Dying on One's Own Terms:
Access to Care, Timing of Death, and Effects on Family Members

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Abstract

Dying on One's Own Terms: Access to Care, Timing of Death, and Effects on Family Members

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Dying on one's own terms involves coordination across the personal, social, cultural, political, economic, and physical environments of dying persons, their loved ones, and care providers. It is influenced by cultural values, spiritual beliefs, and perceptions of the dying person's illness trajectory. The three papers in this dissertation address different combinations of these contextual factors that affect the feasibility of dying on one's own terms.

Paper 1, a secondary analysis of the Medical Expenditure Panel Survey, evaluates policy changes in the Balanced Budget Act of 1997 (BBA 97) on home care utilization at the end of life. Results showed that home care access fell after implementation of the BBA 97. However, those with more functional impairments and less support in the home were both more likely to receive care and receive more days of service.

The "Insights into Hastened Deaths" study provided qualitative data for papers 2 and 3. Paper 2 examines the timing and circumstances of hastened deaths. Twenty-six patients hastened their death at different points in time along their trajectory of illness. Those with an estimated prognosis of <1 week were 'dying and done,' having experienced a final functional loss that signaled the end. Those with <1 month were 'dying, but not fast enough.' Those with 1-6 months saw a 'looming crisis' on their horizon that would prohibit following through with their plans. The patients with >6 months were 'not recognized by others as dying, but suffering just the same.'

Paper 3 illuminates the critical role of family members who participated in hastened deaths. Although families often felt isolated and ill-prepared for their role, they accepted different levels of responsibility: being present at the death, mixing and administering medications, and implementing back-up plans when complications occurred. The illegal environment created barriers to obtaining quality information, care, and support, leaving families on uncertain legal and moral ground.

True choices at the end of life require sophistication, organization and competence by dying persons, families and clinicians. Health care systems, laws and policies must change to promote continuity across settings and to remove barriers that hinder dying on one's own terms.

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Dedication

To all the study participants who shared their stories.

You have been some of my best teachers.

Chapter 1: Introduction

Dying on one's own terms requires communication, coordination, orchestration, and support between the dying person and his or her caregivers and care providers.[1-6] For most people, dying is a process that begins after periods of acute and/or chronic illness and functional decline. The dying process is a journey with many unknowns, including how it will unfold, how long it will take, what the dying person and his or her caregivers will be able to do along the way, and what will become of the person and/or the soul after death. While death is ultimately experienced in the first person singular, dying is a social process. Those who accompany the dying person on the journey to death include family, intimate friends, pets, business, spiritual, and social acquaintances, and health care providers. These companions share similar concerns with the dying person and have additional concerns of their own.[7-10]

Throughout the course of illness, the dying person and caregivers encounter many challenges that call for patience, understanding, options, guidance, negotiation, therapeutic trials, and accommodation. Several authors have written about the characteristics that patients, family members, and care providers attribute to a "good death." The common components related to facilitating a good death include pain and symptom management, having care providers with good communication skills, being prepared for the dying process (including knowing what to expect and what help will be available), having loved ones involved in care without imposing undue burden, taking care of unfinished business and saying good-bye, avoiding financial ruin, and having control over the place, process, and timing of death.[2-6, 11-15]

Health care systems need development and improvement

Palliative care programs are being developed around the country but few are well-established and well-funded.[16-19] The scarcity of programs and clinicians skilled in quality end-of-life care means that few of the components to assure good deaths are currently in place. A minority of health care institutions are effectively managing pain at the end of life.[20] The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) study showed that over half of the

people who died in study hospitals reported having moderate to severe pain the week before death.[21] Additional evidence of poor pain management is reflected by the report that an average of 42% of nursing home residents are in persistent pain.[20] The introduction of efforts to make pain the 5th vital sign has increased awareness of the problem, but there is still room for improvement.[22] There are clinically-effective therapies for other common symptoms at the end of life, including nausea, shortness of breath, fatigue, and constipation.[17] At issue is whether patients are working with clinicians who are trained in these skills. Currently, only about 1% of primary care and subspecialty physicians and full-time nurses are certified in palliative care.[20]

Communication skills are required

Good communications skills are very important to patients and families at the end of life.[2, 6, 14] While the final outcome is sure, the dying process is characterized by uncertainty. Patients need providers who are skilled listeners and who are open, culturally sensitive, and honest about what they know (and don't know), and about how the process might unfold.[14, 23] Some patients may not want to hear all the details related to their illness or may prefer to distance themselves from talking about dying for cultural reasons.[24-28] However, most want to be able to discuss their hopes and fears, wishes and expectations. The most skilled providers are those who can help patients hope for the best while preparing for the worst.[29] These skills are also in short supply, largely due to lack of training and providers' own discomfort with discussing death and dying.[16, 30-32]

Family involvement

Dying persons want their loved ones to be included in the process but worry about being a burden. There is ample evidence to demonstrate that caregiving can be burdensome in terms of time, energy, health status, social isolation, and missed or lost employment, and other economic and social opportunities. While many family members report positive and rewarding experiences related to their caregiving efforts, they also experience high rates of adverse health effects.[33-36] These are reported as high rates of fair to poor health status; high rates of stress-related illnesses including hypertension, anxiety and depression; increased rates of chronic conditions; and

lower health services use.[35-41] In addition, primary caregivers experience higher rates of mortality in the 1-2 years following the end of their caregiving, especially for older caregivers.[39, 42, 43] Caregiving is expensive, both in terms of out-of-pocket outlays for health care, as well as monetary loss from unpaid leave, missed promotions and career advancements due to time taken out of the career path for caregiving, and higher rates of unemployment.[36, 37, 40, 42, 44-47] Still, most families are willing to provide care for their loved ones. They understand their involvement to be a natural extension of their relationship with the dying person and an important expression of their emotional connection, cultural practices and filial responsibilities.[48-52] Caregivers also report growth and satisfaction as rewards for their efforts.[33, 44] It may exhaust them and they pay a price, but far more patients than family members describe this work as a burden.

Control over the dying process

Many dying persons want to have control over the place, process, and timing of death. When asked, over 75% of people say they would like to die at home, precisely because that is the place where they are most comfortable, can maintain a sense of self, be linked to a place that has memories and meaning, and can assert the most control over their dying process.[2, 4, 6, 20, 53-59] In spite of these stated wishes, only about 25% of people currently die at home; the majority of deaths occur in hospitals and long-term care facilities.[20] Institutional deaths decrease patient control over the process and timing of death, as they are organized primarily to meet the needs of health care providers, who in turn care for patients. Once patients move into institutional settings for care, they lose power and control and the ability to be valued as whole persons; the institutions often transform them into compromised bodies in need of caring, feeding, toileting, bathing and turning.[60] For patients who have relationships with providers in community settings, institutional care disrupts continuity of care. This undermines the possibilities to achieve a good death. Patients who die in hospitals and intensive care units are frequently cared for by providers they have not previously met. This discontinuity means that they cannot benefit from established relationships or earlier conversations regarding goals of care and treatment preferences. Under these circumstances, the dying process may be

prolonged and patients may receive many unnecessary and unwanted therapies as a result.[2, 9, 53, 61] In contrast, people who receive home care and hospice have the opportunity to develop care plans around the kitchen table with a team that stays with them throughout the dying process.[62] The ongoing contact engenders trust and allows patients and families to ask questions, explore options, and prepare for contingencies. This level of communication and trust facilitates managing the dying process in accordance with patient and family wishes.

Advance directives

Advance directives, including living wills and durable power of attorney for health care, are another mechanism that people use to assert some control over the dying process in institutional settings, at least to the extent that they can use them to express their preferences for life-sustaining treatments. Much work has gone into increasing access, availability, usability, and completion of advance directives. Efforts began in the mid-1970s with changes in state laws defining patients' rights to refuse unwanted medical treatments.[63-73] This was followed by research and interventions designed to improve the language and format for documenting preferences and to increase the use of advance directives in health care systems.[68, 74-85] Additional community-based initiatives were developed to educate the public and increase completion rates.[86-90] In spite of these efforts, only a minority of Americans complete advance directives. Even when they do, the directives are often ignored, over-ruled or get lost in transit to the hospital, where they would be of most use.[68, 78, 80, 91-96]

A recent critique of living wills outlines five ways in which these documents are untenable: (1) people must complete them, (2) they must accurately predict their future preferences for quality of life and life-sustaining treatments, (3) they must succinctly state these preferences, (4) the documents must be readily available for use when necessary, and (5) the people interpreting these documents must heed the written instructions.[97] The authors argue that these conditions are impossible to meet and that we should abandon this approach to extending autonomy at the end of life. They advocate continued use of proxy decision makers and also endorse the general shift in focus away from the legalistic documents toward the iterative process of

advance care planning, which emphasizes eliciting the goals of care over specific treatment preferences. With advance care planning, patients and families express their values for the process and outcomes, and care providers translate these into treatment options that match these goals.[98] In spite of the critique of living wills, there remains the need to document advance care planning discussions. One effort that has shown positive effects on the outcomes and processes of care is the Physician Orders for Life-Sustaining Treatment (POLST), a specific advance directive organized around goals of care. Evaluations of the POLST have demonstrated progress for both eliciting and complying with patient wishes.[82, 99, 100]

Definitions of 'good' deaths

The Institute of Medicine's Committee on End of Life Care defines a good death as "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards." A bad death is conversely described as one that is "characterized by needless suffering, dishonoring of patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended."[1, p. 25] Currently, our health care system is arguably designed to facilitate more bad deaths than good ones. Patients and families have legitimate concerns about having what it takes to organize a death on one's own terms. In our study of "Insights into Hastened Death," participants described the following factors as influential in their active pursuit of a hastened death: increasing symptoms, functional losses, negative side-effects of pain medication, loss of their ability to partake in meaningful activities, wanting to control the circumstances of dying, long-standing beliefs in favor of hastened death, and fears about the future (including fears about future quality of life and dying that were often informed by negative past experiences with dying, and a fear of being a burden on others).[6, 101] As motivating factors for interest in a hastened death, such issues have been documented by other authors as well.[5, 6, 102-108]

Good palliative care can address many, but not all of these issues: there will be a small number of patients who will continue to view assisted death as a desirable choice and as the ultimate way to assert their rights to dying on their own terms.

Some will decide that hospice and palliative care are not for them, or that some of the choices offered by palliative care, such as the trade-off between pain management and cognitive function, are unacceptable. In addition, some issues, such as the desire to control the dying process and the suffering associated with a loss of functional status and sense of self, are not easily addressed even by the most capable health care providers.

Conceptual Framework for Dying on One's Own Terms

To examine dying on one's own terms, I am using a conceptual framework that embraces a biopsychosocial model, situating the "work" of dying in the context of the personal, social, cultural, political, economic, and physical environments of dying persons, their loved ones, and care providers (Figure 1).[49, 50, 109, 110]

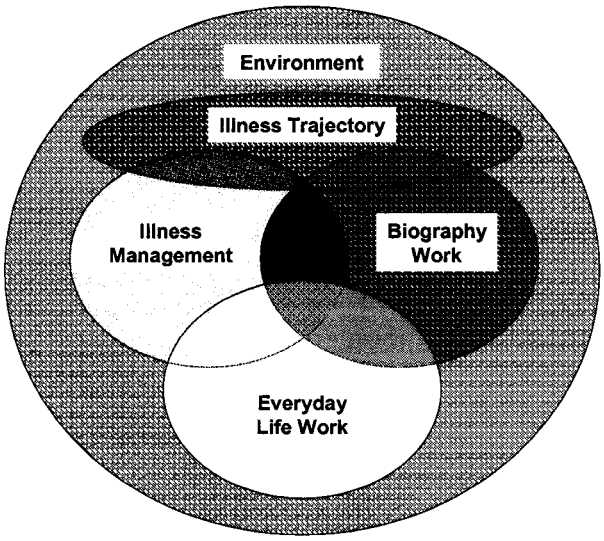

Figure 1: Conceptual Framework for Dying on One's Own Terms

Dying on one's own terms requires a confluence of factors from each of these domains. In addition, the dying person and those closely involved with him or her will each perceive and emphasize different domains as most important to a good death and dying process. As studies have shown, it is a combination of many circumstances across domains that will determine whether the dying person can realize the ideal terms of his or her death.[15, 53, 109, 111]

Environment

The political environment influences the dying process by shaping policies that govern access to and financing of health and social services, and through laws that determine which options people have to control the timing and circumstances of death (such as advance directives statutes and the legal status of physician-assisted suicide). The social environment includes the people in both formal and informal networks who are available to support the dying person and his or her caregivers.

