; positive emotion):** Outlook may relate to caregivers' pre-existing psychological health as well as to reactions to events within caregiving (Hudson, 2003). Some but not all caregivers felt uncertainty or isolation; those with more healthcare experience were more likely to have optimism that VSED would be successful and pain-free. Caregivers were grateful that the patient achieved their goal and had a peaceful death, and many said the period of VSED was an important time for family to grieve but also to see a good death.

> "I don't think she experienced hunger or thirst in a way that would be expected of somebody who chose to stop eating and drinking. None of us experienced anything other than her being comfortable. Which is what then led it to be such a beautiful experience for everybody, because we didn't see her experience any pain or any regret or dismay or anything. The grandkids would come in and they'd share some stories of something they did together. My children had a positive experience of their first real death experience of being with that person before they died." –Patsy

**Personal (caregiver age, gender, and socio-economic status; caregiver burden and health; cultural factors; patient's disease status, level of dependency, and duration of illness):**

Multiple factors affected the practical and emotional burden caregivers carried related to the VSED process. Patients' conditions can shape the course of VSED, either because of comorbidities or because the patient's robust physical health makes dying slower. Patients with an early dementia diagnosis could clearly state and act out their will to die but lacked the executive function to take part in planning, leaving logistics to the caregiver. Caregivers, in turn, felt responsible for the success of VSED, not only in the preparation and care they provide but in their ability to help the patient stay focused and avoid falls or other complications. This near-singular focus could lead to minimising or ignoring the caregiver's own feelings and needs. Caregivers' expectations and fears about VSED also may be shaped by cultural norms about intergenerational relationships, such as a parent living long enough to pass on wisdom at milestones in the child's life. Caregivers like Amy who were younger adults expressed distress about having lost a parent sooner in life than they hoped. Spouses and adult children helping a patient with VSED at the end of a long life were more likely to focus on the satisfaction of helping the patient avoid unwanted future suffering. Such factors influenced how caregivers appraised the overall VSED process and perceived its emotional outcome.

> "[Friends] want to know what's going on, what they can do, how are you feeling. There's all this other weight behind it where it's not just like, 'Oh she's dying because she had cancer or she has an illness.' It's like she's dying because she has an illness but she actually made this decision and I'm trying to process this decision that she made and its intentionality, and that's what I wanted to talk about, and that wasn't something that anyone was good at talking about. And there was a sort of weird back and forth between wanting to honour that this was the way she wanted to go, and be like, 'I'm glad, I'm helpful, I'm doing the things that she wanted,' but also, 'I hate this. This fucking sucks. I'm so sad. And I'm really mad at everybody and I don't want to be here.' So having those two things at the same time was really hard."
> –Amy

Most caregivers in this study noted that the patient or family had the financial resources to hire round-the-clock help, which reduced caregivers' anxiety about ensuring the patient was safe and supported even if the main caregiver was not present. This in turn may have led to caregivers appraising VSED more as a surmountable challenge than a threat.

### *6.1.6 Other factors: structural, legal, cultural*

As noted in Chapter 4, interaction with healthcare professionals is not included in Hudson's stress-coping model as an influencing factor, but it figured prominently in the experiences of both end-of-life and hastened death caregivers. VSED caregivers placed similar emphasis on the importance of physicians, hospice nurses, and home care aides. Physicians who supported and validated the patient's choice for VSED paved the way for hospice access. Physician endorsement and hospice admission provided legitimacy that eased caregivers' concerns about the legality and social acceptability of the VSED process. Hospice staff offered practical guidance on caring for the patient's changing symptoms and needs, such as thirst or regular turning. Skilled aides provided respite with overnight shifts that allowed the caregiver to maintain the stamina needed to coordinate the full duration of VSED. In some cases, the availability of inpatient hospice was pivotal when patients' needs exceeded caregivers' capacity.

> "Hospice nurses in particular are really the experts in my opinion on how people die. So that was a huge comfort also. Brenda used a lot of glycerine swabs to satisfy her dry mouth. She called them lollipops, 'Get me another lollipop.' So that was something I wouldn't have known about without hospice saying, 'We're going to bring you a few dozen of these, let us know when you need more' (laugh). And it was always this being one step ahead and giving you the stuff before you need it." –Jim

Conversely, health professionals could become a source of distress for caregivers if they expressed objection to VSED, were uncomfortable with assisting a patient undertaking it, or simply lacked the experience or knowledge to provide help the caregiver or patient needed. Hired aides ranged from registered nurses skilled in end-of-life caregiving to minimally trained individuals with little apparent training.

> "The aides were not particularly competent. One of them, … I had to ask her for help with everything. Like she knew she had to change my mom's diaper. I like handed her some wipes and she said, 'Do you want me to do the wiping?' That's like literally the only reason you're here. Is to do the diapering. … The second daytime person who came because I didn't want that other one to come back, it was her very first day on the job. Her sister worked there so she got this job and she started crying because her mother died recently. So there was some comforting of the day aide also." –Lauren

Healthcare professions figured prominently in many caregivers' experiences, either as sources of support and information or as threats to the patient's success. Caregivers assume health professionals will have the knowledge or skill to be able to assist in a process that is unfamiliar. Caregivers' relief or distress correlates to whether the professional fulfils that expectation.

VSED takes place within cultural norms and institutional structures that shape the caregiver's experience. Local laws determine whether AID is available and the patient is eligible. These are not part of Hudson's modified stress-coping model but, as demonstrated in Chapter 4, they influence caregiver experience at end of life. Hospices or nursing homes may not have policies to support a patient in VSED. Individual healthcare professionals likewise may actively or passively support or oppose the patient's choice. Public opinion on hastened death varies widely, and caregivers may be hesitant to tell friends or family about VSED for fear of rejection, increasing their sense of isolation.

> "It's a little dicey, you know, who you talk to about stuff like this. It seems like some people are immediately put on edge or offended, maybe, about it. But others are receptive and encouraging and supportive. That was a little bit tricky. We had even said with mom and dad and [sister] was that we wouldn't talk about it necessarily until after. So during the process we didn't want to have somebody feeling like they needed to swoop in and save dad from himself. I just feel like VSED is something that's a bit jarring for a great segment of society, that they can't get past the idea of suicide and the badness or evilness of that. It tends to trigger that kind of response in some people, so I dunno, I feel guarded against." –Scott

Caregivers' steps to secure support for VSED and concerns about external risks or threats appear to be related to internalised understanding of legal, cultural, and social norms about dying.

## 6.2 Summary

The modified stress-coping model (Hudson, 2003) can be used to explore VSED caregivers' experience. Caregivers assisting patients with VSED make appraisals of the overall process and events within it according to how those events help or hinder patients' goal of achieving a peaceful death. Acceptance of VSED as the best option available to the patient often was the result of caregivers' reappraisal of the patient's health or setting revised goals for what a good death would be. Caregivers navigated individual events in the caregiving process with both problem-solving and emotional responses, often setting aside their feelings to focus on the patient's needs. The patient achieving a peaceful death was regarded as a positive outcome and generated a positive emotional response for most caregivers. Caregivers' experiences were influenced by past experience with illness or death, experience as a healthcare provider, and satisfaction derived from being able to provide care for the patient. This analysis also highlighted external factors such as healthcare providers and larger social structures that are not addressed in the stress-coping model but heavily affect caregivers' experiences. The discussion chapter will examine each of these more fully.

# Chapter 7: Discussion

## 7.1 Introduction

To date, empirical research on VSED has been limited to a few surveys of clinicians' impressions of patient motivations for choosing to hasten death by stopping eating and drinking (Bolt et al., 2015; Ganzini et al., 2003; Shinjo et al., 2019; Stangle et al., 2020). These studies present broad statistics about who undertakes VSED and clinicians' impressions of why. However, they leave unanswered questions about what actually happens in the 10 to 14 days that are the typical duration of VSED. Because patients require caregiver support to be successful in VSED (Quill et al., 2018; Schwarz, 2009; Wax et al., 2018), and because patients typically are incapacitated for at least part of the process, caregivers play a unique role in this form of hastened death. This is the first study to look specifically at the experiences of US caregivers who have supported someone through VSED.

The study used both inductive and deductive approaches for thematic analysis of transcripts of 24 interviews with caregivers. Both analyses are rooted in social constructionism, which supposes that individuals singly and collectively interpret their social reality and its meaning (Bryman, 2016). The deductive analysis (Chapter 6), for example, is based on Hudson's modified stress-coping model (Hudson, 2003), which illustrates how individual caregivers' interpretation of events and subsequent responses can be influenced by caregiver traits and experiences as well as the ongoing dynamic caregiving activity. However, theoretical models of caregiving focused on the patient-caregiver dyad fall short of explaining the complexity of VSED caregiving. In this chapter the study findings are fitted into a broader theoretical framing: the socio-ecological model, outlined below in section 7.4.

Inductive analysis produced four major themes of caregiver experience: 1) Caregivers' willingness to support patients through VSED is rooted in their belief that VSED is the best death available to the patient. 2) In seeking resources to support the patient's choice, caregivers act as advocates and feel a sense of risk that the patient's goals will be challenged by healthcare professionals, the community, or legal authorities. Obtaining support from hospice is an important way to legitimise VSED and counter potential objections. 3) Through the VSED process itself, caregivers carry the responsibility for the patient's success as the patient becomes weaker and often confused about what they are doing. 4) Caregivers noted that there is no social script to guide someone aiding a person who is slowly, deliberately trying to die over a period of days. Consequently caregivers choose for themselves what role to play, such as focusing on physical care or being emotionally present as the patient's spouse or child.

Deductive analysis based on Hudson (2003) focused on how caregivers navigate the overall event of VSED caregiving as well as smaller events within the whole process. Caregivers appraised events and their outcomes primarily in terms of whether they facilitated or threatened the patient's goal of death by VSED. Their experience of VSED was influenced by factors such as a sense of competence from having worked in the health professions or the meaningfulness of reciprocating care to a parent. Beyond factors identified by Hudson, however, this study found that caregivers' experiences were shaped heavily by interaction with healthcare professionals, whether positive or negative, and by cultural and structural issues that affected whether caregivers felt their role and the patient's actions were supported by friends, family, or hospice.

To help situate the results of thematic analysis of the primary data, this thesis also includes a systematic review in the form of a narrative synthesis of two bodies of published research on caregiver experience: one on caregivers of patients at end of life generally, and one specific to caregivers of patients pursuing hastened death such as euthanasia or assisted suicide. Both systematic reviews used Hudson's model as an analytic frame, consistent with the deductive analysis of the VSED data (Findings Chapter 2). The first section of this discussion compares the original findings of the VSED caregiver study against the themes from synthesis of end-of-life and hastened death caregiver literature. This comparison helps illuminate commonalities as well as aspects of caregiving that may be unique to VSED. The comparison is also is a first step in exploring the socio-political factors that shape VSED caregiving, which will be the focus of the second half of the discussion.

## 7.2 Theoretical foundations in analysis of VSED caregiving

This research, like most research on caregiving, was conceived as focusing on the relationships between the caregiver and the patient and the caregiver and the caregiving experience itself. The research proposal and interview guide were influenced by Hudson (2003), but also by Swanson's middle-range theory of caregiving and Andershed and Ternestedt's (1999) offshoot theory of end-of-life caregiving, all of which relate to an individual making sense of and responding to immediate surroundings. In gathering and analysing data, however, I found that the patient-caregiver dyad was only part of the VSED caregiver experience. Many events appraised as threats or harms or ending in distress were those influenced by external forces: the healthcare system, the legal system, and society at large, either directly or indirectly. As noted in the systematic review and Chapter 6, Hudson's stress-coping model does not account for healthcare providers, let alone larger social forces. These observations led me to use the socio-ecological model as a means to identify these layers of influence and to the application of critical systems theory to explore the relationships between caregivers and these layers. Critical systems theory acknowledges that actors in complex systems have varying levels of power and influence. I use Foucault's concept of bio-power to explain the interactions with social norms, the health system, and community that affect the VSED caregiving experience. The application of these theories to hastened death is a novel contribution of this thesis.