The cultural environment provides the context for patients and families to make meaning out of illness, suffering, and filial responsibilities. It also influences what customs and mores are appropriate to display. Cultural and belief systems shape the explanatory models of illness and treatment, preferences for disclosure of information and decision making, the families' role in caregiving, and how dying persons and their family members perceive and define the terms of a good death.[24-27, 112, 113] Differences in cultural beliefs also account for variations in how families use health care at the end of life, including hospice, home care and other supportive services.[112, 114] For example, commitments to provide care for loved ones at home vary across cultures and across generations. There is also concern that as the baby boom generation ages, their history of consumption and expectations for service will continue and further strain already-limited health care resources.[115]

The economic environment includes both the resources available at a societal level as well as at the level of the dying person and caregivers. Finally, the physical environment encompasses where the ill person lives and receives care over the illness trajectory. Patients often move across different environments during the dying process either because of their own increasing needs and/or the inability of their caregivers to care for them.[116]

Illness trajectory

The illness trajectory reflects both the facts of how the illness progresses as well as a synopsis of the mental constructs of patients, loved ones and care providers. It is influenced by clinical information and beliefs about body performance and prognosis, will to live, and functional status. How the trajectory unfolds over time

and the decisions made about it are also affected by the different individuals' awareness and acceptance of this information, as well as their hopes, fears, expectations and wishes for the future.[109, 117-119]

Transitions across the illness trajectory are often subtle. How and when the transition between living with chronic illness and dying of chronic illness is noticed and handled differs between the dying person and caregivers. Glaser and Strauss described four states of awareness of dying (closed, suspected, mutual pretense, and open awareness), that each have different consequences for how patients, families and care providers manage and cope with the dying process.[117] Closed awareness is when the person has no idea or no desire to know that s/he is dying. Suspected awareness is when a person suspects s/he is dying because of cues from the body and/or environment (including hints from care providers), but no one has explicitly addressed the issue of dying. Mutual pretense awareness is when the person and those around him or her, either family or health care providers, all know that s/he is dying yet all deliberately refrain from any open discussions acknowledging this fact. Finally, open awareness is when everyone accepts that the person is dying and is able to speak openly about it.

Awareness contexts differ for patients and families, often with families being more aware of or acknowledging the patient's imminent death due to observations of functional decline and conversations with health care providers.[117, 120] In the mid-1960's, the majority of patients in the U.S. died with closed awareness.[117, 118] The current trend is toward more open awareness, as norms in medicine have changed toward more truth-telling and disclosure of diagnostic and prognostic information. This trend is generally viewed positively, as it gives patients and families the time to prepare for the end of life and engage in closure tasks.[118, 119, 121, 122] However, preferences for truth-telling and open discussions about death and dying are not universally endorsed.[113] For example, in some Asian and Hispanic cultures, family decision making and sheltering patients from information about terminal prognoses are values that often guide end-of-life care.[28, 123, 124] While this is not universally true, it points to the need for cultural awareness and sensitivity to different communication needs and styles. It also suggests the need to elicit preferred styles of decision-

making by individuals and families and to try to understand their different awareness contexts.

Facilitating a death on one's terms requires understanding and negotiating these different awareness states. In some cases, the ideal death occurs when the dying person and/or his or her family members remain in closed awareness to shield themselves from unwelcome thoughts.[26, 117, 118, 125] In other cases, orchestrating specific outcomes, such as dying at home or at the time of one's choosing, requires open discussions between the dying person and caregivers so that all parties can focus on realizing the dying person's last set of wishes and goals.[58, 126]

Illness management

Illness management begins before diagnosis with the first perception of symptoms and the decision to seek care. It includes all that is required to diagnosis the illness, develop treatment plans and manage symptoms, provide daily personal care, restore and/or maintain function, preserve energy, and prevent decline and acute events or exacerbations of the underlying disease process.[50, 52, 109] As the dying process continues, this also includes advance care planning and exploring goals of care and treatment preferences in the event of decisional incapacity. Illness management plays a key role in achieving a good death, especially with respect to controlling pain and symptoms and managing functional losses. Caregivers have an important role in this process. They often have the dual task of managing not only their loved one's illness, but also their own, either because of their own history of chronic illness or because new health problems develop in response to the stress of caregiving.[35, 40, 41, 127] Their health and well-being is also important for achieving a desired death as dying persons rely on them for personal care, love, and emotional, spiritual, financial, and physical support.

Biography work

Biography work includes an exploration of the effects of the illness and dying process on an individual's sense of self.[128-130] Changes in functional status and the ability to carry out previous tasks and roles raise questions such as "Who am I?" "What is my role, both within my family and in society?" "What can I do to contribute

and find meaning and purpose in my life?" Dying on one's own terms means coming to terms—perhaps through acceptance, denial, or both—with the end of a life and completing outstanding tasks. As death approaches, biography work involves life review, saying good-bye and working to be at peace with one's life and accomplishments, forgiving mistakes, releasing regrets, and coping with lasting fears of death. It is also a time for spirituality, growth, and transcendence.[121, 128-130] Caregivers must deal with these issues as well, as they assume the tasks and roles of their loved one and contemplate a future without this person.

Everyday life work

Everyday work includes all the instrumental activities of daily living within the household, such as shopping, housekeeping, and cooking, as well as maintaining the responsibilities of a job for those who are employed outside the home.[40, 110] Everyday work also includes the work involved in maintaining and nurturing relationships: between spouses, between parents and children, and between friends and acquaintances. Finally, this work includes the activities required for healthy self care, such as participating in recreational, social and spiritual activities. As dying persons become more frail, they give up many of their everyday work tasks, shifting the responsibility to others.[109] Relinquishing everyday work responsibilities in combination with increasing illness management needs are signs that the dying person is progressing toward death on the illness trajectory.

Dissertation papers

The three papers included in this dissertation (chapters 2-4) each address a different subset of the possible interactions amongst the domains in this conceptual model. Chapter 2 examines characteristics of the policy environment that affect utilization of home care services at the end of life, particularly the effect of the Balanced Budget Act of 1997, which was designed to reduce home care expenditures. Chapter 3 discusses how the timing and circumstances of hastened death are influenced by the dying person's illness trajectory, illness management, biography work, and the legal environment. Chapter 4 explores how family members are affected by their participation in planning and implementing a loved one's

hastened death. In the summary chapter, I discuss how the findings from these papers relate to the conceptual model of dying on one's own terms and the literature on death and dying. I also discuss the implications for policy and practice.

Chapter 2: Effects of the Balanced Budget Act of 1997 on Home Care Use at the End of Life: Evidence from MEPS

Home care provides post-acute hospitalization services and also serves as a substitute for long-term care, particularly for patients who have functional limitations, have limited family or community support, but are still somewhat independent.[131-133] Home care use is a function of need for assistance, availability of caregivers, age, marital status, gender, recent hospitalization, income, and insurance status.[131, 133-143] Between 1987 and 1996, Medicare expanded coverage for home care services, in large part as an alternative to care provided in hospitals and long-term care facilities. Users of home health services during this time typically needed either follow-up care after hospitalization, close monitoring and management of medically complex, serious illness, or acute care due to exacerbations of their chronic conditions. Taken together, these users of home care were typically ill, frail, and had complex medical needs and functional impairments.[144]

Home care utilization more than tripled during this ten-year period, with the number of annual visits growing from 23 to 79. This growth was accompanied by compound annual increases in expenditures of over 25% per year.[145, 146] The fee-for-service organizational and financing structure also encouraged growth: the numbers of agencies participating in the Medicare home care market increased three-fold from 2,900 to 9,000.[147] In response, Congress made significant changes to the Medicare home care program in the Balanced Budget Act of 1997 (BBA 97) with the specific intent to constrain utilization and expenditures.[144, 148, 149]

Previous studies have documented differential access to home care based on insurance type and demographic characteristics.[137-139, 141, 150-155] Reviews of Medicare claims data show that utilization of home care in general has been reduced under the BBA 97.[148, 149, 156] However, these studies did not examine the effects of the BBA 97 on home care use at the end of life, nor in populations who receive home care services paid for by types of insurance other than Medicare or Medicaid. The objectives of this analysis are to examine: (1) which characteristics predict any home care use at the end of life; (2) among those who receive any home care, which

factors are associated with greater use; and (3) whether home care use declined after enactment of the BBA 97.

Methods

Data sources and extraction methods

The Medical Expenditure Panel Survey (MEPS) samples a subset of non-institutionalized persons living in households enrolled in the National Health Interview Survey. MEPS collects data on health services use, demographics, and insurance coverage. MEPS households are sampled and followed longitudinally for a series of up to 5 rounds over approximately two years. The survey rounds overlap across time, thus producing a longitudinal, representative sample of US households. We used data from the MEPS household, medical conditions, hospital, outpatient, and office visit component files for the panel years 1996-2000.

Study sample

The sample included all persons age 18 and older who enrolled in a panel between 1996 and 2000 and died at home, in the hospital, or in other non-institutional settings during any of the rounds between 1996 and 2001. For each person identified, data were merged across rounds from the time of entry into the panel until the round when the person died. For confidentiality reasons, MEPS does not report dates of death. Thus, time in the panel was estimated as the difference between the date of entry into the first round and the end date reported for the last round.

Analytic methods

We used descriptive statistics to examine the characteristics of the study population and the distributions of the data. Home care use was defined as visits by one or more home care or hospice provider(s) on a given day. Hospice care is included but not analyzed separately as 65% of the sample had missing data for this variable: only 4% were coded as having received hospice. Home care days, the main outcome variable, follow a Poisson count distribution with 61% of the sample receiving no home care services. We examined multiple Poisson regression models and determined that a zero-inflated negative binomial (ZINB) model gave the best fit

for the data. Poisson regression relies on the assumption that the conditional mean and the conditional variance of the outcome variable are equal—a fairly restrictive assumption. The ZINB regression adjusts the conditional variance to correct for over-dispersion of the distribution due to a high frequency of zero values in the data set and aligns the variance with the mean. A ZINB model produces two levels of results: the first includes the entire sample and estimates the odds ratios (OR) for the variables that are associated with any use of home care. The second produces incidence rate ratios (IRR) for the variables, which can be interpreted as the percent increase or decrease in the number of days of home care received amongst the sub-sample that had one or more days of care.

The main predictor of interest was insurance type, coded as dummy variables for private insurance, Medicaid, Medicare, dual insurance of Medicaid and Medicare, CHAMPUS/VA, or no insurance. Other covariates in the model included demographic characteristics, self-reports of any limitations in functioning (activities of daily living or instrumental activities of daily living), whether the person reported having one or more priority conditions (defined in MEPS as high cost, life-threatening illnesses, such as heart disease, cancer, diabetes, and HIV/AIDS, as well as chronic illnesses including Alzheimer's disease and arthritis), number of hospital stays and outpatient visits, number of co-morbid conditions, and number of weeks in the MEPS panel. The number of co-morbid conditions was computed using an algorithm that groups chronic illnesses into 17 categories based on their ICD-9 codes. Using this technique, persons in this sample reported 15 different conditions with the number of co-morbid conditions reported ranging from 0-7. The final model was adjusted using the population weights from the MEPS data set. All analyses were conducted using Stata 7.0.[157]

We conducted a secondary analysis to examine whether there may be a spillover effect of the BBA 97 on insurance types other than Medicare. In this analysis, we computed additional interaction variables between year of entry in MEPS in 2000 (significant in the ZINB analyses) with Medicare and with dual Medicare and Medicaid insurance.

Results

Study sample

The sample included 886 persons. The number of persons who died in each year of entry to the MEPS panel was as follows: 235 in 1996, 205 in 1997, 137 in 1998, 173 in 1999 and 136 in 2000. The average time in the panel was 60 weeks (s.d. 39 weeks), with a range of .4-144 weeks. Table 1.1 reports the characteristics of the sample. About a third of the sample was younger than age 65 and 43% had private insurance. In the analyses comparing those who had no home care days (N=544) to those who received one or more days of home care (N=342), persons who received any home care were significantly older (mean age 74.6 vs. 68.6; $p<0.0001$), and had nearly twice as many hospitalizations and functional limitations.

Table 1.1: Characteristics of the MEPS Sample by Home Care Utilization

	No Home Care (N=544; 61%)	Some Home Care (≥1 visit)* (N=342; 39%)	Total (N=886; 100%)	P-value
Sex, %				0.000
Female	47.1%	59.1%	51.7%	
Male	52.9%	40.9%	48.3%	
Marital status, %				0.108
Married	46.1%	40.6%	44.1%	
Not married	53.9%	59.4%	55.9%	
Race, %				0.371
White	77.9%	82.7%	79.8%	
Black	19.1%	15.2%	17.6%	
Asian/Pacific Isle	1.6%	1.2%	1.5%	
Native American	1.3%	0.9%	1.1%	
Region, %				0.677
Northeast	23.3%	19.9%	21.9%	
Midwest	20.8%	22.2%	21.3%	
South	39.7%	40.1%	39.8%	
West	16.3%	17.8%	16.9%	
Age categories, %				0.000
18-64	36.2%	19.6%	29.8%	
65-74	19.8%	21.9%	20.7%	
75-84	27.8%	31.6%	29.2%	
85+	16.2%	26.9%	20.3%	
Income, mean (s.d.)	12,615 (12,076)	12,091 (9,928)	12,413 (11,292)	0.000
Years of education, mean (s.d.)	10.8 (3.4)	10.3 (3.6)	10.6 (3.5)	0.355

Table 1.1 continued

	No Home Care (N=544; 61%)	Some Home Care (≥1 visit)* (N=342; 39%)	Total (N=886; 100%)	P-value
Year of entry into MEPS, %				0.001
1996	24.8%	29.2%	26.5%	
1997	19.7%	28.7%	23.1%	
1998	16.4%	14.0%	15.5%	
1999	21.1%	17.0%	19.5%	
2000	18.0%	11.1%	15.4%	
Insurance Type				0.000
Private	44.9%	39.5%	42.8%	
Medicare	27.0%	28.6%	27.7%	
Medicaid & Medicare (dual coverage)	11.4%	22.5%	15.7%	
Medicaid	6.4%	5.6%	6.1%	
CHAMPUS/VA	2.9%	0.9%	2.1%	
No insurance	7.4%	2.9%	5.6%	
Health Status				
Co-morbid conditions, mean (sd)	1.4 (1.3)	1.8 (1.4)	1.6 (1.3)	0.111
Functional limitations, mean (sd)	1.9 (2.4)	3.8 (2.7)	2.6 (2.7)	0.014
Reported ≥ 1 priority condition, %	70.8%	78.4%	73.7%	0.012
Health Care Utilization				
Days of home care, mean (sd)	0.0 (0.0)	94.8 (114.8)	36.6 (84.9)	0.000
Hospitalizations, mean (sd)	1.2 (1.6)	2.1 (2.0)	1.5 (1.8)	0.000
Outpatient visits, mean (sd)	11.3 (22.5)	13.4 (22.1)	12.1 (20.3)	0.684

* Includes hospice

Predictors of home care use

Table 1.2 reports the mean number of days of home care use amongst those who received any days of care. These data show that the percent of the sample receiving any home care decreased by 35% between 1996 and 2000 and that there was a trend toward fewer days of care over time. Table 1.3 reports the results from the multivariate analyses. These results demonstrate that insurance type had no effect on either accessing home care or on the number of days of home care received. Increased hospitalizations and more functional limitations were associated with increased odds of receiving home care (OR=1.59 and OR=1.30, respectively).

However, entering the MEPS panel in the year 2000 (compared with 1996, the year prior to the BBA 97) decreased the odds of receiving home care by more than half (OR=0.43). This trend began in 1998 and 1999, concurrent with implementation of the BBA 97.

Table 1.2: Average Number of Home Care Days by Year of Entry into MEPS

Year of Entry	N	%*	Mean	Std. Dev.	P-value
1996	100	43	104.4	113.5	
1997	98	48	100.0	122.8	
1998	48	35	83.9	107.5	
1999	58	34	79.7	89.7	
2000	38	28	92.8	139.8	
Total	342	39	94.8	114.8	0.033

* Percent of the sample in that year receiving any home care

Table 1.3: Predictors of Any Home Care Use (N=886)

	Odds Ratio	P-value	95% Confidence interval		Incidence Rate Ratio	P-value	95% Confidence interval	
Insurance Type								
M & M*	1.32	0.4170	0.67	2.60	1.38	0.0940	0.95	2.00
Medicaid	1.58	0.3700	0.58	4.26	1.04	0.9210	0.46	2.35
Medicare	0.82	0.4600	0.49	1.39	1.24	0.2450	0.86	1.78
CHAMPUS/VA	0.82	0.7740	0.22	3.14	1.13	0.7740	0.50	2.56
No insurance	1.05	0.9190	0.39	2.84	0.60	0.2170	0.26	1.35
Other covariates								
N hospitalizations	**1.59**	**0.0010**	**1.20**	**2.09**	**0.91**	**0.0150**	**0.84**	**0.98**
N outpatient visits	1.00	0.9570	0.99	1.01	1.00	0.3710	0.99	1.00
Functional limitations	**1.30**	**0.0000**	**1.18**	**1.43**	**1.18**	**0.0000**	**1.11**	**1.27**
N chronic conditions	1.04	0.7070	0.85	1.26	0.99	0.9170	0.87	1.14
Priority Conditions	1.36	0.2900	0.77	2.40	0.98	0.9260	0.63	1.53
MEPS entry year: 1997	1.17	0.6310	0.62	2.23	1.00	0.9910	0.68	1.49
MEPS entry year: 1998	0.76	0.4560	0.37	1.57	0.62	0.0750	0.37	1.05
MEPS entry year: 1999	0.74	0.3290	0.40	1.36	1.20	0.4170	0.77	1.87
MEPS entry year: 2000	**0.43**	**0.0140**	**0.22**	**0.84**	0.69	0.1550	0.42	1.15
Married	1.13	0.5900	0.72	1.79	**0.58**	**0.0010**	**0.41**	**0.80**
Native American	0.45	0.5090	0.04	4.84	**0.29**	**0.0170**	**0.11**	**0.81**
Asian/Pacific Island	1.20	0.9260	0.02	58.06	0.32	0.1390	0.07	1.44
Black*	0.70	0.1830	0.42	1.18	0.71	0.0830	0.49	1.05
Female	1.08	0.8500	0.48	2.41	0.95	0.8810	0.51	1.78
Log Education	0.89	0.6270	0.54	1.44	1.37	0.0540	1.00	1.88
Log Income	0.92	0.0670	0.84	1.01	1.04	0.3140	0.96	1.12
Weeks in panel	1.00	0.4490	0.99	1.00	1.00	0.1340	1.00	1.01

Table 1.3 continued

	Odds Ratio	P-value	95% Confidence interval		Incidence Rate Ratio	P-value	95% Confidence interval	
Age 65-74	2.10	0.1110	0.84	5.20	0.70	0.3070	0.35	1.39
Age 75-84	1.87	0.1320	0.83	4.25	0.88	0.7390	0.41	1.89
Age 85+	2.34	0.0760	0.91	5.97	1.44	0.4230	0.59	3.55
Age 65-74 x female	0.76	0.6540	0.23	2.51	1.44	0.3620	0.66	3.15
Age 75-84 x female	1.37	0.5560	0.48	3.87	1.25	0.5890	0.56	2.77
Age 85+ x female	2.11	0.2530	0.59	7.63	0.56	0.2640	0.20	1.54
Northeast region	0.80	0.5020	0.41	1.54	0.91	0.6910	0.58	1.44
Midwest region	1.15	0.6760	0.59	2.25	0.88	0.5630	0.57	1.36
South region	0.88	0.6940	0.47	1.65	1.12	0.6240	0.72	1.74
Reside outside MSA	1.31	0.3550	0.74	2.30	1.27	0.2200	0.87	1.86
MSA data missing	1.26	0.4740	0.67	2.36	1.12	0.6390	0.70	1.78

* M&M = dual Medicare & Medicaid insurance

Amongst those who received any home care, more functional limitations increased the number of days of care by 18%. However, while more hospitalizations increased the odds of receiving any home care, they reduced the number of days of care received by about 10%. Being married also reduced days of care by 42%. In addition, people who identified as Native American received 71% fewer days of home care as compared with Whites, although these estimates are based on a small sample size (n=3) and thus should be interpreted with caution.

When the interaction terms between MEPS entry year 2000 and Medicare and dual insurance were included in the multivariate analyses, the overall results were similar with the exception that the effect of entry year 2000 was no longer significant (data not shown). This suggests that there was no spillover effect of the legislation on other insurance types.

Discussion

This study examined home care utilization in a nationally representative sample of non-institutionalized adults age 18 and older who died, to identify the factors associated with home care use at the end of life and to evaluate the effect of the BBA 97 on reducing access to home care services. These findings extend previously reported research by focusing on home care use at the end of life and in a mixed population with Medicare and non-Medicare insurance. Several authors have

reported that the BBA 97 effectively reduced access, quantity, and type of home care services amongst Medicare beneficiaries.[149, 156, 158] Our data support these findings, demonstrating that by 2000, the odds of receiving any home care at the end of life were reduced by more than half. In addition, our analyses suggest that there was no discernible spillover effect of the BBA 97 legislation to the non-Medicare population. Congress reported that many home care agencies went out of business as a result of the BBA 97, but that these closures were a reduction in over-supply and had no impact on Medicare beneficiaries.[158] The finding of no differences in access to home care or number of days of care by insurance type suggests that the non-Medicare populations also were not adversely affected by agency closures.

People at the end of life frequently have high needs for personal and skilled nursing care.[13, 137, 159] Consistent with the literature, poor health status (as measured by hospitalizations and functional limitations) was related to initiating home care.[136, 138, 140, 152] Those with more functional limitations also received 18% more days of care, which suggests that their care was congruent with need. However, those with more hospitalizations received fewer days of care. This may be due to more acute needs following hospitalization or may suggest that those referred to home care through sources other than hospitals were receiving care for chronic conditions. Conversely, since about 75% of deaths occur in hospitals, it may be that those with more hospitalizations died there, thus reducing the need for home care.[20]

Also consistent with the literature, our results show that those who were not married received more days of care than those with spouses, suggesting that home care is supplementing or substituting for informal care.[140] Of concern is the finding that Native Americans received 71% fewer days of care. This finding is worth further study to determine if this is due to differences in provision of care, cultural preferences or some other reason.

Several of our non-significant findings differ from other published reports. We found no differences in either access or number of days of care received by age, gender, geographic region or urban/rural location.[139, 141, 160, 161] The differences in our findings from those of previous research may be due to our specific focus on home care use at the end of life.

In addition, there are several important limitations of the MEPS data and this analysis. The MEPS sample includes over 10,000 representative U.S. households, yet because death is a relatively rare event, this analysis was based on a fairly small sample size of 886 adults. Of these, only 342 people had at least one day of home care. While all the participants in our study died, the amount of time in the MEPS data set varied from less than a week to 3 years. This analysis could be strengthened by focusing on utilization in the last 6 months of life. However, the total number of home care days was reported only by the round and not by date. It was not possible to map the data to the month within the round when home care services were used. Thus, we were only able to analyze total home care use, but the factors associated with any use are likely to differ over time. Additional studies are needed to determine how service needs at the end of life differ from general supportive services for adults with serious illness and functional limitations.

This analysis presents evidence that, consistent with the intent of the BBA 97, access to and number of days of home care services at the end of life were reduced for a diverse population of adult persons who died. MEPS data limit our ability to evaluate how this reduced access was related to the quality of end-of-life care for these persons. These results also suggest, however, that while overall access was restricted, services may be appropriately targeted to those with greater functional and social support needs. Persons with more functional impairments and less support in the home received more days of home care services.

Chapter 3: Why now? Timing and Circumstances of Hastened Deaths

For patients who express a serious interest in hastening their death, what are the conditions that signal that the day to die has arrived? What aspects of a patient's suffering trigger the move from interest in hastened death as an abstract option to the concrete action of taking lethal medications? These are questions that have yet to be fully explored in the literature. They are important questions for clinicians to consider, as there are legitimate concerns that patients may consider hastening their death because of unmet needs that might respond to therapeutic intervention.[162-165]

Several issues have been identified as motivators for interest in hastened death, including inadequate treatment for pain or other symptoms;[105, 163, 166-171] psychological issues such as depression and hopelessness;[103, 104, 167, 172-175] concerns about losses (including physical functioning, control, sense of community and sense of self/autonomy);[101, 102, 106, 108, 165, 169, 170, 176] and concerns about being a burden on others.[171, 177] Reports from Oregon suggest that patients who are seriously interested in hastened death are typically people who have been involved in decisions about their care and want to have a say about the timing and location of death.[177-180] Their interest in hastened death is one way for them to manage their dying process and gain reassurance that they may maintain some control over the many uncertainties posed by serious, life-threatening illness. As their illness progresses, patients gain experience regarding which losses they can accommodate to and which ones become increasingly unacceptable. Time and uncertainty about the future become forces that challenge patients to find the balance between not letting go too soon and not hanging on too long, lest their circumstances change and they cross a threshold where their lives become what they consider to be a fate worse than death.