## 7.3 The modified stress coping model: comparison of VSED, AID, and end-of-life caregiving

There are no other studies of VSED caregiving with which to compare the results of this study. One way to situate the experiences of VSED caregivers is to compare them with the experiences of other types of caregivers – those caring for patients at the end of life generally and those assisting patients pursuing other forms of hastened death. Hudson's modified stress-coping model (2003), used in Chapters 4 and 6, provides a useful template for comparing the original data on VSED against the two narrative syntheses on end-of-life and hastened death caregiving. Whilst the original VSED data are more robust than syntheses of studies that used a variety of qualitative analyses, a comparison highlights ways in which VSED caregiving may be different than other types of care – which has implications for clinicians seeking to support patients and caregivers.

Comparing findings using the modified stress coping model as a frame, many aspects of caregivers' experiences with patients at end of life are universal, regardless of the type of death (Figure 7.1., below). Each type of death, meanwhile, has some aspect of caregiving that is unique only to it. VSED and end-of-life caregiving also can be prolonged processes requiring extensive physical and logistical caregiving, compared with the relatively immediate act of a patient dying via AID. I explore each type of death and each intersection in detail below.

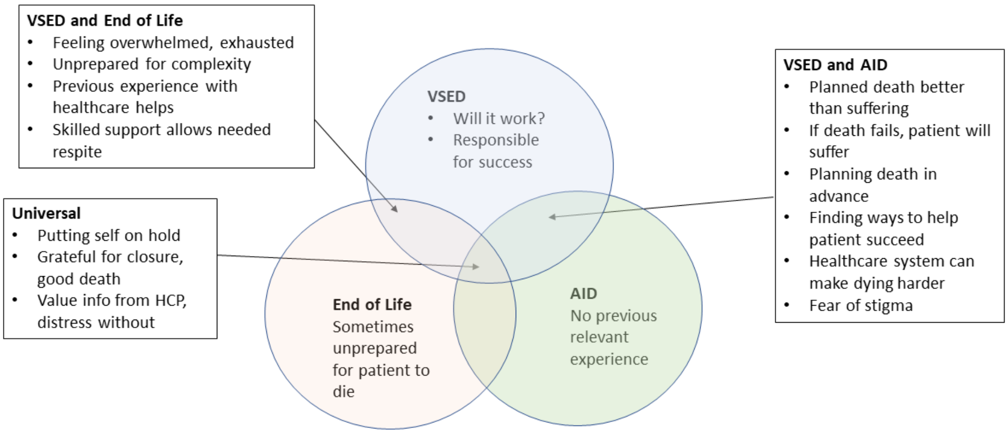

**Figure 7.1.** Intersections and differences across experiences of VSED (original research) and end-of-life and AID caregivers (from systematic review)

**Universal caregiving experiences.** Across all three analyses, caregivers saw the end of life, whether natural or hastened, as an opportunity for closure. They found meaning in the chance to spend time with the patient and help fulfil last wishes. When caregivers anticipated patients' deaths, they were grateful when the patient had what the caregiver considered a good death, consistent with the patient's wishes (Funk et al., 2010). Many universals of caregiving can be seen in subthemes of one of the themes identified for VSED caregivers in Chapter 5: there is no script. Caregivers in VSED, AID, and end of life all expressed anticipatory grief, hope for the chance for closure, and setting the self aside (Broady, 2017).

Regardless of the type of caregiving, analysis of emotional and problem-focused coping found caregivers consistently put their own needs on hold to focus on the patient (Andershed, 2006; Funk et al., 2010). Beyond the components of Hudson's modified stress-coping model, caregivers in all three analyses valued support and information from healthcare professionals who could help caregivers anticipate what to expect and address complications. When healthcare support did not meet caregivers' needs or expectations, they expressed distress.

**End-of-life caregiving**. Analysis of emotional outcomes for caregivers of patients at the end of life found that some, but not all, felt distress witnessing the patient's condition decline and felt unprepared for the patient's death (Coristine, 2003; Hasson et al., 2010;  Hasson et al., 2009). This source of distress was unique to the end-of-life caregiving data, whereas all caregivers in the VSED and AID analyses understood that the patient was going to die. Their sources of distress, by contrast, related to factors that threatened or complicated the patient's death, or in some cases to moral distress about the patient's choice to die (Gamondi et al., 2018).

**AID + VSED.** The intersection of VSED and AID caregiving reflects two themes identified in Chapter 5: VSED as the best death available to the patient, and the intertwined concepts of risk and legitimacy, in which caregivers weigh the patient's goals against potential legal risk or social stigma. Both the VSED study and the AID literature analysis carry some subthemes of the theme of carrying responsibility for the patient's success as well, such as project-managing the death.

In the analyses of VSED and AID caregiving, caregivers usually (but not always) were resolved that the hastened death was preferable to the illness trajectory or suffering that awaited if the patient did not act (Gamondi et al., 2018; Ganzini et al., 2009; Holmes et al., 2018). In both the VSED study and in the analysis of AID-related studies, caregivers tried to identify potential barriers to success and make plans to overcome them. Caregivers feared that patients would suffer if the hastened death failed. Some VSED caregivers worried that healthcare professionals would not support or help the patient, making the goal of hastened death more difficult to achieve (Georges et al., 2007). Other caregivers reported isolation resulting from fear of social stigma or legal reprisal, a concern echoed in a Swiss study of assisted suicide and in an early study in Washington before AID was legalised (Back et al., 2002; Gamondi et al., 2018).

**VSED + end-of-life caregiving**. VSED caregivers shared several characteristics with those identified in the analysis of caregivers of patients at end of life, as the duration of caregiving could be taxing and the timing of death uncertain. Caregivers in both the VSED study and end-of-life analysis reported feeling overwhelmed or exhausted, and sometimes unprepared for the complexity of patients' needs (Andershed, 2006; Bee et al., 2009; Funk et al., 2010; Stajduhar et al., 2010). Accordingly, having previous experience as a healthcare provider was valuable preparation for some caregivers, and having skilled help, either family or paid aides, allowed caregivers to take needed respite (Andershed, 2006; Martín et al., 2016).

**AID**. In contrast to caregivers of VSED and patients at end of life, caregivers of patients undertaking AID could not draw on previous experience, specifically previous relevant experience as a healthcare professional that could make physical caregiving easier. The AID process was new for all (Buchbinder et al., 2018; Gamondi et al., 2018). Previous experience, in Hudson's modified stress-coping model, informs influencing factors such as competence and preparedness, which may relate to whether caregivers appraise events as a threat or challenge, for example. In Buchbinder's study of AID in Vermont, some caregivers noted that the process of preparing the lethal medication and witnessing the patient ingest it was improvised and determined by the patient's wishes (Buchbinder et al., 2018). The lack of frame of reference may fit with the "There is no script" theme found in the VSED study, but there is insufficient evidence in the current body of AID caregiving literature to make this determination.

**VSED caregiving.** Unique to VSED, caregivers worried that the patient might not die despite their wishes. Caregivers cited concerns about the patient being too physically healthy to dehydrate quickly or the patient forgetting about the goal and giving in to thirst. For patients with dementia, caregivers worried about missing the window of opportunity in which the patient retained the focus and executive function to be successful. In turn, caregivers in VSED felt responsible for helping the patient succeed, and some wished that AID, which is faster, were an option.

One aspect of VSED caregiving that appears to be unique is that of choosing what role to play. VSED caregivers expressed that there is no social script to guide them in what to do, how to feel, or how to pass the time during VSED. Effectively, then, they created a script for themselves. Because VSED caregivers usually were very aware that the patient was planning to die and that the process would take some time but not go on indefinitely, many VSED caregivers specifically thought about and planned for whether they wanted to focus on emotional support, hands-on care, or both, and sought resources that gave them the capacity to do so.

No aspect of caregiving experience was common to AID and end of life that was not also found in VSED. VSED shares the intentionality and sometimes uncertain social acceptability of AID but the duration and uncertain timing of end-of-life caregiving (median 10 days, range 2-28 for VSED). But VSED is unique in that, without help, patients might not die despite their wishes. VSED caregivers carry responsibility for facilitating not only the patient's physical comfort and acts of closure, but also for their intentionality to die in a situation when neither their illness nor artificial methods will help them do so. Thus many aspects of the third theme from Chapter 5, carrying responsibility for the patient's success, are not evident in other caregiving literatures.

Using the modified stress-coping model to compare and contrast experiences of VSED caregivers helps situate those experiences in broader context. As suggested in Chapters 4 and 6, Hudson's model overlooks the important role that healthcare providers play in shaping caregivers' experience in all end-of-life settings. In VSED and AID, interactions with those providers can be positive or negative depending on whether the provider supports the patient's goals. Those interactions are further shaped by social norms about the acceptability of hastened death. These analyses suggest that to thoroughly understand VSED caregiving, one must examine not only the caregiver's interpretation and response to individual events, as described by the modified stress-coping model, but view these events in a larger socio-ecological context. The second half of this chapter applies socio-ecological modelling to VSED caregiving and explores theories that can help interpret VSED caregivers' experience with their broader environment.

## 7.4 Applying the socio-ecological model to VSED caregiving

Implicit throughout the experiences of VSED caregivers is their positioning within relationships, institutional structures, and the broader community and culture. The key findings of this research centre not only on the VSED caregiver's relationship with the patient, but on the social networks such as family, the resources and policies of the local healthcare system, and the legal and cultural climate of the community and even nation. Robin's experience caring for Willie was influenced by the availability of a residential hospice. Andrea's frustration in caring for Maureen stemmed from policies at their assisted living community that worked against Maureen's goals. Ted's perception of the quality of Wanda's death was influenced by AID not being legal in their state. As important as these interactions are, they are not part of most theoretical models of caregiving, whether Hudson or Swanson, nor are they explicitly drawn out in most meta-analyses of end-of-life caregiving literature in general (Funk et al., 2010; Stajduhar et al., 2013).