The following analysis is from a descriptive qualitative interview study with patients and family members who were recruited because they had a serious interest in pursing a hastened death.[6, 101, 181] The objective of this analysis is to examine what circumstances led some patients to decide that the day to die had arrived and others to die of their illness. We examine these issues from several angles. One addresses the different places along the trajectory of illness decline and the kinds of suffering

associated with the decision to die at these different points in time. We also describe the situation of those who died of their illness and the factors that explain why they did not ultimately hasten their death. Finally, we discuss other issues related to the timing of death, including why some deaths were completed by patients alone and others included assistance from family members.

Methods

Participant recruitment and data collection

A detailed account of the recruitment and data collection methods is described elsewhere.[6] Briefly, we used intermediaries in Washington and Oregon states (such as Compassion in Dying, the Hemlock Society, hospice agencies, and grief counselors) that had current or previous contact with patients and families to recruit two participant cohorts. One included family members of persons who had already died (retrospective cohort). The other included patients and their family members (prospective cohort). We asked the intermediaries to distribute information statements to their clients who had expressed a serious interest in a hastened death. Interested participants called the study office and spoke with one of the investigators who explained the study procedures, answered questions, obtained verbal informed consent, enrolled participants, and collected demographic data.

We thus recruited 60 individuals from 35 families: 28 family members reporting on 23 patients in the retrospective cohort and 12 patients and 20 of their family members in the prospective cohort. We assigned a case number and code name for each family to maintain confidentiality. All contact information was destroyed upon completion of all interviews. We did not ask anyone to sign a consent form nor maintain any documents with identifying information to protect participants from any potential legal issues.

We conducted multiple, semi-structured interviews with patients and family members. All interviews were audio-taped and transcribed. All members of the multidisciplinary research team read the transcripts in their entirety, discussed them at weekly meetings, and generated follow-up questions for the interviewer (when appropriate). Members of the retrospective cohort were interviewed 1-2 times,

including one interview conducted at least 12 months after the patient had died. Members of the prospective cohort were interviewed at enrollment and at approximately 3-month intervals until the patient's death, and then again within 3 months of the patient's death to obtain the death narrative and the family member's reaction to the death. A final interview was conducted with prospective family members about a year later. Five investigators conducted interviews; the same investigator interviewed all participating members of a family. We used an interview guide to assure coverage of the following topics: the progression of illness, symptoms, and therapeutic and palliative interventions from diagnosis until death; the planning process for the hastened death including obtaining medications; and the death narrative including implementation of the hastened death. Additional topics included a character sketch of the patients and their beliefs about hastened death, suffering, religion, spirituality, and the afterlife. All recruitment, consent, and data collection procedures were approved by the Human Subjects Committee of the University of Washington.

Data analysis

We used qualitative content analysis methods,[182-184] which are "a dynamic form of analysis... oriented toward summarizing the informational contents of data."[183, 184, p.338] Codes were derived from the interview guide and the transcripts. We systematically reviewed the transcripts and codes multiple times to describe patterns and summarize details within and between cases. The analysis involved an iterative process with three goals: (1) to document the time involved in planning a hastened death; (2) to characterize the timing and circumstances associated with the different types of deaths (self-administered medications, other-administered medications, underlying illness and other); and (3) to identify the factors that triggered the decision to hasten death.

To document the planning process, one investigator (HS) wrote a 2-3 page chronology of events for each case by reading through the transcripts for that case. When there were multiple respondents for a case (n=17), the reported events and dates were compared and reconciled. The chronologies included the dates of the initial diagnosis of the (terminal) illness, when treatments were accepted or declined,

when the patient initiated contact with an advocacy organization, when s/he acquired medications to hasten death, and other important events (such as family or provider involvement in planning activities). The chronologies ended with the date and a synopsis of the death. Not all of the narratives had specific dates for each of these items, but usually named the month and year when the event occurred. When exact dates were missing, we coded the date as the 15th of the month. This allowed us to estimate the number of months between (a) diagnosis, (b) initiation of request for help from an advocacy organization to hasten death, and (c) obtaining medications, and death.

The two internists on the study team estimated each patient's life expectancy at the time of the hastened death. The four time periods were chosen to mirror the common clinical practice of discussing prognosis in days, weeks, or months. They independently reviewed the transcripts and used their clinical judgment based on the patients' reported symptoms and functional status. They concurred in their assessment of life expectancy for 24 of the 26 cases and resolved the two disagreements by consensus.

We organized the cases by the manner of death and by the estimated prognosis at the time of death (for those who hastened their death) and then reread the transcripts grouped in this way. This iteration of reading the transcripts served to identify patterns in the narratives about the circumstances and catalytic factors that initiated the hastened death, and conversely, for those who died of their illness, the factors that explained why they did not hasten their death.

Results

Patient characteristics

Details of the study patients are published elsewhere.[6, 101, 181] We summarize several characteristics here that are relevant to this analysis, including patients' ethnicity, spirituality, access to health care, and beliefs about hastened death. All 35 patients were white and had insurance coverage. Their mean age was 68 years (range 33-99) and half were women. Two-thirds of the patients had pursued curative therapy or had an illness for which there were no curative options. Those who had

the option of curative therapy but did not pursue it were among the majority of the patients who received palliative care either from home care (n=6), hospice (n=19) or both kinds of services (n=2). The eight people who did not receive home care or hospice were under the care of health providers at the time of their death or the end of the study. Their reasons for declining hospice included not having a terminal diagnosis or believing they did not need care (n=2), not perceiving they were sick enough to need it (n=2), wanting to avoid getting so sick or debilitated that they would need it (n=2), and being worried that hospice might interfere with their plans to hasten death (n=2). These results suggest that the 35 patients in this study had access to health care services and chose the care they felt was most appropriate to their illness, situation, and wishes.

Religion or spirituality was somewhat or very important for 23 (66%) of the patients; 18 believed in and 5 hoped for some kind of an afterlife. Ten of the patients had no religious or spiritual preference and simply viewed death as the end. Regardless of their preferences, most of the patients expressed that interest in hastening their death was consistent with their religious or spiritual beliefs. They either believed that their God was "loving and merciful who would not want [them] to suffer" or were unconcerned about moral judgments of their actions.

Respondents reported that all patients experienced forms of suffering that presented as physical pain, other physical symptoms, and psychic or emotional suffering (described as feeling lonely, having no energy left to fight against the illness, and fears about the future). Many experienced a kind of existential suffering that wasn't related to transcendence, fears of death, or punishment by their God. Rather, their suffering related to the succession of multiple functional and social losses that undermined their sense of self, a future, and purpose.

The patients in this study had articulated their beliefs in the right to choose a hastened death for a median of 14 years (range 1-50+ years). The respondents stated that these beliefs developed in reaction to witnessing other family members and friends die protracted deaths, and through discussion of public cases such as Karen Ann Quinlan and the deaths of Kevorkian's patients. These beliefs conformed to the patients' other important values including the desire to maintain independence,

and to control the dying process and the location of death, especially avoiding hospitals and nursing homes.

Timing and circumstances of the deaths

Patients had lived with their illnesses for a median of 2.5 years (range: 1 month to over 20 years) and had been actively planning their death for a median of three months (range: 1 day to 3 years), as indicated by the timing of their reported initial contact with an advocacy organization prior to death. In most cases, the patients had been discussing the idea of hastened death in general terms with their family members for months or years before they contacted the advocacy organization. The initiation of that contact usually signaled an active shift toward the practical and logistical details of planning for a hastened death. The patients who acquired lethal medications did so about a month before death. The four persons who acquired but did not use medications had them for about 18 months. They sought these medications early in their illness as insurance that they would have control over their future.

The patients were at various points on the illness and dying trajectory when they decided to hasten death. Table 2.1 shows the distribution of the patients' manner of death by the estimated prognosis for those who hastened their death (n=26). These estimates were not applicable (N/A) for those who died of their illness or were still alive at the end of the study period.

Eighteen of the 26 patients who hastened their deaths were actively dying or soon would be, as reflected by their prognosis of one month or less. Sixteen of these patients had either cancer or AIDS; the other two had neurological conditions. Cancer also was the diagnosis for 4 of the 5 patients with a prognosis of less than six months. The three patients with a prognosis of more than 6 months all had chronic, progressive illnesses with considerable physical and emotional disability that they perceived as signs that their condition was worsening, coupled with a potentially long decline.

Two factors were each necessary, but alone were insufficient, for patients to successfully hasten their own death: (1) the availability of lethal medications and (2)

having the mental and physical capacity at the time of death to self-administer medications. When one or more of these factors was absent, patients either died with the help of others or died of their illness. The one exception was a man who used a shotgun to kill himself when he was unable to obtain medications.

Table 2.1: Manner of Death by Estimated Prognosis at the Time of Death

Manner of Death	Hrs – 7 days	1 – 4 wks	1 – 6 mos	> 6 mos	N/A	Total
Self-administered medications	6 *(17)*	3 *(8)*	5 *(14)*	3 *(8)*	0 *(0)*	**17** *(48)*
Self-administered gunshot wound	0 *(0)*	1 *(3)*	0 *(0)*	0 *(0)*	0 *(0)*	**1** *(3)*
Other-administered medications	5 *(14)*	3 *(8)*	0 *(0)*	0 *(0)*	0 *(0)*	**8** *(23)*
Other						
Underlying illness	0 *(0)*	0 *(0)*	0 *(0)*	0 *(0)*	8 *(23)*	**8** *(23)*
Alive at study's end	0 *(0)*	0 *(0)*	0 *(0)*	0 *(0)*	1 *(3)*	**1** *(3)*
Total	**11***(31)*	**7***(21)*	**5** *(14)*	**3** *(8)*	**9** *(26)*	**35** *(100)*

Results are reported as numbers and percents. Percentages do not always add up due to rounding.

A common theme across all patients, regardless of prognosis, was that they were ready to end the struggle with their illness. What differed was the threshold for deciding when the burdens of illness outweighed the benefits of life. Figure 2 depicts the main themes across the different time points of the trajectory of terminal decline. We identified a number of commonalities among the patients, based on our estimates of prognosis. The patients with less than a week to live were 'dying and done', while those with less than a month to live were 'dying, but not fast enough'. The patients with longer life expectancies (1-6 months and > 6 months) hastened their death to interrupt their trajectory of illness before it became a fate worse than death. Those with a prognosis of 1-6 months foresaw a 'looming crisis' in which their health status would change and they would no longer be able to take medications. The three patients with an estimated prognosis of more than 6 months were 'not recognized by others as dying but suffering just the same.' We elaborate below on each of these themes with additional quotes from the narratives.

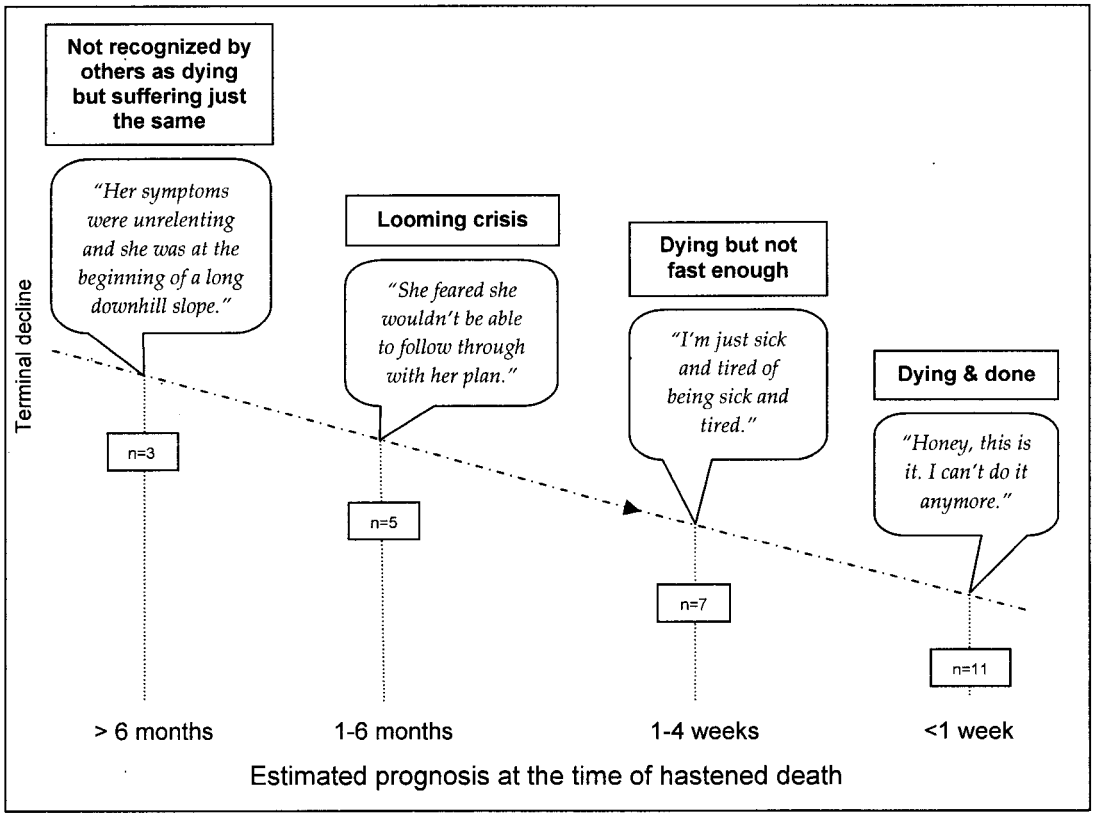

Figure 2: Timing and Circumstances of Hastened Deaths

Hours to 7 days: Dying and done—*"Honey, this is it. I can't do it anymore."*

The 11 patients with less than a week to live when they hastened their death had worked hard to stay alive and continued to find reasons to live throughout their functional decline. Then they experienced a final loss that signaled a point of no return and the inevitability of death—in these cases, within a matter of hours to days. Examples included rectal bleeding from radiation that threatened a bleed-out, constant vomiting from an intestinal obstruction, "messing the sheets" from uncontrollable diarrhea, and for a man with amyotrophic lateral sclerosis (ALS), a final fall (of many) from which he could no longer pull himself up. Whether the patients administered medications on their own or required help from families depended on their physical and mental ability. One man was still mentally clear but asked his wife to administer the drugs because he was no longer able to keep anything down. Her description of his final state reflected their mutual understanding that he was at the

end and the time had arrived. This theme was present for all of the individuals who hastened their death at this point. His wife said,

> *He couldn't even drink his Gatorade and water anymore, and that had become this really important thing to him, you know, that this is the one thing he gets. Smoke cigarettes and drink Gatorade. And he was throwing that up. ...I would give him the medications to stop [throwing up], and it didn't stop it. ...He said, "You know what? I'm not going to get any better. I'm done. ...I'm tired of this; there's just no reward." (Case 21-pro)*

The five patients whose family administered the medications had all lost decisional and physical capacity. Family members were willing to honor the patients' prior requests because they saw that their loved ones were actively dying and wanted to abbreviate the dying process and assure a peaceful death. They had received many signals prior to the final moment, sometimes just hours beforehand. As one woman reported about her husband, "[At dinner] he said, 'I'm ready.' He had swollen up more; it was just more work. ...By about 4:00 [the next afternoon], he was mostly unconscious. ...And so there was no doubt in my mind that that was the evening we would do it." *(Case 9-retro)* Another man spoke of his desire to intervene after his partner had honored his earlier request to delay the date and give them a little more time together.

> *A. died in June. In February, he had just had an awful hospitalization. The pain was just unbelievable. Shortly thereafter—this was on a Tuesday—he woke me up early and said, 'I think I'd like it to be Saturday morning. I've chosen that day and time.' I told him I would support him in that, but after thinking it over, I had hoped we'd have a little more time together. [In May, A. stopped eating and drinking] and he just sort of slipped into a coma. ...When I [decided to] hook up the morphine pump, I wanted to make the process [go] a little bit faster. He had been incommunicative for a couple of days. And I wanted to do it just to be absolutely certain that he wouldn't linger any longer than necessary and that pain would not be an issue. (Case 10-retro)*

Another family had mixed feelings about how to respond to the patient's request for lethal medications. He asked for them after he developed severe stomach pains and was on increasing doses of morphine. His family denied his request for the secobarbital at that time because they interpreted his pain as a side effect of radiation, which their oncologist had been saying was common. They wanted to wait a while longer to see if his pain would improve. However, two days later, when it was clear he was actively dying and no longer able to talk, his family did give him some of the secobarbital to make sure he would be comfortable and would not wake up again. It was only after he died that his family came to understand that his pain was likely due to the progression of his cancer and not the radiation.

The 11 people who waited until they were at the very end of their lives to hasten death did so because they had reasons to keep living until that time. When the six persons who self-administered medications hastened their deaths, they were absolutely done, had reached a turning point and were ready to die, and couldn't endure even a few more hours or days of the dying process. For the five persons who had passed the point of being able to take medications on their own, their families intervened, in part to honor their intent, and in part because they felt that their actions and requests to wait a little longer may have contributed to the patients' loss of capacity to act on their own.

1-4 weeks: Dying but not fast enough—*"I'm just sick and tired of being sick and tired."*

The six patients with a prognosis of about one month also felt they were actively dying but the process was taking longer than they felt they could manage. They had already endured many losses, were getting weaker, were tired of fighting, and did not want to wait any longer for the end to come. This man's report of his partner's final request reflected the situation of all of these patients:

> *He would say, "It's not my choice to hang on. I mean, I can't. It's not a choice left anymore. I'm dying, and there's nothing we can do about that. [The doctors] think [I have] lymphoma, but they say I'm so sick they can't operate to determine it. And so my life is ending. I want it to end the way I choose, not painfully." (Case 17-retro)*

One woman, who had been on hospice for about three months and had stopped eating and drinking, asked for her family's assistance when she learned the dying process was going to take even longer than she had expected:

> *My mom had this understanding that once she got on IV morphine, she'd be dead in a week. She got her IV morphine drip, and was waiting out her week, and you could just kind of see her being patient, waiting out her week. Then the hospice nurse came and saw her. Mom asked her, "How much longer do you think it's going to be?" The hospice nurse says, "You've got great blood pressure. It's 120/80, your pulse is at 90—you've got weeks." And my mom just looked at her and said, "I thought this was only going to take a week." And the nurse said, "It can take up to a month." The nurse left and my mom went back to sleep. When she woke up, she said, "I can't do this for a month." (Case 18-retro)*

The patients in this group were not imminently dying but knew that it was only a matter of time. They had reached the end of their curative options and now were simply waiting it out. They chose to hasten their death at this point because they were exhausted from the effort and life was no longer worth the struggle. One man summed it up, reflecting on his mother's decision: "So what it gets to is [that] the good days aren't worth what the bad days cost you." (*Case 8-retro)*

1-6 months: Looming crisis—*"She feared she wouldn't be able to follow through with her plan."*

The trajectories of illness for these patients included multiple functional losses and the realistic expectation of even greater impairments on the near horizon. The next steps on their trajectory not only threatened their quality of life but also their ability to hasten their death—neither of which were acceptable outcomes. One woman with breast cancer had metastases to her spine and was at high risk of vertebral collapse, which meant that she would lose control of her bowel and bladder. Her daughter described her desire to hasten her death as a way to avoid that undesirable future: "She knew at some point she'd be somewhere down on the curve, that she had given up so many things that it wasn't okay. And rather than wait to get

there and have to figure out where that point was, she wanted to just die before it got any worse." *(Case 1-retro)*

Another patient in this group had multiple sclerosis (MS), which was changing dramatically but on an uncertain timeline. This man feared that he would lose his ability to swallow and thus would not be able to take his medications. His wife recounted their discussion about deciding on the timing:

> *It was very scary because MS is such an uncertain disease, and he knew what could happen, that he could become a vegetable. He was losing daily use of something, some kind of function. Plus he was in pain, and he couldn't sleep, and he was losing weight and all the things that happen when you're dying. He, finally, one day said, "I've made up my mind. If it's going to go on like this, I can't, and I want to die." (Case 11-retro)*

The patients in this group qualified as having a terminal illness and chose to hasten their deaths to avoid further functional declines leading toward unacceptable quality of life. In addition, while they maintained their mental and physical capacity, they anticipated the likelihood of changes in their health status that would compromise their ability to hasten their death and thus add to their suffering.

<u>> 6 months: Not recognized as dying, but suffering just the same</u>—*"Her symptoms were unrelenting and she was at the beginning of a long downhill slope."*

Two of the three patients in this group were in the prospective cohort. We interviewed them about what motivated them to hasten their deaths, given potentially months to years of remaining life. All three of these patients had chronic conditions that were not deemed terminal unless they stopped palliative therapy and let the disease process take its course. They had lived with their illnesses for a long time—one woman had a congenital malformation of her spine that had caused her significant pain all her life. She described her situation this way:

> *I was and am limited in moving so as not to throw the spine and neck out, and every move I make is programmed, calculated, planned and controlled in every part of my body. Now the spine or neck or both will be injured just while I'm sitting and doing nothing. I'm in an invisible prison. Every move I make is an effort. I*

can't live like this because of the constant stress, unbearable pain, and the knowledge that it will never be any better. It's impossible because I'm in pain all the time. And I am internally losing it 24 hours a day. I can't stand it anymore because I know it's getting worse. And I feel like I'm dying from so many chiropractic treatments. I can't stand that. (Case 30-pro)

The other patient we heard from had a chronic lung disease that was controlled with high doses of steroids. She had been hospitalized twice with secondary infections due to the steroids. After the second hospitalization, she decided her time was getting close.

What's very clear to me is that I've not only reached a point of probably as far recovered as I would get, but also of two other scary things. One is the knowledge that probably I'm going gradually downhill in an irreversible way. And the second thing is that because I've been taking drugs that impair your immune system even further—and mine is already depressed—now I am subject to any kind of infection at any time, which puts you at the point where you feel, oh, my God, I'm going to have to go through that whole crashing down procedure again. (Case 23-pro)

The third patient (from the retrospective cohort) had an autoimmune disease that caused profound itching and progressive paraplegia, which would not only leave her unable to engage in her favorite activities of cooking and painting, but would also make it impossible for her to end her life. She was a holocaust survivor and abhorred the idea of being institutionalized and unable to control her life. She and the other two patients had endured high levels of suffering and were faced with the prospect of continuing palliative therapy, with its incumbent side effects, in the face of increasing disability. The returns on the therapy—and on life, given their burden of illness and potentially miserable future—were no longer worth it to them.

Died of underlying illness

Eight patients did not hasten their deaths for one of three reasons. We include them in this discussion because the circumstances of their deaths reveal how the abstract desire for hastened death does not always translate to the practical realities of the dying process. One woman changed her mind after a positive

experience with hospice. Another four patients lost either the physical or decisional capacity to self-administer the medications and did not have family members or others who were willing to do that for them. The other three individuals had not acquired medications; one person had recently moved to a new city to be with family and did not have any established relationships with health care providers. The other two were less focused in their planning process and died somewhat unexpectedly of exacerbations of their illness.

Other issues related to the timing of death

For some patients, there were additional factors that influenced how they chose the specific day to die. Four people had timed their deaths around a party to say goodbye to their friends and loved ones. Because they knew they would die, they could plan a final event. The people invited to these parties knew the patients' intentions and often described these events as celebrations. For example, one person decided on a Thursday that he was ready to die. On Friday, he invited 60 friends from around the country to attend his final "awake," which he scheduled for the following Sunday because that was the soonest day they could all come. About an hour after the guests left, he took his medications with only his partner in attendance and died half an hour later. Other families had parties where those who were invited said final goodbyes and then stayed to witness the deaths.

Coordinating logistics with others was another issue that affected choosing the date. Some delayed their initial dates to avoid dying on a holiday or other special family date. They also chose dates to accommodate family members' previously scheduled vacations and professional engagements, and to correspond to return dates for out-of-town visitors. In a few cases, the date picked was simply the first day when all of the patient's inner circle could be assembled together. Finally, for the cases in our sample from Oregon (n=6), the specific date often was determined by the mandatory 15-day waiting period; as soon as these patients had complied with the law, they implemented their plan to hasten death.

Discussion

This qualitative study describes patient and family perspectives on the timing and circumstances of hastened deaths. These findings suggest that most patients took a long time to reach the point where they were ready to hasten death. They exhausted most options for treatment before acting and adjusted their views on timing up until the end. Similar to studies from Oregon, this cohort of patients had long-standing beliefs in hastened death and was determined to exercise control over their dying process, especially when they perceived a future of intolerable suffering or no possibility for their sense of personal integrity to be restored.[171, 177, 180, 185] All of the patients in the study experienced one or more forms of suffering (physical, psychological and/or existential) and had made many accommodations to their illness. Those who hastened their death had experienced an acute event or the threat of one that motivated them to act. Their decisions regarding the timing of their death demonstrated different thresholds for tolerating suffering, including their ability to cope with being weak, vulnerable, and dying. The threshold varied based on their remaining course of illness, their willingness to stay engaged with the struggle, and the availability of others who were willing or able to help them. Those who were recognized by others as being terminally ill stayed with the struggle for longer periods of time. Yet waiting longer to hasten their deaths carried the risk of losing the capacity to self-administer medications. For four of the patients in this study, waiting longer meant that they died of their illness because they did not have others who would intervene. Other patients were motivated to assert control while they still could, especially as their future became more uncertain, in part because they were unwilling to take the risk of losing capacity.