Applying a socio-ecological model to VSED caregiving can help illuminate the external factors that shape individual caregivers' experiences. As proposed by Bronfenbrenner, the socio-ecological model comprises layers of systems that define an individual's experience, from the microsystem of place and roles, such as being a caregiver to a patient at home, outward to a macrosystem of institutions and culture (Bronfenbrenner, 1977). The model has been widely used and adapted for a range of purposes, particularly in public health, including violence prevention (Centers for Disease Control and Prevention, 2020) and rural health promotion

(Health Resources and Services Administration, 2020). The socio-ecological model has not been applied to experiences of caregivers, aside from one model for caregivers of children with disabilities (Raina et al., 2004). I propose a socio-ecological model for caregiving (Figure 7.2.) that can be used to frame experiences of caregivers supporting VSED:

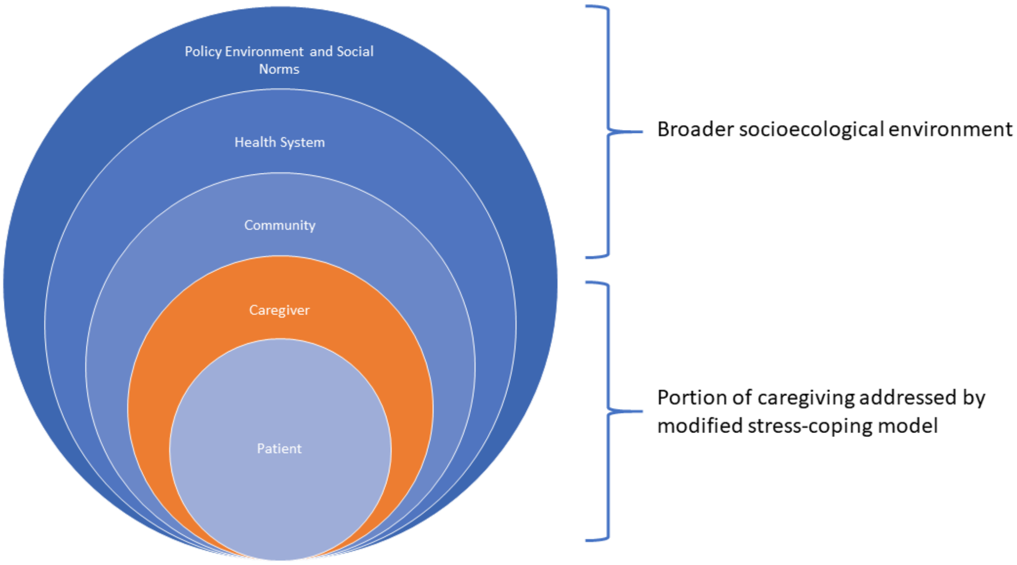

**Figure 7.2.** Socio-ecological model of VSED caregiving

**Caregiver**. The caregiver ring represents the VSED caregiver's relationship with the patient, their own feelings about the patient's impending death, and factors that influence their ability to cope with caregiving, such as fatigue or experience as a healthcare professional. Most of the elements of VSED caregiving addressed by Hudson's modified stress-coping model, therefore, are housed in the caregiver layer of the socio-ecological model, in which the caregiver's own resources and limitations and their relationship with the patient form the basis of their appraisal and response to various caregiving events.

**Community**. Surrounding the immediate VSED caregiving experience is a layer of intimate community: other family members, friends, and paid aides who provide physical, logistical, or emotional support to the patient, caregiver, or both. The community layer may not always be supportive, however. Within the stress-coping model, community may relate to the influencing factors of social support or respite.

**Health system**. Representing the institutions of hospitals, hospices, local or regional health systems, as well as individual physicians and other practitioners, the health system represents the resources available to the patient and caregiver where professional care or information are required. The health system figures prominently in the experiences of VSED caregivers (Chapters 5 and 6), but it is not included in Hudson's stress-coping model.

The health system comprises individuals, institutions, and rules that are not necessarily aligned or may work inconsistently. Some caregivers were able to secure support from the patient's primary care physician for VSED, but others encountered providers' personal or organisational objections to VSED.

VSED caregivers looked to the health system for practical support, access to medication, information about the patient's dying trajectory and how to meet their needs, and an implicit endorsement of the patient's choice of VSED that offered social legitimacy. Many caregivers had no direct experience with providing health care, particularly at the end of life, making the health system a vital source of support. The importance caregivers placed on the health system's role is evident by the distress caregivers expressed when support or information were inadequate, such as Andrea's frustration that assisted living staff would not help honour Maureen's wishes. Similarly, many VSED caregivers viewed asking a physician about assisting with VSED as a challenge: unsure of what the dying process would entail, they sought support they were not always sure they would receive.

**Policy environment and social norms**. VSED caregivers' experiences were shaped by state and national laws that define what health services are available and to whom, laws defining whether AID is available and to whom, and religious and other cultural norms about dying, including the acceptability of hastened death. These environmental factors affected caregivers both directly and indirectly. Caregivers and patients in Washington state, where AID has been legal since 2009 (Washington State Department of Health) were able to find information about alternatives, such as VSED. Many caregivers of patients who had dementia or progressive illness mentioned hesitancy, or at least careful consideration, about sharing the patient's plans for VSED with broader social circles for fear of social stigma or being reported to legal authorities. Stigma was mentioned less by caregivers of patients who were "done with living," perhaps because the patients usually were relatively old or frail and their death might not be unexpected.

The layers of the socio-ecological model therefore frame what the stress-coping model alone does not: the biome in which VSED caregiving happens. The interactions with hospice, the strictures of state laws, and the support or scepticism of friends and family all influence cycles of event appraisal, coping, and resolution that make up the VSED caregiving experience. This novel application of the socio-ecological model may be useful more broadly in helping describe the environment in which other types of end-of-life caregiving take place. As demonstrated in the first part of this chapter and in the systematic review, reviews of literature on end-of-life and AID caregiving also suggest that interaction with healthcare providers is an important factor in shaping caregiver experience. Full analysis of the socio-ecological environment for end-of-life caregiving, including perspectives from patients, paid caregivers, clinicians and healthcare administrators, is beyond the scope of this thesis but may be useful for future study.

## 7.5 Critical systems theory: explaining interaction among layers of the socio-ecological model in VSED caregiving

The socio-ecological model is a way to parse the layers of interaction and influence that shape VSED caregivers' experience, but it does not explain those interactions or influences other than to position them. The following sections first consider the interactions of different actors in complex systems, followed by an analysis of assumptions of overt or implied power that may influence how each layer interacts with caregivers.

### *7.5.1 Soft systems and critical systems theory*

Critical systems theory applies notions of power imbalance to soft systems. The premise of soft systems is that human organisations or interactions are not consistent input-output models but comprise diverse actors who may have different priorities, goals, or conceptions of what a problem situation is, along with different ideas about how to solve it or what constitutes a desirable or possible solution (Flood & Jackson, 1991). Critical systems theory, building on soft systems theory, acknowledges different actors within a system have not only different interpretations and goals for a problem, but different amounts of power (Oliga, 1991; Watson & Watson, 2013).

In such systems environments, individuals may entertain a range of values, beliefs, and behaviours. Oliga (1991) proposes that systems of human interaction have a social order in which individuals are told that things 1) exist or do not exist, 2) are desirable or not, and 3) are possible or not. Entities that hold more power can dominate the general order of what is believed to exist, be desirable, or be possible. In such an environment, an individual may agree that the state of things is inevitable, or may believe that they could be better (Oliga, 1991). Whilst critical systems theories have been applied to a broad range of organisational and management research inquiries, they also can serve as a frame for conceiving the complexity of interactions among the socio-ecological layers that comprise VSED caregiving. Seen through critical systems theory, each layer not only has a differing agenda related to health and dying, but different amounts of power and influence.

### *7.5.2 Power in the socio-ecological model of VSED*

Each layer of the socio-ecological model for VSED described above exerts a different influence on caregivers' experience, from caregivers' sense of unease about the social acceptability of VSED to specific anxieties about whether a primary care physician will support the patient's choice and provide a hospice referral. The layers interact with each other as well. Whilst critical systems theory acknowledges that power, and power imbalances, exist among the actors in these layers, the theory itself is broad and does not suppose the nature of the power. Accordingly, specific power theories are needed to explain each socio-ecological layer's interaction with VSED caregivers (Figure 7.3.).

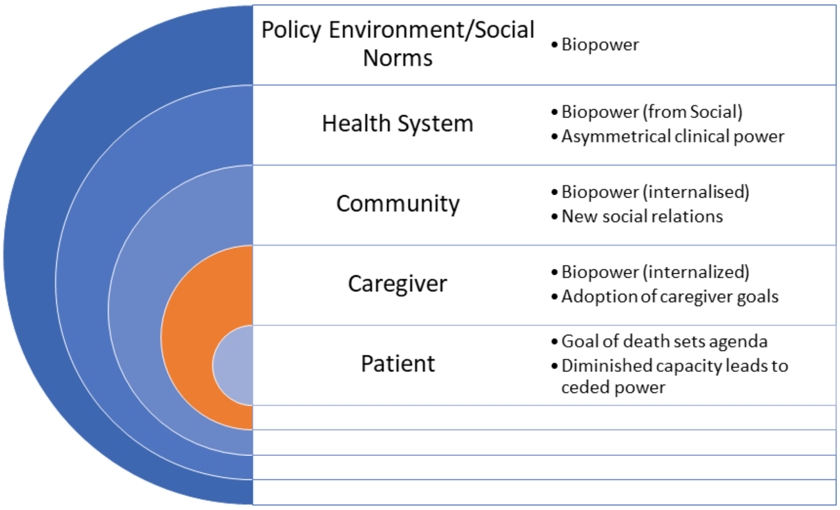

**Figure 7.3.** Application of theories to socio-ecological model of VSED caregiving

**Policy environment and social norms**. Historically, according to Foucault, sovereign power included authority over life and death – a leader could declare war or impose capital punishment. In the modern era, he argued, power has migrated instead to life:

> "But this formidable power of death – and this is perhaps what accounts for part of its force and the cynicism with which it has so greatly expanded its limits – now presents itself as the counterpart of a power that exerts a positive influence on life,

> that endeavors to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations." (Foucault, 1979, p. 136)

The locus of social power shifted from the sovereign's right to order a subject to die or fight in a war, Foucault argued, to political power derived from administering life. Those in power can bolster their position by fostering societal beliefs in which life is sacrosanct. Death is still of interest to those who hold power because it is the moment at which an individual becomes free of that power's influence on life (Foucault, 1979, p. 139).

In bio-power, life is a resource from which regulatory entities can build and maintain power (McDorman, 2005). Health is regarded as a human right and a global priority (World Health Organization), and governments establish laws and services to promote and preserve health, reinforcing their power by reinforcing the notion that life is to be preserved (McDorman, 2005). In the United States, all three branches of government embody political power and exert influence over what care is available and to whom (Jacox, 1997). National and state legislatures set budgets for services, license clinicians, and regulate services and supplies. For example, a largely symbolic 1997 law bans the use of federal funds for purposes of assisted suicide (H.R. 1003 -- Assisted Suicide Funding Restriction Act of 1997). Courts interpret what services are legal, and the executive branch oversees services and programmes. For example, also in 1997, the U.S. Supreme Court rejected a constitutional right to AID for terminally ill individuals, leaving the matter to states (Mariner, 1997). Private entities, whether for-profit corporations or not-for-profit services such as hospitals run by religious orders, provide a large portion of direct services, with both private and government insurance providing payment. Although their specific missions may differ, all are aligned to preserve health. The National Cancer Institute's definition of hospice, for example, frames the patient's experience in terms of quality of life, not the dying process (National Cancer Institute). Clinicians, patients, and caregivers whose goals don't align with the policy-enshrined health-related values adopted by the government, therefore, may find themselves vulnerable to loss of services, loss of licensure, or even legal investigation (McDorman, 2005).

A bio-power-infused environment informs the VSED caregiver experience directly and indirectly. Laws allowing AID are available in states and districts where public discussion about patients' rights to autonomy and avoiding suffering have influenced ballot initiatives, legislation, or court decisions. The resulting regulations carefully prescribe who may use AID, and who may not. Patients with dementia are ineligible, for example, so the power to choose to die through AID rests not with individual patients but with society's criteria (less than six months’ life expectancy, cognitive capacity) carved out from the general interest of protecting life under the auspices of bio-power. Some patients in this study who might have chosen AID therefore looked to VSED as an alternative.

Several caregivers mentioned fearing that neighbours would be alarmed to learn that a patient was undertaking VSED and would call authorities to intervene. The caregivers were voicing an acknowledgment of the general social valuing of life and the general astonishment, as Foucault states, that anyone would choose not to live. Only one case in the study actually had an incident of a caregiver being reported for possible elder abuse, but the fear of that potential shaped how caregivers planned the conduct of VSED, whom they interacted with, and where they felt they could find social support. The concept of bio-power influenced their actions not only through its structural and legal manifestations but by their own internalisation of it. Notably, caregivers of patients who fit in the “done with living” category for the most part did not mention concealing the patient’s impending death or having difficulty obtaining a referral to hospice even in the absence of a clear qualifying diagnosis. The patients’ advanced age or frailty appears to have made their dying plausible and acceptable to others in the community or to the medical establishment, sparing their caregivers from conflict with bio-power at the societal level.

**Health system.** The health system comprises multiple manifestations of power that affect VSED caregiver experience. Healthcare entities, such as hospices, and individual clinicians are affected by policies shaped by cultural-level bio-power. The Catholic church’s affirmation of the value of life and the role of nutrition and hydration ("Nutrition and Hydration: Moral and Pastoral Reflections: Committee for Pro-Life Activities National Conference of Catholic Bishops April 1992," 1992) meant that the only hospice in town, affiliated with a Catholic charity, was unwilling to provide care at all for Fran and Teresa’s husbands when they undertook VSED. The U.S. government’s interest in regulating spending on health dictates that Medicare, the federally funded health payment system for adults older than 65, will reimburse for hospice services only if the patient has a prognosis of less than six months to live (Centers for Medicare & Medicaid  Services). That requirement informed some caregivers’ anxiety about seeking a hospice referral for their patient; caregivers believed hospice support would be essential for the patient achieving a comfortable VSED death, but only a few patients in this study clearly fit hospice eligibility requirements. With eligibility uncertain, caregivers’ hopes for hospice rested on the primary care physician or the hospice intake staff first generally supporting the patient’s goals and then finding a plausible way to qualify the patient.

Within the environment of bio-power, individual clinicians' own comfort with hastened death shapes patient and caregiver experiences (Gamondi, Borasio, Oliver, Preston, & Payne, 2019; Starks et al., 2007). Physicians control access to healthcare services, having consolidated their power as gatekeepers through legislative actions in the past century (Starr, 1982). Consequently, "the doctor-patient relationship is asymmetrical with the doctor possessing legitimate, reference, and expert power" (Beisecker, 1990, p. 106). McDorman suggests that physicians regard death as an enemy because it marks the point at which their expertise fails, and that physicians become instruments of the state's bio-power: "When preserving life is identified as the ultimate goal by the state-buttressed by their self-proclaimed (and judicially legitimated) claim of an unqualified interest in life – the physician can be utilized as an instrument for transmitting the ideology" (McDorman, 2005, p. 266). Except for Paul's mother, who did not expressly state her plans to pursue VSED in advance, all patient-caregiver dyads in this study consulted with physicians to secure support for VSED in the form of hospice referral, prescriptions for medication to manage anxiety and other symptoms, or both. A physician's support offered both practical assistance and legitimacy. The physician's status as arbiter of who is healthy or ill in the United States could effectively give caregivers and patients a buffer against bio-power. If a physician acknowledged and supported the patient's path to death, the death must be legitimate. Amy's experience illustrates this concept: she felt relief at having hospice support in part because it provided an effective counter to neighbours or others who might worry about elder abuse. When patients are dependent on institutions such as nursing homes or assisted living for basic care, those institutions' policies and staff carry similar authority to physicians in terms of shaping caregivers' and patients' experiences. Maureen's VSED attempt failed, Andrea believed, in part because it conflicted with institutional norms.

**Community**. Caregivers navigate VSED within networks of family, neighbours, friends, and local community that may support the caregiver's role or may exert real or anticipated pushback to the idea of VSED because of internalised conceptions of bio-power and social proscriptions against suicide. The interaction between caregiver and community is not well-studied and does not appear in major meta-analyses of end-of-life caregiving literature (Funk et al., 2010; Martín et al., 2016; Stajduhar et al., 2013), but does appear in studies about AID (Gamondi et al., 2015; Holmes et al., 2018) in which caregivers describe feeling the need to keep information about the patient's choice to die hidden from family members or friends who might object. That this phenomenon of caregivers concealing the patient's intent from close relations appears in hastened death studies but not general end-of-life caregiving underscores the way in which hastened death violates bio-power norms in a way that general dying does not.

At the same time, hastened death is not necessarily an isolated act. Canadian and American studies of VSED describe communities of friends and caregivers coming together to bear witness to the patient's death from AID (Buchbinder, 2018; Holmes et al., 2018). Many VSED caregivers recounted either calling on friends to assist with caregiving or inviting visitors based on the patient's interest and energy levels. Indeed, the duration of VSED could create a lively environment as family and caregivers sought to distract the patient and pass the time. Buchbinder's ethnography of AID in Vermont (2018) calls out this way in which hastened death is distinct from conventional notions of suicide: "While public discourse characterises AID as a mechanism for achieving an individually controlled, autonomous death, the medicolegal framework that organises it practically enlists social support and cultivates dependencies" (Buchbinder, 2018, p. 12). VSED, in which patients seek help from and eventually cede control to a caregiver or team of caregivers, is similarly social. These examples in AID and VSED illustrate a social construction in which an individual can reclaim bio-power for themselves with community support and endorsement, despite general social proscription against suicide. Community support appeared to be an important mediator of caregivers' experience in both AID and VSED. Swiss caregivers who felt unable to share their experience reported distress and feelings of isolation (Gamondi et al., 2015), whereas sociality of the death was an important part of positive outcomes for caregivers in this VSED study and in American AID cases (Buchbinder, 2018).

**Patient**. In VSED and other forms of hastened death, the patient's wish to die shapes the agenda and terms of engagement for how the caregiver and patient will interact. In a systematic review, Gamondi et al (2019) found that caregivers in assisted dying commonly share values about suffering and death, the autonomy of the patient to make a choice to die, and the conclusion that a hastened death is better than the alternative. Such shared beliefs formed a foundation allowing the caregiver to proceed to more practical issues of assisting with preparations and saying goodbye. VSED caregivers in this study mostly shared this aligned perspective. Many patients in this study were determined to die but physical illness or faltering cognition limited their ability to plan and prepare independently, and caregivers took on much of the logistics. Unique among forms of hastened death, VSED's slow trajectory also imposes a gradual diminishing of the patient's capacity, requiring the patient to hand off control over the environment and events around VSED entirely to the caregiver.

In many cases, at some point the caregiver, not the patient, was in charge of whether the patient would succeed. VSED caregivers, then, allow the patient's goals and will to supersede any other priorities the caregiver might have during the VSED process.

## 7.6 Conclusion: VSED caregiving is a complex system

VSED caregivers interpret and create meaning in an environment marked by competing goals, implicit and explicit manifestations of power, and complex interpersonal relationships. Some share culturally informed reservations about the permissibility of VSED, but their commitment to the patient's goals is paramount. To enact those goals, caregivers navigate an uncertain path through community, the health system, and broader society. They seek types of practical and emotional support readily available to caregivers of patients whose deaths are not hastened and try to avoid or minimise the influence of individuals or organisations whose expressions of bio-power might undermine the patient's goal. For caregivers' full experiences to be understood, they must be examined within the context of this larger social framework.

This study is the first to document these experiences in VSED and the first to demonstrate the power dynamics and layers of social interaction that shape VSED caregiving. Starting with well-established theories pertaining to the patient-caregiver dyad, in this thesis I have argued that the full experience of VSED caregiving can be understood only when the field of view is expanded to include the layers of the community, health system, and society. These layers practically shape the caregiver's landscape for helping a patient successfully complete VSED, but they are laden with explicit and implicit power and agendas that may impede or facilitate the caregiver's efforts. The combination of a socio-ecological model, critical systems theory, and bio-power therefore make a unique contribution to the growing body of research and critical thought pertaining to hastened death.

## 7.7 Reflection

This study is the first study to document VSED caregiving and one of only a handful of studies worldwide to explore the experiences of caregivers in any form of hastened death. In addition to the challenge of identifying individuals who have had this unique experience and wish to share it, conducting research on such an intimate and highly emotional topic is taxing for the researcher. I believe the results are worthwhile, although they came with a price of emotional fatigue and frequent VSED-related nightmares. Fortifying the effort of data collection and analysis was the enthusiasm of the participants themselves. While some have become advocates and educators around VSED, others have told few people about their experience. All were enthusiastic about sharing their story, even as many of them wept whilst telling it. Presenting a careful analysis of the data, here and in publications, is the best way I can honour their contribution.

This study was conceived using the scant available literature on VSED, which presents VSED as an alternative to AID (Quill et al., 2018) or emphasises the role of palliative consultation in addressing unmet symptom management needs that may be precipitating the patient's decision (Wax et al., 2018). Public information about VSED comes primarily from organisations like Compassion and Choices or Death with Dignity, which advocate for AID and patient self-determination. Thus the available scientific and cultural narrative on VSED is relatively clinical and political. Many of the cases in this study are neither. No caregivers spoke about their experiences or patients' choices in terms of social justice, and most had minimal interaction with physicians beyond enrolment in hospice. Notably, a third of patients described in the study did not have a terminal diagnosis but were simply "done with living" and another third were in the early stages of dementia and could expect years of life ahead. This finding appears consistent with Dutch data from Bolt (2015) in which a quarter of patients pursuing VSED appeared to be primarily motivated by existential suffering rather than physical symptoms, but it runs counter to the predominant American narrative that hastened death (specifically AID) is primarily a pursuit of people who "are terminally ill, in great pain, and who have no chance for recovery" (Compassion & Choices). The deaths described in this study suggest that hastened death in the form of VSED is happening quietly in a manner different than either the political or medical narratives in the United States.

Methodologically, the structure of the thesis also derives from the study's status as the first on the topic. Using complementary inductive and deductive approaches to reflexive thematic analysis is a novel approach that appears to be consistent with Braun and Clarke's most recent reflections (Braun & Clarke, 2019a, 2019c), but this particular combination of tandem inductive and theory-driven deductive analysis has not been previously described in the literature. I developed this approach pragmatically based on two challenges of the research: first, because no other literature on VSED caregiving was available, conducting systematic reviews of studies on adjacent caregiver populations was the most logical way to contextualise VSED caregiver experience. A theory-derived coding structure helped clarify commonalities and differences. Second, early use of the deductive codes in the systematic reviews revealed that the deductive scheme by itself would leave many important aspects of the VSED process itself unexplored. For example, a single vignette might be layered with inductive codes about the stage of the VSED process, patient symptoms, and caregiver interactions with family, as well as the appraisal, response, and other phases of the modified stress-coping model. Ultimately, the two analyses complemented each other and facilitated deeper understanding of interactions that shaped the final theoretical framing. For example, deductive analysis helped isolate a request for support from the patient's physician for VSED as its own cycle of appraisal and response. But inductive codes about the law, alternatives to VSED, and hospice eligibility helped situate it in a broader social context. Similarly, contrasting original VSED data against two adjacent types of caregiver experiences drawn from systematic reviews helped make sense of the overall findings: what is ultimately unique about VSED caregiving? The thread of social constructionism ties together all the analyses of this thesis and extends consistently through the theoretical discussion above. I believe the thesis effectively uses multiple data sources, analyses, and layers of theory to build a comprehensive and coherent initial picture of VSED caregiving experience.