Previous reports from this study identified three main areas of motivating factors for interest in a hastened death: illness-related experiences, issues of loss and control, and fears about the future.[6, 101, 181] We examined these issues as the catalytic factors that triggered decisions to hasten death. Illness-related issues were most salient for those with days to a month of remaining life. They were exhausted, done fighting, and ready to die. Issues of loss, control, and fears about the future were important to all but were especially so for those who were not imminently dying.

Those who had 1-6 months were in the end (but not final) stage of their illness. They also had endured many functional losses and feared a future when they would no longer be able to control their fate. Similarly, the people with the longest life expectancy faced what they deemed as only undesirable choices: prolonged suffering and a long, slow decline.

Opponents of physician-assisted suicide worry that it will be used most by people with depression, hopelessness, and untreated symptoms that could be ameliorated with better palliative care.[163, 186] However, empirical studies of patients who successfully hastened their death have shown that the typical patient is not depressed, has been offered or received palliative care and hospice, has insurance and family support, and places high value on independence and the desire to control the future.[177-179, 181, 187] This suggests that perhaps the patients most likely to be interested in a hastened death are those who are adamant about being in control and remaining independent. Since people interested in hastening death report this as an enduring, long-held value, clinicians should consider asking about these beliefs with their patients with serious, life-threatening illness, including chronic progressive illness with a long and uncertain trajectory. Discussions could focus on patients' questions or fears about the future, with clinicians exploring any plans or strategies patients have thought about to cope with these fears.

This qualitative descriptive study offers an in-depth examination of the context of patients' decisions to hasten their death and provides details about a process that remains largely out of view. The findings, however, must be interpreted with the following limitations in mind. First, our sample included a group of highly self-selected individuals who were motivated to volunteer because they wanted to share their stories, both good and bad, about implementing a hastened death, mostly in an illegal context. Second, the interviews were structured with multiple goals, one of which was to obtain details about the planning and implementation process. Respondents were free to shape the interviews and the investigator-interviewers had different styles and opportunities to probe for specific details. Thus the chronologies were constructed from the narratives with differing levels of specificity. Nonetheless, the time estimates are intended to show that patients had spent a fair amount of time coping with their

illness and thinking about hastened death, and that their decisions to act were not based on impulsive reactions to bad news. Third, family members reported all of the descriptions of the deaths and were the only respondents for two-thirds of the cases. We cannot report on the effect of their perspectives or the magnitude of recall problems. However, when we had multiple reporters, those accounts were generally consistent. Fourth, this analysis was organized around estimates of prognosis to identify how the issues triggering the decision to hasten death differed across the illness trajectory. Although the estimates were made by the internists on the research team, (not by clinicians involved with these patients' care), the two who reviewed the cases agreed on their independent evaluations, suggesting their categorization has face validity. In spite of these limitations, the characteristics of our sample and the issues illuminated by these narratives suggest that the patients in this study are similar to patients in Oregon and elsewhere, and hence, their narratives about the timing and circumstances of their death are likely to reflect other patients who are interested in hastening their death.[177, 179]

Clinicians who work with patients with serious, chronic illness may need to explore how patients define and experience suffering, and their thresholds for tolerating the source of distress. Kohlwes and colleagues relate that asking about why a person wants to die now may reveal multiple opportunities for intervention, including therapies to address lack of energy and fatigue.[188, 189] In an earlier paper from this study, we learned that patients use hastened death as a gateway to talk about dying.[6] For patients with psychological or existential concerns, clinician openness to discussing these issues can be a therapeutic intervention of itself. However, open discussions about these topics pose particular challenges. Dobscha and colleagues report that some Oregon physicians responding to patients' requests were unsettled by the conversations with patients who were alert and functional.[180] In addition, while they admired their patients' drive, they were frustrated by the struggle for control. Some viewed their patients' rejection of proffered care as a failure on their part. Yet they also expressed personal growth and felt the interactions made them better able to deliver high quality end-of-life care.[180] Thus engaging openly and

honestly with patients around these issues may have positive benefits for the clinician-patient relationship.

The lessons from this study warrant careful consideration by clinicians who are asked for aid-in-dying. Recommendations for evaluating requests focus on identifying and addressing patients' depression, pain and other symptoms.[162-164] The patients in this study who hastened their death perceived themselves as dying, and for many, the timing was not fast enough. The prospect of death occurring over the course of a long, slow decline created an additional source of suffering for some. The data from these narratives suggest that clinicians also should ask about a patient's comfort with the pace of dying and regularly assess patient's perceptions of where they are in the dying process.

Chapter 4: Effects on Family Members of Participating in a Hastened Death

For us, there were profound things that didn't go the way that was expected. We're like, 'oh, no one told us about this.' But also we hadn't really planned. So I certainly would like to prevent other people from having to go through the kind of horrendous mess that can happen when you're injecting stuff, which we started to do. (Mrs. C's daughter)

Dying is a social process. It engages seriously ill persons, their families, friends, and professional care providers in a series of tasks, including illness and symptom management, participating in everyday life activities, life history review, and closure work.[4, 50, 109, 110, 190, 191] For dying persons who are interested in hastening their death, there are the additional tasks of acquiring "how to" information, lethal medications, and the overt or covert support of family members and health care providers. These include such challenges as how to approach health care providers with a request, what medications to ask for, how to save and store medications for future potential use, and how to get the death reported without initiating a legal investigation. Importantly, because aid-in-dying is illegal in most states, these tasks are radically different from other types of care for serious, life-threatening illness.

Family members involved in the dying process have multiple needs as they assume caregiving roles for their loved ones. They need understandable, timely information and training to better prepare them for the practical and emotional aspects of their role. They often need help and guidance defining their roles and responsibilities in patient care and decision-making, and benefit from compassionate recognition of their anxiety, suffering, and hard work.[49] When family members are asked to help their loved one organize a hastened death, they face the added challenges of deciding how to mesh their desire to support their loved one's wish with their own moral values and potential for personal harm. Where aid-in-dying is illegal, there are few resources to guide and support families in their role as witness to (and sometimes facilitator of) a hastened death. The book *Final Exit* provides some guidance about medications and general ideas about how to organize a hastened death, and advocacy organizations such as Compassion in Dying and End-of-Life

Choices (formerly the Hemlock Society) provide education and counseling services for patients and families.[192-194] Yet not all families know about these organizations or how to access them. In addition, very little has been written about the role of family members in planning and implementing a hastened death, in spite of their important function in all aspects of end-of-life care, and the fact that they must live with the legal, moral, psychological, and social consequences of their participation.

This paper reports on three cases from a qualitative study of 35 families who seriously pursued a hastened death. The family members in these three cases encountered complications during the dying process. We discuss the ways in which they were involved and subsequent positive and negative consequences. Our objectives are to characterize (1) what involvement in a hastened death adds to typical family caregiving responsibilities at the end of life, and (2) how families handled complications during the dying process.

Participants and Procedures

These cases are from the "Insights into Hastened Death" study that was conducted from 1997 through 2000. We have published details of the recruitment and data collection procedures elsewhere.[6] To summarize, we used intermediary sources to recruit family members of persons who had died before the study began (a retrospective cohort), as well as patients who were still alive and their family members (a prospective cohort). Interested participants called and spoke with an investigator who explained the study procedures, answered questions, obtained verbal informed consent, enrolled participants, and collected demographic data.

Our definition of "family member" includes chosen families and close friends, as well as blood and marital relatives. Five of the investigators conducted interviews with 48 family members from the two cohorts: 28 reporting on the 23 patients in the retrospective cohort and 20 reporting on the 12 patients in the prospective cohort. Investigators were assigned to families and conducted all interviews with members of that family. Interviews were audio-taped and transcribed. The topics addressed in this paper include family members' roles in providing care and support during the patient's illness, their involvement in planning and implementing the hastened death,

descriptions of complications encountered during the dying process, and their bereavement experience and reflections after their loved one's death. To assure participants' confidentiality, no written consent forms or documentation with identifiers were maintained. In addition, all identifying information was removed from the transcripts and the audio tapes were destroyed. These procedures were approved by the University's Institutional Review Board.

Characteristics of the patients and family members in the 35 families are detailed elsewhere.[6, 101, 181] We report a few relevant details here. Of the 35 patients, 26 hastened their deaths either by self-administering medications (n=18) or by having someone else administer the medications, either with concurrent consent (n=3) or prior consent (n=4) by the patient. One man died of a self-inflicted gunshot wound when he could not obtain medications. Eight people died of their illness and one woman was still alive at the end of the study period. The majority of the 48 family members (90%) provided substantial support in terms of both hands-on care with activities of daily living as well as instrumental activities of daily living. All of the family members provided emotional support in terms of listening, companionship, and counseling.

Analytic Methods

Choosing these cases involved several steps. First, the investigators read the transcripts and discussed the themes and issues at weekly meetings. Second, the interviewer and another investigator coded the transcripts into broad categories using Atlas.ti [195] to manage the transcript data and extract the codes for "planning the hastened death," "family involvement in planning and the death," "death narrative," "complications during the dying process," "reactions to the death," "grief responses," and "reflections on the whole process." Third, two of the investigators reviewed these data, starting with the planning process, followed by the death narrative, and ending with the family members' accounts of their bereavement and reflections. After discussing a set of codes, we documented our interpretations in coding memos. We used content analysis [182-184] to identify three styles of decision making and divisions of labor with respect to how patients and families participated in the planning process and apportioned responsibility (see Table 3.1).

Table 3.1: Decision-making Styles and Division of Labor within Families

Family Involvement Style	Definition
Patient takes primary responsibility[1]	Patient takes full responsibility for planning and implementation but asks for family support and a commitment to be present at the death
Patient and family share responsibility[2]	Each does what they're capable of, respecting and relying on each other's contributions
Patient delegates details to family[3]	Because s/he couldn't manage the details due to illness

[1] n=11; 7 had a hastened death (HD); 1 had a complication
[2] n=19; 17 had a HD; 4 had complications
[3] n=5; 3 had a HD; 1 had a complication

We again read the transcripts and codes, grouping the 35 cases by these decision-making styles. Finally, we chose one case from each style where the family had to manage complications during the dying process. While these cases were a minority, they are a powerful illustration of what can happen to families involved in a hastened death, and the consequences to them when things do not proceed according to plan. Six of the 35 families encountered complications. All were related to medications—either a less efficacious type was used or an insufficient dose was ingested. None of the patients vomited. "Near miss" cases (n=2) were those in which the patient took over 11 hours to die, although neither woke up after having ingested the medications. Family members did not intervene in these cases other than to wait out the dying period. "Failed attempts" included cases where the patients woke up after having taken an initial dose of medications and expressed anger or disappointment that they were still alive. Family members intervened in each of these cases, by administering other drugs or substances, and additionally in one case, by placing a plastic bag over the patient's head to assure his death. The following case reports include one "near miss" (Mrs. A) and two "failed attempts" (Mr. B and Mrs. C).

We analyzed these cases using a theoretical framework developed by Brown and Stetz[50] on the labor of caregiving, which identifies four phases and the associated tasks for caregiving at the end of life (see Table 3.2). We used this framework to examine how the dying person's desire for a hastened death added to and/or shaped the caregivers' labor during the phases of "becoming a caregiver" and "taking care." In addition, we examined how complications during the hastened death process

affected the phases of "midwifing the death" and "moving ahead." While the three cases do not necessarily represent the majority of cases in each group, we include them because they highlight different styles, divisions of labor, and responses from family members, and reveal important lessons for clinicians.

Table 3.2: Theoretical Framework of the Labor of Caregiving at the End of Life: Phases and Tasks*

I. Becoming a caregiver	II. Taking care	III. Midwifing the death	IV. Taking the next step
a. Facing the present *(responding to the initial diagnosis/recurrence)* b. Choosing to care *(commitment to care, defining role based on relationship, time, skill)* c. Developing competency *(expertise in caregiving, learning about managing the illness)* d. Looking to the future *(maintaining hope while anticipating death)*	a. Managing the illness *(providing physical care, monitoring progression of the illness)* b. Struggling with the health care system *(negotiating care needs with clinicians, navigating health care system)* c. Managing the environment *(seeking /obtaining information, organizing resources)* d. Coming to know one's strengths *(recognizing competencies, learning to live with the situation)* e. Personal suffering *(emotional work, stress, exhaustion, anticipatory grief and loss)* f. Responding to family issues *(brokering information, managing family conflicts)* g. Facing and preparing for dying *(saying goodbye, arranging for impending death)*	a. Waiting and doing *(waiting for death to occur, attending to dying person's final needs)* b. Hoping for a 'good' death *(assuring dying person's wishes, "last chance to do things right")*	a. Experiencing relief *(end of dying person's suffering, freedom from intense caregiving duties)* b. Tying up loose ends *(after-death estate/ financial management, distributing personal effects, fulfilling last wishes)* c. Dealing with regrets *(identifying what they could have done differently to lessen suffering, wishing for less conflicted relationship with the dying person/other family members)* d. Moving ahead *(grieving their loss, building a new life without their loved one)*

* Adapted from Brown and Stetz, 1999. Examples *(in italics)* are included from the original paper to illustrate tasks/skills in the themes.