Engaging with the methodology, analysis, and theories applied to VSED caregiver experience in this research process over two years evolved my thinking and sense of agency as a researcher. Despite being able to trace in literature the evolution of the stress-coping model or other theories of caregiving, for example, I originally planned this research viewing them as fully formed tools available for a student researcher's use. I had expected to faithfully apply other researchers' theories to my own data analysis. Instead, this thesis reflects a process of intellectual engagement and growth that resulted in questioning and suggesting additions to existing theories and developing new models for thinking about the socio-ecological positioning of caregiving. The experience has reinforced and expanded my alignment with constructionism and interpretivism: The work presented in this thesis involves not only building new sets of meaning about VSED caregiving but rethinking and evolving the tools with which that meaning is built.

# Chapter 8: Conclusion

This research, at the time of its completion, is the only qualitative study of VSED caregiving and one of only a few studies to examine VSED at all. VSED sits alongside AID in the current discourse around autonomy, suffering, and the right to die in the United States. Despite VSED's proximity to AID, this study found that VSED is distinct both in terms of who elects it and what is required of caregivers to support them. The research question – What are the experiences of caregivers supporting patients who elect VSED? – was intended to shed light on what happens during that two-week period of dying, previously undescribed.

VSED caregiving shares with other forms of hastened death properties of intentionality that influence how caregivers agree to participate, anticipate loss, and seek closure. But VSED caregiving also is a lengthy process, often starting well before the cessation of eating and drinking, that exacts a physical and emotional toll similar to general end-of-life caregiving. What is unique to VSED is the responsibility VSED caregivers take on to ensure the patient's success as they lose capacity. This places a burden on VSED caregivers unlike any other, particularly when some patients may not be frail enough to die otherwise.

This social constructionist study, drawing in part on Hudson's modified stress-coping model, demonstrates how caregivers interpret events and create meaning around an experience that falls outside of social norms for caregiving of the dying. This research further uses layers of health and social theories to contextualise the experiences of 24 VSED caregivers more broadly as part of a layered ecosystem of relationships, institutions, and society (Bronfenbrenner, 1977), and as participants in a complex interaction of actors all nominally focused on health but with very different goals, values, and amounts of power (Foucault, 1979; Starr, 1982; Watson & Watson, 2013). VSED is a challenge to bio-power, and that challenge affects the daily lives of caregivers seeking support for the patient and themselves.

## 8.1 Contributions to knowledge and practice

These findings represent several contributions to scholarship on hastened death in particular and caregiving in general. Understanding the experience of VSED caregivers helps distinguish it among other forms of hastened death and sheds light on how patients and families choose and undertake intentional dying. The experience of caregivers of people who chose VSED not because of illness but because they were done with living also challenges assumptions that VSED is pursued only when AID is unavailable.

Public and political discourse around hastened death is evolving rapidly in the United States, as one in five Americans now lives in a jurisdiction where AID is legal. For those who live elsewhere or who fall outside the strict qualifications for AID, VSED may increasingly become an option of interest. However, this research suggests that few healthcare providers or organisations have experience in providing support for patients pursuing VSED and their caregivers. Identifying similarities and differences between caregiver experiences and needs in VSED and at end of life can guide care planning for hospice and palliative professionals, as well as primary care clinicians, as they may be the first to learn of patients' intentions.

By testing the modified stress-coping model of caregiving (Hudson, 2003) against original data as well as findings from available literature for two different types of caregivers, this thesis makes a strong argument that the model could be improved by the addition of interaction with health professionals as an influencing factor. For researchers and theorists, the addition of socio-ecological layering and critical systems theory onto the patient-caregiver dyad highlights the complexity of the caregiving environment and opportunities to create more robust theories of caregiving.

## 8.2 Strengths and limitations

The scant research conducted on VSED mostly has taken the form of clinician surveys (Bolt et al., 2015; Ganzini et al., 2003; Shinjo et al., 2019). Although these surveys suggest the prevalence of VSED in various countries and the reasons patients undertake it, the true population of VSED caregivers is unknown. A strength of this research is that it was able to access a diffuse population and investigate their experiences for the first time. A further strength is that caregivers' characterisations of patients' reasons for pursuing VSED are consistent with findings from Bolt and Ganzini in terms of somatic and psychosocial reasons for wanting to die. This suggests that the study has captured some of the breadth of types of VSED cases. The demographics of participants – white and highly educated – may not reflect the true diversity of individuals undertaking VSED or VSED caregiving; however, in the United States patients who pursue hastened death are mostly white and educated (California Department of Public Health, 2019).

Because no organisation represents VSED caregivers and VSED caregiving takes place with minimal clinical intervention, recruitment for this study involved snowball sampling as clinicians, journalists, scholars, and end-of-life choice advocates forwarded recruitment materials to caregivers they knew. These caregivers in turn suggested other caregivers in their communities who wanted to talk about their experience, but some also mentioned caregivers who had had negative VSED experiences and were unlikely to participate in the study. Thus a limitation is that most caregivers in this study viewed VSED positively; the views and experiences of caregivers who felt differently are not well represented beyond the experience of Paul. Caregivers also shared experiences in their past. In this study, patients had died several months to 10 years prior to the interview, and caregivers' perceptions of events may have changed over time (Campbell, Nadel, Duke, & Ryan, 2011).

Some of the conclusions drawn in the Discussion chapter are based on juxtaposition of original data on VSED caregivers compared with analysis from systematic reviews of published literature on end-of-life and AID caregiving. Although each set of data was analysed using a common code set derived from Hudson, published results are inherently different from original data, and the theories those studies' authors chose to emphasise may not align well with the modified stress-coping model. Results may have been different in a true comparison of original interviews with each type of caregiver.

## 8.3 Future research directions

VSED caregivers play an active role before, during, and after the VSED process and are the closest witnesses to the goals, feelings, and experiences of patients, but their interpretations may be coloured by their own beliefs and their relationship with the patient. Future research could explore the motivations of individuals seeking VSED themselves or capture the day by day experience of an individual undergoing VSED until loss of consciousness. Such research could inform clinical care before and during VSED. A study conducted with multiple palliative care or hospice programmes could systematically document the incidence of VSED-related inquiries and attempts in a population.

This study also suggested variability in how physicians, hospitals, and other healthcare entities acknowledge and respond to VSED. Future research could use survey or case study models, for example, to study physician and hospice staff beliefs about VSED, as well as hospice policies around VSED, particularly around eligibility for services.

## 3.9 Dissemination

The documents for informed consent in this study state that participants' names and identifying details will be changed so that individual participants, patients, or others cannot be identified through dissemination. All participants gave permission for information from their experience to be used in articles, training materials, or other dissemination channels. Final results of the study were accepted for presentation at the 2020 American Academy of

Hospice and Palliative Care scientific meeting (cancelled because of COVID-19) and will be submitted to journals for publication. A review article based on the background chapter has been submitted to the Annals of Palliative Medicine as part of a special issue on hastened death. The systematic review of end-of-life caregiving also has been submitted for publication. Findings, particularly those related to experiences of caregivers of patients with early dementia, also have been presented as part of a bioethics work group on “Dementia and the Ethics of Choosing When to Die,” an initiative of the Hastings Center, an ethics research institute. They will be presented as part of a panel discussion on the topic at the World Congress of Bioethics in 2020. Most participants requested to see final results of the research.

## 8.4 Final words

This study explored the experiences of caregivers assisting with a way of dying that falls largely outside of medical practice or legal policy in the United States, and for which the full population remains unknown. The experiences of VSED caregivers are shaped by their own beliefs about the right to die and their relationship with the patient, but also by layers of external influence, from physicians’ attitudes to state law. VSED caregivers share commonalities with other caregivers at end of life and in other forms of hastened death. Uniquely, though, they carry a strong sense of responsibility for the patient’s successful death: without their support, the patient might not die despite their wishes. Understanding this experience, through this and future studies, can inform the environment in which patients and their caregivers seek the best death available to them, from conversations with clinicians, to hospice and long-term care policies, to discussion about approaches to care for conditions such as dementia, and most broadly to ways society acknowledges and responds to individual suffering.

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## Appendix A: Sample memo

Memo: Planning and being deliberate (June 27, 2019)

One thing that comes up in a number of different ways across the VSED interviews is what is afforded by the ability to plan. In some cases the patient is very clear in their will and also very capable and they orchestrate the entire thing, down to the menu to be served at their memorial.

But in others, when there is advance warning and maybe particularly when the patient has dementia, the caregiver often has time to plan. Effects of planning:

- The caregiver can find all the information they need, take care of legal and medical paperwork, and interview and hire a care team.
- The patient or the caregiver may decide to take advantage of residential hospice, if one is available.
- The caregiver gets to decide what they want their role to be: from hands-on and doing most or all of the caregiving to purely emotional support, or just being a spouse/child/parent. Several recognised ahead of time that either they didn't have the ability to physically provide care, usually because of age or lack of previous experience, while others recognised that they had their own needs in the process and they did not want to be distracted from connecting with the patient at a meaningful time, so they were happy to assign the physical care to others.

Some people were very aware and planned extensively and thought about what they needed themselves. Some planned but only around the patient's needs, not really their own. And people whose parents fit the "done with life" category generally had the least chance to plan as it came upon them fairly suddenly and they had to just start.

The planning also is possible in part because everyone recognises that the patient is ceding power to the caregiver sooner or later (sooner for dementia). So the caregiver, in taking that up and anticipating it, has a chance to consider what they think will make it work successfully and to recognise that they're an important piece of the puzzle.

For some caregivers, their own needs are decent sleep, or being able to shower every day, or not having to bathe their partner's shrinking body. That said, not all caregivers realised they had needs.

So some caregivers sort of respond the way general end-of-life (EOL) caregivers do -- putting themselves on hold. But the differences are that they know VSED will be done in a couple weeks, so they know they won't be indefinitely exhausted and they know they can hire help for the duration (in my population anyway) if they want. And I think there's more awareness of themselves as a key to the success that feels different than general EOL as well. Not just wanting to do right by a dying family member, but the sense that the stakes are high because the success rests with them.

That's an interesting distinction. In general EOL caregiving, the patient is going to die eventually regardless and it's a question of helping them be comfortable for however long (I think). But in VSED, if you leave the patient alone they might NOT die, or they'll suffer needlessly, and I think that agency is pivotal in the process and might be more pronounced in VSED than in AID.

## Appendix B: Invitation email

Dear _______

I'm writing to ask for your assistance in my PhD research in palliative care through Lancaster University in the UK. We [establish context – met at a conference, talked previously, etc] and at the time you indicated that you might know of people who had been a caregiver for a patient who had opted to hasten death by voluntarily stopping eating and drinking (VSED). I have received approval from the university ethics review committee (Reference Number: FHMREC18020) and am hoping to interview people who have been VSED caregivers.

If you think you know of anyone who might be interested in participating and are willing to help, I would like to send you an information sheet about the study and an email that you could forward to those people. If they are interested in participating, the email and info sheet have information about what's involved and how to contact me. I will not ask you to follow up, or to be involved in scheduling.

To describe the project in a little more detail now:

This is a qualitative study comprising interviews with VSED caregivers. I'm interested in multiple aspects of their experience, including their caregiving duties, what sources of support they and the patient had, their interactions with the patient and other family or caregivers, and their overall feelings about the process of caring for someone through VSED. The interviews will take about 90 minutes and will be done in person if possible. [Add information here if needed about researcher's plans to be in the region.]

Again, thank you for your interest in this research project. If you have questions about the project, the ethics review, or any other aspect, please let me know.

Best wishes,

Jane Lowers

# Participant Information Sheet

## *Caring for Someone Who Has Chosen to Stop Eating and Drinking to Hasten Death*

My name is Jane Lowers and I am conducting this study as a student in the PhD programme in health research at Lancaster University, Lancaster, United Kingdom. I'm an American and a former medical journalist.

### What is the study about?

The purpose of this study is to describe the experiences of people who have been caregivers of family or friends who decided to hasten their death by voluntarily stopping eating and drinking (VSED).

### Why have I been approached?

You have been approached because the study requires information from people who have been caregivers of someone with serious illness who has chosen to stop eating and drinking to hasten their death.

### Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

### What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to meet with the researcher in person or by phone for an interview lasting 60 to 90 minutes. The researcher will ask you questions about your time as a caregiver. The interview will be audio recorded. The researcher will ask you to fill out a short form with basic information about you and the person you cared for. The researcher will ask if it is OK to contact you again by phone or email about other questions in the future. It is OK for you to say no – there is no penalty for doing so.

### Will my data be identifiable?

The information you provide will be made anonymous. The data collected for this study will be stored securely and only the researcher conducting this study and her supervisors will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been examined as part of the requirements to complete the PhD.
- Hard copies of forms will be digitally scanned and then destroyed.
- The files on the computer will be encrypted (that is, no one other than the researcher will be able to access them without passwords) and the computer itself password protected.

- The transcript of your interview will be made anonymous by removing any identifying information including your name, the patient's name, or details such as your location. 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.
- All your personal data will be confidential and will be kept separately from your interview responses. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: **www.lancaster.ac.uk/research/data-protection**

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 a research supervisor. 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 dissertation and will be submitted for publication in an academic or professional journal. They may also be used to develop education for the public or for healthcare professionals.

## Are there any risks?

There are no risks anticipated with participating in this study, but talking about your experience might be upsetting. You can stop the interview at any time. If you experience any distress following participation you are encouraged to inform the researcher and contact the resources at the end of this sheet. (These will be added for each individual participant based on location.)

## Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Some people may find it helpful to talk about VSED with someone who is familiar with the process.

### What if I change my mind?

You may cancel your interview, leave the interview at any time, or inform the researcher after the interview that you do not want your data to be used in the study. There are no penalties or consequences for doing so. Once data from several interviews have been analysed together, about a month after the interview, it may be difficult to remove the ideas of an individual person, but the researcher will make every effort to do so if requested.

## Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (Reference Number: FHMREC18020).

## Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
*Jane Lowers, MPA*

*Postgraduate Programme in Palliative Care*
*Lancaster University*
*j.lowers@lancaster.ac.uk*
*415-279-8917*

*Study Supervisors:*

| | |
|---|---|
| *Nancy Preston, PhD* | *Sean Hughes, PhD* |
| Professor | Lecturer |
| Lancaster University | Lancaster University |
| n.j.preston@lancaster.ac.uk | sean.hughes@lancaster.ac.uk |

**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 the head of the palliative care department:

Professor Catherine Walshe
Tel: +44 (0)1524 510124
Head of Department
Email: c.walshe@lancaster.ac.uk
Faculty of Health and Medicine
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You may also contact the associated dean for research:

Professor Roger Pickup
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Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
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Lancaster University
Lancaster
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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. Hospices and palliative care programs frequently offer bereavement support programs and can suggest the names of local counsellors who are trained to work on grief issues.

# Appendix D: Consent form

## Consent Form

## Study Title: Caregiver Experience with Voluntarily Stopping Eating and Drinking

We are asking if you would like to take part in a research project about the experience of caregivers supporting patients who choose to hasten their death by voluntarily stopping eating and drinking. 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 before signing the consent form please speak to the principal investigator, Jane Lowers.

Please initial each statement

1. I confirm that I have read the information sheet (version Nov. 20, 2018) 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 anonymous 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 at any time without giving any reason. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. Recordings may be withdrawn for up to 2 weeks. ☐
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 the researcher will discuss my data with their supervisor as needed. ☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with an appropriate person. ☐
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
12. I consent to take part in the above study. ☐
13. OPTIONAL: I am willing to be contacted with follow-up questions. (If checked, please indicate preference for phone or email, and provide contact information below.) ☐

**Name of Participant__________________**

**Signature____________________ Date ___________**

**Name of Researcher __________________**

**Signature ____________________Date ___________**

**OPTIONAL:**
**I am willing to be contacted (check all that apply) __ by phone __ by email with additional questions. The best way to reach me is:**
**(Phone)__________________________**

**(Email)___________________________**

**Note: You may also contact the researcher if you think of other details you want to share:**
*j.lowers@lancaster.ac.uk*

***415-279-8917***

## Appendix E: Interview guide

# Interview Guide: Caregiver Experience with Voluntarily Stopping Eating and Drinking (VSED)

Introduction (5 minutes)
1. Welcome
Hello. My name is Jane Lowers and I'll be interviewing you today.
This interview is part of my research for a PhD in palliative care with Lancaster University in England.

2. Background and Disclosures
There are no financial sponsors for this research.
My research is looking at the experiences of people who were caregivers to people who were ill and chose to take control of their death by stopping eating and drinking. By talking to people like you, I hope to learn what that experience is like, what is important to people who are providing that care, and what doctors or hospice staff might need to know to support caregivers in that situation.

I'm here today to learn about what matters to you. I want to learn about your experience, what that time was like for you, and what you think was important about it.

As it said on the information sheet, I'll be recording our conversation. The purpose of recording is not to identify you, but to be able to make an accurate written record of what you said. I will not use anyone's real name in my research, or details about you or anyone in your story that would help people identify you. May I begin recording now?

[If phone interview, start recording.]

[If a phone interview, at this point ask if the participant has the consent form available. Read the form aloud, asking for consent at each point and documenting it on copy of the form.]

3. Go over ground rules.
Now, I'd like to go over some basics for our discussion today.

Our conversation should last about an hour, but possibly up to 90 minutes.

We won't be taking any formal breaks, but at any time you may get up to go to the restroom [DESCRIBE LOCATION IF IN PUBLIC SETTING] or to get something to drink.

We'll be talking about some serious issues today, and the discussion could bring up some memories or feelings that are uncomfortable. If you feel like you want to step away or take a break, please know that that’s OK. If it seems like the conversation is uncomfortable, I may move on to a different topic.

There are no wrong answers to any of the questions—I’m interested in hearing your true opinions.

We have a lot to talk about today, so there may be times when I need to move the discussion along. Please understand that when I ask that we move to a new topic, I don’t mean to be rude.

If you have a cell phone, please make sure to set it to “vibrate.”

Do you have any questions?
[If in-person interview, ask permission to record and begin recording.]

Note: Bulleted items reflect general prompts and potential areas for discussion only.

Background [10 minutes]

- Introduction to participant, including demographics
- Relationship between caregiver and patient
- Details about patient: demographics, personality, spirituality, family independence
- Summarise patient's illness and its effects
- When patient first mentioned VSED as possibility: reasons, reactions, how caregiver and patient learned about VSED as an option
- Who else knew about interest in VSED (family, friends, physician), reactions
- How caregiver decided to support patient's choice of VSED

Preparation [15 minutes]

- The patient's planning process: medical, legal, logistical, timeframe
- The care team: members, roles played, concerns
- Patient's goals for experience, death
- Caregiver's thoughts/reactions to preparation
- Caregiver's perception of own role and relationship to patient
- Caregiver's concerns about what was going to happen, own preparation

The VSED process: early days (patient is alert, mobile, communicative) [10 minutes]

- How and when patient started VSED
- Logistics/location/supports (e.g. hospice, other team members)
- Patient's needs, caregiver's role
- Unknowns
    - Were there problems you had to solve? What happened?
- Caregiver's thoughts and feelings in that time
    - What made things easier or harder
    -

Middle stage (patient is weakening, may have other symptoms) [10 minutes]

- What changes caregiver noticed, reactions
- Patient's needs, caregiver's role
- Communication with patient and others
- Role of other caregivers and hospice
- Unknowns
    - Were there problems you had to solve? What happened?
- Caregiver's thoughts and feelings in that time
    - What made things easier or harder

Late stage (patient is unresponsive, nearing death) [10 minutes]

- What changes caregiver noticed, reactions

- Patient’s needs, caregiver’s role
- Communication with patient and others
- Role of other caregivers and hospice
- Unknowns
    - Were there problems you had to solve? What happened?
- Caregiver’s thoughts and feelings in that time
    - What made things easier or harder
    -

Death [10 minutes]

- The patient’s death
- Feelings at the time
- What caregiver thinks about death, whether it was death patient wanted, why
- Caregivers’ actions post-death

Grief and aftermath [5 minutes]

- Caregiver’s life in days/weeks following death
- Communicating with others about death, including whether VSED was mentioned
    - Do you feel like you can talk about the way [patient] died?

Summing up [10 minutes]

- What was most important about going through VSED with patient?
- What went well, and what parts were hardest?
- What does caregiver wish had gone differently?
- What could others learn from this experience?

Thank you and next steps [5 minutes]

Thank you again for taking the time to talk with me today. We covered a lot. I want to remind you that the information sheet has resources about bereavement and other support locally. As a reminder, all information about your experience will be anonymous. If you change your mind about wanting your story to be part of the research, please let me know within the next two weeks. Once your story is transcribed and is analysed with others’ stories, it will become more difficult to separate out, although I would try to do so.

You noted that I [could/should not] contact you about follow-up questions. Thank you for considering it. Before we close, is there anything else you’d like to tell me about your experience, or do you have any questions?

## Appendix F: Code tree

| Subcodes | Codes | Subthemes | Themes |
|---|---|---|---|
| • Caregiver believes people have a right to choose a dignified, pain-free death<br>• It is not an easy choice to make, so respect it, honour the person<br>• Patient’s decision is utterly his/her own<br>• Patient chooses to go meet death | The right to choose | People have the right to choose how to die | **VSED is the best death available to the patient** |
| • Patient would have wanted AID if legal and available<br>• Dementia patient won’t qualify for AID | Other hastened death | AID is unavailable | |
| • Recognising patient is considering suicide because of not wanting this state | Family recognises illness | VSED is different than suicide | |
| • Patient considers suicide | Other hastened death | | |
| • [VSED is] not shocking to caregiver like finding a suicide | Bad ways to die | | |
| • Better than suicide | Least bad choice | | |
| • VSED is beautiful, natural<br>• VSED is pragmatic and in control | Quality of death | VSED is the best death available | |
| • It’s the second-best death after dying suddenly in one’s sleep<br>• Getting to live right up to the end | Good ways to die | | |
| • Being in a care facility is unacceptable<br>• Every day is going to get a little worse | What makes life worth living | | |

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| • Relief that patient won’t have to suffer through it all<br>• Knowing patient’s life and in future is not at all what patient wants | Family recognises illness | | |
| • Death by the diagnosed condition would have been an awful way to die<br>• Dementia would have been a horrible death | Bad ways to die | | |
| • A natural death | VSED overall reactions | VSED was peaceful | |
| • VSED is beautiful, natural | Quality of death | | |
| • Patient is at peace, looks same as ever<br>• The dying process unfolds naturally and sacredly<br>• Courageous, respectful, natural | Good ways to die | | |
| • The certainty that patient is dying is a gift, directs caregiver to closure | Good ways to die | VSED can be a gift to caregiver | |
| • It’s a gift to know the patient is dying because you can say all the things you would want to | Chance for closure | | |
| • Giving the gift of not having to provide care<br>• Patient didn’t want to be a burden<br>• Caregiver feels patient dying gave back years of freedom that would have been spent caregiving | Patient personality traits | | |
| • It’s great to be able to talk about the fact that you’re dying<br>• It’s a gift to know patient is dying | Saying goodbye | | |
| • Hospice feels like legitimation in case anyone is suspicious | Community | Will healthcare providers support VSED? | **Risk and legitimacy** |