Case Reports of Hastened Deaths

The study participants for the first and third cases were the patients' daughters (two in each case). In the second case, the patient and his wife were both in the

study. Some of the details of the cases have been changed to preserve confidentiality of the respondents' identities.

Case #1: Mrs. A.—Patient takes primary responsibility

Mrs. A. was divorced and died in her mid-70's. For about two years before her death, she had lived with an autoimmune disease that affected her skin, causing disfigurement, itching and discomfort. It also caused muscle deterioration that increasingly left her very weak with intermittent periods of paraplegia. Toward the end of her life, she was losing her ability to maintain her independence.

Initially Mrs. A. wanted to die alone to spare her three adult children the burden of assisting in and witnessing her death. During Thanksgiving dinner, she told her children about her plans. Her son, who lived in another state, spent a week with her researching information about macrobiotic diets and alternative therapies. She politely acknowledged his efforts but declined to follow-up on his suggestions. After that, he decided that he could not support her choice and would not be present at her death. One of her daughters lived in the same city and the other lived three hours away. Although they did not agree with the timing of her decision because they felt she was dying too soon, they supported her right to choose and convinced her that they would prefer to be with her when she died.

Mrs. A. took primary responsibility for the planning process, in part to minimize her daughters' sense of responsibility for her death. She got a copy of *Final Exit* [194], researched what drugs she would need and how she would get them. She approached her physician, who empathized with her request, but felt he could not prescribe secobarbital, a barbiturate, so prescribed flurazepam (a less potent sleeping agent) instead. One daughter helped her calculate the lethal dosage for this medication, but otherwise her daughters had no involvement with planning her hastened death. Mrs. A. did not seek help from local advocacy organizations, nor did she discuss back-up plans with her daughters in the event of complications.

It took over three months for Mrs. A to accumulate a sufficient supply of medications. During that time, her daughters made an effort to spend time with her, help her organize her affairs, write good-bye letters, and send gifts to lifelong friends.

In February, Mrs. A. picked a Sunday as the day she would hasten her death. Her daughters spent Saturday night at her house and prepared her "favorite meal of apple dumplings with tons of butter and sugar." The following morning at 9:00, she took her pills and went to sleep. Her daughter said, "And then the horrible part started, because then she wouldn't die." Her daughters experienced the next 11 hours as an agonizing vigil, during which they were "freaking out" wondering if she was "just going to be indefinitely in [a] coma" or if they would "have to notify the authorities and take her to a hospital because it didn't work."

After six hours, they called a pharmacist to find out if she had taken a lethal dose. They worried the call might precipitate getting turned over to the police, but decided they had to risk it to find out. The pharmacist told them that the dose was probably high enough, but that it might take a long time to work. Eventually she died without waking up, but then the sisters had to endure another kind of agony. The younger sister said,

> *We phoned 911 to report a suicide. And that was awful. We got two really young firefighters who were in a panic because there was still some question about resuscitation. Then, a cop came in and guarded us. ...He was not allowed to leave us alone because of the suicide, and so he sat there and tried to chat. ...Finally, after two hours, the medical examiner and her assistant arrived. They were a little bit more clued in. They didn't try to chat. But we were worried about them, and this is where we thought problems might start.*

She continued,

> *We told them the truth [about what happened]. ...So they did take her away, and an autopsy was done. And we didn't hear from them for a while. But eventually, we got the death certificate, and we never heard anything.*

Both sisters were glad they had participated in the death, but the fact that it took so long and was filled with such uncertainty left a strong negative impression on both of them. The younger sister described her reaction as follows:

> *I think the unfortunate thing was that I was in shock because of the difficulty of that last day. It was such an emotional rollercoaster that it was a while before I*

could actually focus on the fact that my mother was dead. I certainly grieved a lot after she died, but that day itself was so difficult that it overshadowed a lot of the other things. And even now when I think of her dying, I think of that last day, and it's like a nightmare. There she is lying on her bed breathing, and there I am in a panic for hours that she's not going to die. I think the anticipation of [legal] problems because she committed suicide was something that was with me for a long time. Luckily there were none.

The older sister's reaction was one of emotional numbness.

I was numb through the whole thing. I was just so shut down, emotionally, that I wasn't reacting to it; I wasn't crying; I wasn't feeling. I felt really guilty that here I was worrying about my emotional state when this was really about my mother. ...But now, the more I think about it, the more I'm glad that I experienced my mother's death at home and in a controlled setting that we were able to structure and support each other in. Having it be purely a choice about quality of life, while it was so hard at the time, in retrospect it feels like it was easier because it was sort of clean. And so, as intense as the experience was, in a way I'm grateful that it was, under the circumstances, okay.

In the end, both sisters came to see many positive aspects to their mother's death—particularly that she was able to have the kind of death she wanted. The older sister sought psychotherapy to deal with her reactions and ultimately had a good outcome. However, it was over a year before both of them felt that the trauma of the dying process abated.

Case #2: Mr. B.—Patient and family share responsibility

Mr. B. was in his mid-60's when he was first diagnosed with bladder cancer. He had surgery, chemotherapy, and radiation after the initial diagnosis, and subsequently remained free of symptoms for about 14 months. Then he began having renewed pains in his abdomen. After several months of inconclusive diagnostic tests he had exploratory surgery that confirmed widespread, inoperable tumors. His physicians told him he had about six months to live and sent him home with a referral to hospice.

During his initial cancer treatment and again after the second surgery, his wife took a leave of absence from work to care for him full-time. When he came home on hospice, he raised the idea of hastened death with his wife and hospice nurse. The nurse referred them to an advocacy organization, but they did not pursue this resource because they felt well-supported by hospice, and were, as his wife said, "people that [weren't] real dependent on the system. We sort of [took] care of things our own selves. ...We talked about [hastening his death] a lot. And I kept saying, 'Oh, don't worry about it; it's not that hard'."

Over the course of four months, Mr. B's health progressively declined: he was confined to a chair, hardly eating, and on increasing doses of morphine for pain, yet he maintained a positive outlook and was in no hurry to die. He gradually increased his pain medications and decreased his intake of food and fluids. He was sustained on "Gatorade and cigarettes" for the last few weeks of his life. When he reached the point where he was vomiting everything, including ice chips, he knew he had reached the end. By this time, he was too weak to self-administer any medications. He said to his wife, "You know what? I'm not going to get any better. ...So I want you to do it; I want you to do it tonight." He told her that he had some phenobarbital in the house that was there for him in case he had trouble sleeping. He asked her to give it to him and she agreed. She had been giving him IV morphine for weeks and had no problem with the idea of giving him more drugs to end his pain.

That night, they stayed up reviewing their life together. They slept in the early morning and agreed that sundown seemed the appropriate time to give him the medications. But their plan failed when he had a rare and unusual reaction to the phenobarbital. She described it this way:

> *I was just sort of painting a beautiful picture for him on the way out. I said, "We're walking down this long, long rose arbor, and there's petals everywhere, and the smell is wonderful, and everything's in full bloom, and it's just an endless tunnel of roses we're walking through." ...And then he said, "And it opens up and there's the sea, right?" And I said, "Yeah. Now you're going to get on this big cloud." So I was just telling him all this as I was injecting him. And his eyes were just partly open, and he was just going, "Oh, my God, this is so wonderful; Oh, God, this is*

great." Then his breathing slowed down, and I'm waiting and waiting. And then his breathing got real deep like his body went into this overdrive thing. So I gave him three more of these vials. ...And his breathing got shallower and shallower and then the same thing; he started gulping air and sort of rousing again. So then I gave him the last three and the same deal. His breathing was slowing down, and I was like, okay, this has got to be it. And he just started jerking, lurching, breathing deep, and his body just wasn't going to go down. And so then I took the hypodermic, and I started sucking morphine out of the bag and bypassing the machine and injecting that. And at some point I realized I just wasn't going to be able to overdose him; it just wasn't possible. But now I was really scared because I was out of everything, and he couldn't take anything orally. And so that was when I called the hospice nurse and said, "Oh, my God, we're just about out of medications."

It took three more days before she could get re-supplied with other medications. During that time, she stayed with him alone, monitoring him around the clock and keeping him sedated. On the third day, he "kind of came to in the early afternoon and he was really pissed off, and he was slamming one hand against the other. And you know, looking at me, just mad; that he woke up again, that he was alive." This was the one moment that caused her regret. Later that day she got a supply of pentobarbital and administered it, with two friends there to support her. When he finally stopped breathing she "just felt this sense of relief." She said, "I was just—whew, he wasn't going to have to wake up again." Immediately after the death, she described her reaction as mixed:

At first I felt really guilty for doing it and then I felt guilty for failing, all at the same time. ...I truly didn't think it would be hard. I mean, I knew it would be emotionally difficult; I just didn't think it would be physically difficult. ...I wish I had known better what to do.

However, after a year, the complications and the hastened death were a relatively small part of the overall dying experience for Mrs. B. She said,

The only regret is that it didn't work the first time; that's truly the only thing I feel quite badly about. ...I'm just really grateful for the time that we spent together, especially those last five or six weeks. I feel really fortunate to have been able to be here with him, not having to go to work, to have hospice care, and to be able to really give him all the pain meds that he needed. ...That last night we stayed awake all night talking. That was the real gift. I'm real glad I had that. I'm glad we both had that. ...So even though his whole death scene was such a beautiful moment that went so damn haywire, there were still some things that really worked out well, and that was one of them.

Case #3: Mrs. C.—Patient delegates the details to her family

Mrs. C. had focused the first part of her adult life on raising her five children and supporting her husband's career as an executive. After her children were grown, she began working in a program for people with HIV/AIDS, during which time she became an advocate for aid-in-dying. While doing this work, she was diagnosed with ovarian cancer and spent the next six years going through two rounds of chemotherapy with prolonged periods of remission. When the cancer returned for the third time, she refused additional chemotherapy. About four months before her death, Mrs. C. enrolled in hospice and her husband and two of her daughters began rotating 8-hour caregiving shifts.

Mrs. C.'s family was well aware of her general views about aid-in-dying, but she never had communicated any specific plans to hasten her death. She had decided after enrolling in hospice that because she was getting weaker, all she would need to do would be to just "stop eating, go on the morphine pump, and [she'd] be dead in a week." However, after a week on the morphine pump, her hospice nurse told her that "it could take up to a month" for her to die. After she heard this news, she told family members "I can't do this for a month. I want to die, you've got to help me."

Her husband, four of her children, and her best friend had a meeting to confirm they had all heard her request and to decide if they were prepared to help her. Most were in agreement except for her youngest daughter, who felt that her

family was "always trying to control the situation." She wanted to slow the process down and simply be allowed to care for her mom until she died. The rest of the family convinced her that it was her mother's wish to die so she went along with the plan, in spite of her opposition. The next morning when Mrs. A awoke, they told her they would help but only if she initiated the process. She started "pushing the button," but then things didn't go quite as anyone imagined. The younger daughter said,

> *We put everything we had into the bag. I mean we were putting all this stuff into her central line and it was like it wasn't even going in her. We kept looking around, trying to figure out where it was leaking out. We were getting frantic. By then we were a couple of hours into this whole thing.*

Her older sister said,

> *My dad was looking just sick, there's no other word for it. We didn't have any drugs left. We'd actually gone through the sharps container and squeezed all the morphine out of the previous bags to take every little bit we could. It wasn't doing anything. She just kept snoring away, didn't change her pulse, didn't change her respiratory rate—nothing.*

The family took a break and strategized about what to do next. After an intense discussion one of the daughters decided she would be willing to push air into the line. She said,

> *We were all looking at each other and crying and my dad said to me, 'OK. Could you do it?' And I said 'yeah'. ...And then, after everything was done, we called everybody upstairs again and said, mom's died. They all came up and we told them what had happened.*

Then there was a dramatic shift in the energy of the house and amongst the people present. The younger daughter talked about it saying,

> *There was this sense of peace in the room. We then bathed her and put this white gown on her and put her cross on and took all her stuff out really quickly, all the needles and stuff, and she was exquisite. We combed her hair. She looked beautiful. We were just kind of like, [in a] completely altered state at that point,*

and this is profound. And it was, like, the deepest prayer I'd ever been in… . And my dad even took a picture of her dead because she was so exquisite looking.