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|---|---|---|---|
| • Interviewing hired staff in advance to alert them about VSED, find someone else if there are objections<br>• Hired aides question whether VSED is voluntary<br>• Death midwife provides counselling for patient, who can’t tell a mandatory reporter about when he plans to start | Professional caregivers | | |
| • Local hospice is religious, won’t accept VSED patients<br>• Untrained health aides don’t understand/aren’t comfortable with VSED, give water<br>• Specialist MD says he won’t refer to hospice<br>• Hospice doctor at intake says she won’t speed up death | Healthcare provider objections | | |
| • As proxy, could I stop it, legally or ethically? | Whether to stop VSED | Is VSED legal? | |
| • Researching legality | Choosing VSED | | |
| • Not sure how to talk about VSED to people who might think it’s suicide<br>• Not wanting to tell the neighbour in case they call APS<br>• Hospice feels like legitimation in case anyone is suspicious<br>• Hearing about neighbours who objected to VSED in other cases | Community | Will family or community challenge VSED? | |
| • Challenge: not being able to tell counsellor, who is a mandatory reporter | Caregiver self care | | |
| • Doing the planning and logistics<br>• Keeping the house running/logistics<br>• Trying to keep things normal for patient<br>• Coordinating volunteer and hiring paid aides<br>• Making sure patient gets needed meds<br>• Advocating to HCPs for patient to get symptom relief, hospice, or support for VSED (Andrea, Brian, Sam, Lauren, Paul)<br>• Advocating: working the system to get outcome patient wants<br>• Researching VSED to figure out how to honour patient’s wish<br>• Trying to coordinate and provide all aspects of the care | Caregiver role | Project managing the death | **Carrying responsibility for the patient’s success** |

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| • Caregivers take on responsibility for getting the necessary help once patient makes up mind to start VSED<br>• Patient relies on caregiver to advocate to healthcare providers<br>• Patient states trust in caregiver, but caregiver wants to be sure it's patient's choice<br>• Caregiver feels patient was aware of no longer being able to be in charge, needing to trust someone else | Patient handing off power | Feeling responsible for the patient's success | |
| • Caregiver helps track quality of life markers<br>• Caregiver worries about starting too late | Choosing a start date | | |
| • Helping confused patient focus on the goal<br>• Telling patient you can't forbid them to drink but you will remind them of their goal | Thirst | | |
| • Consulting attorney who says not to tell neighbours about VSED<br>• Constantly vigilant against visit from APS | Risk of elder abuse reporting | Being vigilant for threats | |
| • Fear patient will fall<br>• Fear patient will break hip<br>• Fear emergency department will hydrate patient<br>• Fear patient will end up in rehab facility and lose window of opportunity | Risk of hospitalisation | | |
| • Just a little water is enough to revive the patient's clarity, but they realise they've lost ground | Thirst | | |
| • Constant vigilance is exhausting<br>• Wondering how long it will last<br>• Needing 24-hour help to get through | Caregiver endurance | | |
| • Watching to make sure patient doesn't fall<br>• Reminding patient of goals | Caregiver role | | |
| • Asking family not to arrive until later so as not to derail | Saying goodbye | | |
| • I'm glad to help patient do this, but it also sucks<br>• Giving patient a good, desired death doesn't comfort the grief | VSED overall reactions | Anticipatory grief | **There is no script** |
| • Exhausted and emotional | Caregiver endurance | | |

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| • Hope for a good death vs sad/dread/anger about losing parent | Caregiver reaction to VSED | | |
| • Trying to process the intentionality of patient’s death<br>• Realising the patient’s life can never again be what it was<br>• Loving the patient enough to let him go<br>• Sad to lose patient | Sadness | | |
| • Being present with patient<br>• Caring for other caregiver<br>• Trying to keep things normal for patient<br>• Trying to find own ways to get closure<br>• Helping patient pass the time<br>• Doing whatever the patient wants<br>• Trying to coordinate and provide all aspects of the care<br>• Be a shamanic lover | Caregiver role | Choosing what roles to play | |
| • Supporting the patient is the most important role<br>• Second-tier caregivers provide support to main caregiver<br>• Having physical care aides allows caregiver to focus on emotional support | Emotional support | | |
| • The patient makes amends<br>• The family, and children, get to witness a good death<br>• Family members get to do their grieving in advance<br>• Family who witnessed the VSED are more comfortable about patient’s death than those who did not<br>• It’s a gift to know the patient is dying because you can say all the things you would want to<br>• Patient can say goodbye to everyone<br>• It’s a chance to die at home with just family around, not at hospital<br>• Not getting closure because patient is too far into dementia or withdrawn<br>• Patient gets to choose who to see, what to give away<br>• Patient can hand off knowledge or roles (the chocolate cake recipe) | Chance for closure | The chance for closure is a gift | |
| • Family is alerted to plans and has time to come say goodbye/help<br>• Family comes together to support patient | Family involvement in death | | |

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| • Patient has chance to spend time saying goodbye to each grandchild<br>• Patient plans how and when to say goodbye to different family members<br>• Caregiver is proud family put dysfunction on hold for a week to honour patient’s wishes | Family dynamics |  |  |
| • The certainty that patient is dying is a gift, directs caregiver to closure | Good ways to die |  |  |
| • Hard to get closure with person who isn’t capable of it anymore<br>• There’s no script – is everything I do going to be associated with patient dying?<br>• Finding ways to have meaning even if they don’t seem to matter to the patient<br>• Trying to hold it together to care for patient | Saying goodbye | There is no script |  |
| • Time gets weird<br>• The unknown: how will starting VSED resolve?<br>• Nervous about how to make it work but wanting to honour patient’s wish | Caregiver reaction to VSED |  |  |
| • Trying to find closure<br>• Listening to music, watching movies and TV<br>• Trying to find outlets for grief and anger<br>• Patient is bored, waiting for something to happen | Passing the time |  |  |
| • Disconnecting from emotion to focus on care<br>• Putting self on hold<br>• Feeling completely overwhelmed<br>• Physical and logistical care demands overwhelm ability to be emotionally present<br>• Needing to stop physical care to provide emotional care | Caregiver endurance | Putting self on hold |  |
| • Hope for a good death vs sad/dread/anger about losing parent<br>• Initially opposed but relented when realised extent of patient’s suffering | Caregiver reaction to VSED |  |  |
| • Letting go of own feelings so the patient’s choice can happen | Caregiver role |  |  |
| • Telling patient it’s OK to die now | encouraging to die |  |  |
| • Recognising own pain in loss but making patient’s goals take precedence<br>• As secondary caregiver, giving primary caregiver permission to tell patient it’s time to start VSED<br>• Letting patient know they’ll be OK without patient | Permission and closure |  |  |

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| • Focusing on rest of family<br>• Burying feelings until there is time for them | Setting emotions aside | | |
| • Realising in retrospect that caregiver was not doing ok | Caregiver self care | | |

## Appendix G: RATS Review Criteria

| **RATS (Modified from BioMed Central Qualitative Research Review Guidelines** s https://bmjopen.bmj.com/content/suppl/2012/03/01/bmjopen-2011-000511.DC1/bmjopen-2011-000511-s1.pdf) | |
|---|---|
| **Assessment Question** | **Text in Manuscript** |
| **Relevance of study question** | |
| Is the research question relevant to this review? | Research question explicitly stated |
| | Research question justified and linked to existing knowledge base |
| **Appropriateness of method** | |
| Is the methodology appropriate for the study aims? | Study design described and justified |
| **Transparency of procedures** | |
| Sampling | |
| Are the participants appropriate for the knowledge sought? | Criteria for sample selection explained and justified |
| Is the sampling strategy appropriate? | |
| Recruitment | |
| Were recruitment methods appropriate? | Details of how recruitment was conducted and by whom |
| Could there be selection bias? | Details of nonparticipants |
| Data collection | |
| Was data collection systematic and comprehensive? | Methods outlined and examples given |
| Are characteristics of study group and setting clear? | Study group and setting clearly described |
| Why and when was data collection stopped, and is it reasonable? | End of data collection described and justified |
| Role of researchers | |
| Might the researchers bias the conduct of the study or results? | Do the researchers occupy other roles (clinician)? Are ethics discussed? Do they explicitly examine their own relationship with the research question and data? |
| Ethics | |
| Was informed consent sought and granted? | Informed consent process detailed |
| Were participant anonymity and confidentiality ensured? | Anonymity and confidentiality discussed |
| Was the study approved by an appropriate ethics committee? | Ethics approval cited |
| **Soundness of interpretive approach** | |
| Analysis | |
| Is the type of analysis appropriate for the study? | Analytic approach described and justified |
| Are the interpretations clearly interpreted and supported by evidence? | |

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| Are quotes used appropriately and effectively? | Description of basis for quote selection, context |
| Was trustworthiness/reliability of data and interpretations checked? | Method of reliability (e.g., audit trail, triangulation) described; method of disagreement resolution described |
| Discussion and presentation | |
| Are limitations considered? | Strengths and limitations explicitly described and discussed |
| Is the manuscript well-written and accessible? | Adherence to format, additional details in appendix, audience-appropriate |
| Red flags | |
| Is study mis-described as grounded theory? | |
| Is study jargon-filled? | |
| Are data over-interpreted? | |
| Is analysis superficial? | |

## Appendix H: A priori codes adapted from Hudson's conceptual model of family caregivers for palliative care

| | |
|---|---|
| Event | Change in environment or patient status, e.g. new information, worsening of symptoms, return home from hospital |
| Appraisal | Determining whether event is relevant to caregiver or patient's wellbeing |
| Threat | Event poses a threat to patient or caregiver wellbeing that may be outside of caregiver's capacity to address |
| Challenge | Event poses a potentially surmountable obstacle within caregiver's capacity |
| Harm | Event leads to direct harm to patient or caregiver |
| Benign | Event is unlikely to change patient or caregiver status or may improve it |
| Irrelevant | Event has no bearing on patient or caregiver status |
| Coping | |
| Problem-focused coping | Acting on oneself or the environment, such as seeking information |
| Emotion-focused coping | Changing the relationship to the environment, or changing the relational meaning of the experience to avoid stress |
| Event Outcome | |
| Favourable resolution | Outcome is consistent with goals and values |
| Unfavourable resolution | Outcome is contrary to goals and values, such as harm |
| No resolution | Situation persists without opportunity for change |
| Emotion Outcome | |
| Positive emotion | Favourable resolution leads to satisfaction, end of coping |
| Distress | Unfavourable resolution of event leads to distress |
| Meaning-based coping | Unfavourable or no resolution leads to adapting one's mental state to be able to respond to an event |
| Positive reappraisal | Finding meaning in the event based on beliefs and values |
| Revised goals | Adjusting goals for situation to obtain control |
| Spiritual beliefs | Activating spiritual beliefs to fuel emotion- or problem-based functions |
| Positive events | A satisfactory outcome to the event leads to positive appraisal |
| Variables | |
| Preparedness | How ready the caregiver perceives being, regardless of actual skill or knowledge |
| Mastery | Sense of control and enhanced self-esteem through overcoming a stressor, development of new abilities, very broadly (not task-specific) |
| Competence | Perception of self as adequate at caregiving specifically |
| Self-efficacy | Belief in one's own ability to manage a situation. Not an inherent trait but event- and task-specific |
| Anxiety, depression and distress | Negative psychological effects of ongoing caregiving demands |
| Social support | Interactions with friends, family, coworkers. Can be positive or negative, or absent. |

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| Information | Seeking information to assess problems and solutions. Successful information seeking facilitates more effective coping. |
| Rewards | Satisfaction, positive emotional gains from caregiving, such as receiving love from patient, seeing patient content, feeling accomplished |
| Meaningfulness | Caregiver sees role as worthwhile investment or challenge |
| Positive emotions | Feelings of happiness, satisfaction, recognition as opposed to stress |
| Optimism | Inherent trait that buffers caregiver against strains of caregiving |
| Mutuality | Gratitude and meaning and idea of reciprocity in relationship with patient, closeness |
| Respite | Activities or interactions outside of caregiving that reduce stress and allow caregiver to recognise their own needs and interests |
| Cultural factors | Expectations about familial roles that shape expectations of caregiving and influence stress and coping (e.g. duty or honour to care for spouse or parent) |
| Caregiver burden and health | Physical, emotional, psychological, financial, or social problems related to caregiving, e.g. lack of sleep, numbed emotions, isolation |
| Choice and commitment | Making a conscious choice to take on caregiving role |
| Patient's disease, dependency, and illness duration | Patient's physical needs, psychological aspects of illness, and own recognition and outlook on illness |
| Caregiver age, gender, SES | Unclear but possible relationships in response to caregiving based on relationship status, age (physical ability), economics. |
| | |
| Additional codes | |
| External influences | Legal, economic, or other structural factors that shape the environment in which care is provided overall and the caregiver's options for providing care (e.g. insurance, sick leave) |
| Grief | Anticipatory or posthumous grieving |

## Appendix I: Articles included in end-of-life caregiving systematic review

| | Author, Country | Number of caregivers, patient condition | Key findings/themes | Quality assessment |
|---|---|---|---|---|
| 1 | Angelo, et al, 2014, New Zealand | 6, not specified | • Food<br>• Spirituality<br>• Family involvement | Strong |
| 2 | Aoun, et al, 20212, Australian | 16, MND | • The work of MND caregiving<br>• Change from spouse to carer<br>• A series of losses<br>• Coping mechanisms<br>• Supportive and palliative care | Self-selecting participants, no reflexivity |
| 3 | Bentley, et al, 2016, Australia | 12, MND | • Accessing appropriate supports<br>• Accessing information<br>• Feeling prepared | Self-selecting participants, no reflexivity |
| 4 | Carlander, et al, 2011, Sweden | 10, not specified | • Challenged ideals<br>• Stretched limits<br>• Interdependency | Strong |
| 5 | Cipolletta, et al, 2015, Italy | 13, MND | • Meaning of MND<br>• Family relationships<br>• Healthcare context | Scope not solely end of life |
| 6 | Clukey, 2007, USA | 22, cancer, heart disease, COPD, hepatitis | • Presence<br>• Anticipatory grief and mourning<br>• Role of hospice | Strong |

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| 7 | Clukey, 2008, USA | 9, not specified | Processes of anticipated mourning:<br>• Realisation<br>• Caretaking<br>• Presence<br>• Finding meaning<br>• Transitioning<br>Characteristics of anticipated mourning:<br>• Having a common knowledge<br>• Acknowledging terminal status<br>• Sharing<br>• Attending to business<br>• Changed relationship | Analysis method not clearly described, reflexive |
| 8 | Coristine, et al, 2003, Canada | 18, breast cancer | • Assuming the caregiving role<br>• Putting caregiving for the patient with advanced breast cancer in context<br>• Care tasks over time<br>• Understanding and managing the patient's medical needs<br>• Medical management during the terminal stages<br>• Emotions and their consequences to the patient–caregiver relationship. | No reflexivity |
| 9 | Dobrina, et al, 2016, Italy | 114, cancer | • Remaining attached to my life<br>• Detach myself from life, immediately<br>• Dealing with the dying process<br>• Starting to think of life without me | Strong; themes combine caregivers and patients |
| 10 | Dumont, et al, 2008, Canada | 18, cancer | • Characteristics of caregiver and patient<br>• Symptoms of illness<br>• Relational context<br>• Social and professional support<br>• Circumstances surrounding death | No reflexivity |
| 11 | Fisker, et al, 2007, Denmark | 8, not specified | • Shared grief<br>• Structural disintegration in time and space and primary needs<br>• Lifelines and supports<br>• Viable grief | Single site, PI is director |

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| 12 | Glass, 2016, USA | 4, Alzheimer’s | • Consequences of site of death<br>• Challenges of caring for individuals with dementia<br>• Navigating the healthcare system<br>• Hospice use<br>• Support and information | Convenience sampling, lack of diversity |
| 13 | Grbich, et al, 2001, Australia | 12, cancer | • Lack of information; ineffective communication with health professionals<br>• Inadequate emotional support<br>• Need for assistance with physical care and household tasks<br>• Support for caregiver health and wellbeing<br>• Financial issues | Recruitment poorly defined |
| 14 | Hasson, et al, 2010, Northern Ireland | 15, Parkinson’s | • Carers’ role and burden<br>• Palliative care<br>• Bereavement<br>• Access to health and social services | Informal recruitment |
| 15 | Hasson, et al, 2009, Northern Ireland | 9, COPD | • Impact of caring experience<br>• Lack of support services<br>• End-of-life and bereavement support | No reflexivity |
| 16 | Hughes, 2015, Australia | 28, not specified | Strengths in caregiving: courage, determination, acceptance, humour, empathy | Strong |
| 17 | Johnson, 2003, Australia | 1, not specified | Reflection on roles of patient and family caregiver | Author’s experience as narrative |

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| 18 | Kalnins, 2006, Latvia | 18, cancer, stroke, heart disease | • Disruption of life patterns<br>• Taking on the caregiver role<br>• Developing new patterns and learning caregiving skills<br>• Engaging with the patient in preparation for dying | No reflexivity |
| 19 | Linderholm, et al, 2010, Sweden | 14, cancer | • Becoming a carer<br>• Being a carer<br>• Not being a carer anymore | Strong |
| 20 | Lyckhage, et al, 2013, Sweden | 6, not specified | • When illness gets a grip on everyday life<br>• Home stands for sovereign value and health<br>• Encountering caring and uncaring in relation to others<br>• An existential break in relation to self<br>• Hospital is the good illusion<br>• Confronting the sick body<br>• Being in liminality | Note: not all patients had died |
| 21 | Mangan, et al, 2003, USA | 15, cancer | Problems:<br>• Medical care<br>• Quality of life<br>• Unhelpful help from others | No reflexivity |
| 22 | Mohammed, et al, 2018, Canada | 61, cancer | • Taking charge<br>• Navigating the system<br>• Engaging with professional caregivers<br>• Preparing for death<br>• Managing after death | Strong |

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|---|---|---|---|---|
| 23 | Mori, et al, 2012, Japan | 34, cancer | Caregiver perceptions of experience in terms of care given and relationship with patient | Location of caregiving not clearly stated |
| 24 | Payne, et al, 2015 England | 59, cancer, other | • Decision-making processes in managing end of life medication at home<br>• Managing end of life medication at home: concerns and rewards | Strong |
| 25 | Robinson, et al, 2017, Canada | 29, cancer | • Context of providing care<br>• Supportive antecedents to providing care at home<br>• Determination to provide care at home<br>• Enabled determination | Strong |
| 26 | Sheehy-Skeffington, et al, 2014, Ireland | 16, cancer, heart failure | • Issues with administration of medication<br>• Use of syringe drivers<br>• Use of medications as needed for symptom control<br>• Other issues with managing medications | Reviewers not specified |
| 27 | Sinding, 2003, Canada | 12, breast cancer | • Imperatives of care<br>• Value of closeness<br>• Negotiating life and death | No limitations listed |
| 28 | Stajduhar, et al, 2013, Canada | 114, not specified | How family caregivers learn:<br>• Trial and error<br>• Active information seeking<br>• Application of previous knowledge or skill<br>• Guided by others | Data from previous studies; no limitations |

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| 29 | Stone, et al, 2012, USA | 35, lung cancer | - Situational influences on communication<br>- Relational influences on communication<br>- Managing communication challenges | No reflexivity |
| 30 | Strang, et al, 2003, Canada | 15, cancer | Coping with the caregiving experience: facilitating and interfering factors | No limitations noted |
| 31 | Thomas, et al, 2018, England | 30, cancer, other | Caregivers' relevant background worries | No reflexivity |
| 32 | Totman, et al, 2015, England | 15, cancer | - Responsibility<br>- Isolation<br>- Death<br>- Meaningfulness | Strong |
| 33 | Turner, et al, 2016, England | 17, cancer, other | - Willingness to care<br>- Ability to care | Secondary data |
| 34 | Wong, et al, 2009, Australia | 23, cancer | - Discovering strength<br>- The relationship<br>- Personal growth<br>- Reflections on positive aspects of caring | Strong |

## Appendix J: Articles included in hastened death systematic review

| | Author, year, country | Number of caregivers, patient condition | Key findings/themes | Quality assessment |
|---|---|---|---|---|
| 35 | Albert, et al, 2005, USA | 80, MND | Patients acting on wish to die is more common when family are supportive | Analysis method not well described, no reflexivity |
| 36 | Back, et al, 2002, USA | 35, cancer, AIDS, neurologic, other | Patients and family members value clinicians':<br>• Openness to discussion about AID<br>• Expertise in dealing with the dying process<br>• Maintenance of therapeutic relationship even when patient and clinician disagree about AID | Strong |
| 37 | Buchbinder, 2018, USA | 19, not specified | Caregivers provide emotional and instrumental support for AID, including support for preparation, ingestion, waiting for death, and after death | Strong |
| 38 | Buchbinder, et al, 2018, USA | 34, cancer, MND | Orchestrating AID results in social dependency and creates collaboration between the patient and caregiver | Described in other papers |
| 39 | Gamondi, et al, 2015, Switzerland | 11, not specified | • Moral dilemmas<br>• Isolation of families<br>• Management of secrecy associated with assisted suicide | Strong |
| 40 | Gamondi, et al, 2018, Switzerland | 11, cancer, AIDS, neurologic, other | Five stages of assisted suicide preparation:<br>• Contemplation<br>• Gaining acceptance<br>• Gaining permission<br>• Organisation<br>• Aftermath | Strong |

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| 41 | Georges, et al, 2007, Netherlands | 87, cancer, MND | Caregivers felt AID contributed to patients’ quality of life by preventing suffering | Recruitment at MD discretion, primarily quantitative analysis of interviews |
| 42 | Holmes, et al, 2018, Canada | 18, cancer, organ failure, neurologic | • Caregivers were eventually supportive of patients’ interest in AID<br>• Helping prepare for AID<br>• Death was peaceful<br>• AID has some advantages over natural death | Strong |
| 43 | Jansen-Van Der Weide, et al, 2009, Netherlands | 86, cancer, other | Caregivers don’t perceive visits consulting physicians as burdensome to patients seeking AID | Recruitment at MD discretion, primarily quantitative analysis of interviews |
| 44 | Snijdewind, et al, 2014, Netherlands | 26, cancer, old age, neurologic | AID involves decision-making among physician, patient, and relatives | Recruitment at MD discretion, reflexive |
| 45 | Starks, et al, 2007, USA | 48, not specified | • Becoming a caregiver<br>• Taking care<br>• Midwifing the death<br>• Taking the next step | Strong |