The younger daughter found the aftermath of the death to be amazingly beautiful, yet the lack of planning gave her no time to adjust and she found herself going along because she did not feel that she had a choice. She described the long-term effect on her:

The impact of this is so huge—it took us by surprise. I've become socially isolated, exhausted. It's demolished my social structure. I have a few friends but it was all I could do to go to work, then come home and rest. It's been about three years since I've had a life. I was taking care of her for about six months and then she hastened herself. I'm still not sleeping well. It's all very complex and difficult to sort through. I think we did the right thing, but then sometimes I'll wake up around 4 [a.m.] thinking, did I kill her? There's still this little, glitchy place in me that still goes, I killed my mom. The 'I-killed-my-mom thing' is big, still. Because it's the truth—how do I come to some resolution around that?

By contrast, her sister seemed fairly at peace with the process.

I have no problems with what happened. 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. I've been—it's been fine. I'm two-and-a-half years out and it still affects me that she died. It's really hard to separate how much is the parent dying versus the actual events of the death. I tend to just spend time talking to her still, and there is a very definite awareness of my mom.

The Labor of Caregiving as it Relates to Hastened Death

Much of the family members' labor was devoted to the typical tasks of caring for a loved one who is dying, as outlined in Brown and Stetz' framework (Table 3.2).[23, 50, 52, 110, 196] The following analysis extends this framework to the context of hastened deaths and examines what it adds to and how it is different from typical family caregiving responsibilities at the end of life.

Becoming a caregiver

The legal and moral issues associated with a hastened death add another dimension to the task of "choosing to care." Family members must decide whether they can support this kind of dying, as was the case for Mrs. A's her son, who ultimately decided he could not be present at her death because of his discomfort with her choices. Thirteen of the 35 families in the study shared similar concerns; this explained why the patient took primary responsibility in 7 of the 11 cases where this was the family style. This also was an issue in all five cases where the patient delegated responsibility for planning to the family. Family members in four of these cases opted out of the process. The one exception was Mrs. C's daughter described above, who experienced complicated grief symptoms as a result of her participation.

"Developing competency" in this context relates to acquiring the knowledge and skill to successfully plan and implement the hastened death, which was often done with help from case managers or health care providers with prior experience of participating in a hastened death. None of the three cases described here had this kind of support, thus these families had little opportunity to develop this skill. The lack of it contributed to the complications they encountered. In contrast, 27 other cases in the study had professional support, which reassured family members and increased their comfort with their role and involvement.

Taking care

Where hastened death is illegal, patients and families have the additional tasks of negotiating with health care providers for information and prescriptions for lethal medications, with (or without) overt support. These encounters were another type of "struggle with the health care system." In Mrs. A's case, being upfront with her provider back fired: her open request resulted in a prescription for a less potent medication that prolonged the dying period and caused her "near miss" complication. Five other families in the study encountered similar struggles during negotiations with health care providers over procuring medications. Additional tasks to "manage the environment" included getting assurance that providers would sign death certificates or make referrals to hospice to minimize the risk of investigating the death and

preparing back-up plans in the event of complications. Family members who were not involved in conversations with health care providers or advocacy organization personnel were left without the resources to help them cope when things went awry.

The hastened death process added several dimensions to family members' personal suffering, including the need to reconcile differences about the timing of death and dealing with worries about legal issues. For example, Mrs. C's younger daughter felt pressured to let go of her desire to care for her mother and acquiesce to the family's plan. Mrs. A's older daughter also reacted by "going numb" and feeling selfish and guilty that her mother's request made her pay more attention to her own needs than the fact that her mother was dying. In addition, both of Mrs. A's daughters worried that calling the pharmacist for advice would result in a call to the police.

On the other hand, the patients and family members in this study were fully aware that the patient was dying, which created many opportunities to purposefully engage in closure. [117-119] Having an explicit date meant that families could plan final celebrations and life review, as was demonstrated by Mrs. A and Mr. B and their families. "Facing and preparing for dying" was enhanced for most of the 35 families in the study because of this open awareness. This also helped families later with "dealing with regrets," especially those related to the complications. Conversely for Mrs. C's younger daughter, the lack of preparation and the last-minute decision to intervene led to her adverse reaction.

In addition to these tasks of "taking care," these cases identify ways in which planning a hastened death prompted patients and family members to safeguard the other from potential harms. Mrs. A tried to protect her daughters by assuming all of the responsibility for the details to minimize their involvement and leave them with 'clean' hands. Yet, her actions did not shield them from the emotional consequences of having to sit and watch her die for over 11 hours. Mrs. B maintained a constant 3-day vigil after the initial attempt failed to prevent her husband from waking and suffering any more. However in Mrs. C's case, the protection got turned around when her plan to end her family's extended caregiving by simply going on a morphine drip

for a week failed. Once again, the legal and moral hazards associated with hastened deaths accentuate the need for this kind of mutual protection.

Midwifing the death

The task of "waiting and doing" may be better seen as "doing, waiting and doing" in cases of hastened death. The deliberate act of administering lethal medications shifts the uncertainty from knowing when the active dying phase begins to knowing how long the dying process will take and how the outcome will turn out. This was true for the all the cases of hastened deaths in our study. However, the waiting phase was particularly difficult for the families that encountered complications. In addition, midwifing these deaths meant that families' roles shifted from witness to facilitator, a role for which Mrs. A's and Mrs. C's daughters were completely unprepared.

Taking the next step

For many of the families in the study, "experiencing relief" came only after cremation of their loved one's remains. This dimension of "experiencing relief" was related to the risk that family members would be implicated in their loved one's death. Thus, dealing with legal authorities became another issue in the "tying up loose ends" phase immediately following death. Medical examiners investigated four of the deaths in the study. In three of these cases, families were forthcoming that the deaths were suicides but remained anxious about their involvement until the deaths were cleared, as was the case for Mrs. A. In one case, however, family members chose to conceal the specific circumstances because they wanted to honor their loved one's wish that her memory be spared the stigma of suicide.

Different types of involvement shaped the way families had to "deal with regrets." As was the case for Mrs. B, family members felt responsible when their loved one regained consciousness after administering medications. Two families, whose loved ones delegated responsibility, felt they could not administer medications because of legal and moral concerns and potential conflicts with other family members who were not supportive. They regretted their inaction as they then watched their loved one die precisely the kind of death they had hoped to avoid.

"Moving ahead" and adjusting to the loss was delayed for four of the families that encountered complications, as exemplified by Mrs. A's and Mrs. C's daughters. Both of these women had prolonged bereavement periods. Mrs. C's daughter and two other families experienced symptoms of clinical complicated grief that lasted for 1-3 years. These family members became isolated after the death because they were not comfortable sharing all of the details of their stories and involvement. Maintaining secrets and trying to track whom they had told what about the death kept some of them from being able to "move ahead."

Discussion

Families are the primary source of caregiving and support through serious illness and the dying process. Caregiving is hard work, yet family members report positive gains from their experience, in terms of deeper relationships with the care receiver or other family members, personal growth, an enhanced sense of meaning or purpose, and satisfaction when they rise to the challenge.[33, 34, 44, 191] The cases reported here demonstrate additional caregiver responsibilities that carry legal and moral consequences above and beyond those typically encountered in end-of-life care. On the positive side, patient interest in a hastened death prompted open communication about dying and facilitated closure and life review. When planning occurred, families had an understanding of how their loved ones conceptualized a "good" death and ideas about how to make it happen. On the negative side, discomfort with those plans meant some families pulled back and distanced themselves from caregiving.

Family members agreed to participate to support their loved one's wishes, yet they often were frequently ill-prepared for their role. When families were not involved with advocacy organizations or experienced clinicians, they were on their own to deal with these consequences. In addition, worries about legal consequences and the social stigma associated with suicide meant that some families felt isolated and had limited support in their bereavement process.

Cooke and colleagues reported that caregivers who participated in hastening the deaths of their partners dying of AIDS were especially committed to caring and

saw it as an expression of their love. However, they also reported that 69% of the caregivers who had increased medications to hasten their partner's death were somewhat to extremely uncomfortable doing so. The authors conclude that there was "no evidence of harmful psychological repercussions in short-term follow-up" because only 3% of these caregivers were still uncomfortable with their role 3 months after the death.[197] Studies from the Netherlands have reported on bereavement outcomes of family members whose loved ones died by euthanasia.[198, 199] Swarte et al conclude that family and friends of cancer patients who died by euthanasia had fewer grief symptoms and post-traumatic stress reactions than a comparable group of family members of patients who died of their illness.[199] Similar to the findings of our study, they attribute this difference to the openness of the dying process and the opportunity to say goodbye. van den Boom found no association between depressive symptoms of family members of AIDS patients who did and did not die from euthanasia.[198] However, he found that when complications occurred, survivors had a higher risk of experiencing symptoms of complicated grief.

In the United States, clinicians are regularly asked for aid-in-dying and they frequently comply with these requests.[102, 105, 165, 176] However, except in Oregon, where physician-assisted suicide is legal, clinicians are rarely present during a hastened death. Yet they have a role in educating patients and families about what to expect—about the dying process in general, but also about possible complications associated with using medications to hasten death. [170, 200] Our cases demonstrate four additional tasks associated with the labor of caregiving for a loved one interested in hastened death: "taking care" included mutual protection between patients and family members, lack of professional support before and during "midwifing the death" left families unprepared for adverse events, "tying up loose ends" included dealing with family members' fear of legal consequences, and "moving ahead" was more difficult and increased the risk of complicated grief when families encountered complications during the dying process.

Family members who participated in a hastened death felt they were on uncertain legal, emotional and moral grounds. They took on different levels of direct and indirect responsibility in planning and implementing the hastened deaths from

being present at the death, to mixing and administering medications, and implementing back-up plans to assure their loved one's death. Regardless of the level of their involvement, they experienced both positive and negative consequences. These cases highlight some of the risks and benefits for both patients and family members of participating in a hastened death. Clinicians, patients, and families can use them to inform all parties engaged in planning a hastened death about these issues to prepare them for the possible consequences of their decisions.

Chapter 5: Summary and Implications

The facts of life and death remain the same. We live and die, we love and grieve, we breed and disappear. And between these existential gravities, we search for meaning, save our memories, [and] leave a record for those who will remember us. Thomas Lynch [201, p. 91]

To whom does a death really belong? Does it belong to the person who is dying or to others? ...To evaluate a death as "good" requires that we look at it from various sides and listen carefully to how others who've shared in such an event express their feelings about what was missing, what was right, what went wrong, and what made it special. Stephen Jamison [202, p. 157]

Death is universal, yet each time a person dies, it is a unique, life-changing event for those involved. The dying process is shaped by multiple factors from the dying person's life experience, illness trajectory, and his or her cultural values and spiritual beliefs. It is also shaped by the values, beliefs, and experiences of the dying person's intimate others, and by the clinical, social, and legal options available throughout the process. The overlap and interactions between these factors create the context for dying on one's own terms.

The findings from the three papers in this dissertation highlight how the different domains from the conceptual framework affect the context of dying. A common desire is to be able to die at home where familiar surroundings make it a little easier to be sick and vulnerable. Home is a place that connects dying persons to family and times and memories of a self that was intact, productive, and loveable. One of the main reasons that people state they would prefer to die at home is because it affords them more control over their daily experience.[4, 53, 203] When we take people out of their homes or the places where they practice the rituals of daily life, we cause disruption in their personal identity and relationships with others.[60, 204, 205] Home care services bring important clinical skills and support into private homes and help dying persons remain at home and avoid institutionalization at the end of life.[137, 206]

Implications for policy

The study using MEPS data affirmed that the Balanced Budget Act of 1997 achieved the policy goal of reducing access to home care services. The policy was not explicitly formulated to target access for persons at the end of life, thus raising concerns that dying persons, who often have significant care needs, would be especially adversely affected by the change in policy. The nature and limitations of the MEPS data and the study design prevent direct evaluation of the role of home care in meeting the goals of care for the study participants, all of whom died. They also limit evaluation of how decreased access was related to the quality and appropriateness of overall end-of-life care. Nonetheless, a positive finding is that those with greater functional limitations were both more likely to receive home care and received more days of care, as compared to those who died without home care. This suggests that the changes in the organization and financing of home care under the BBA 97 did not reduce services to those with greater needs.

The MEPS analysis also showed that being married reduced home care days by 42%. While this suggests that those with less support in the home received more days of care, it may also mean that the BBA 97 policy change could undermine another important value at the end of life: patients' desires to minimize burden on family caregivers. This is a valid concern given that caregiving can have serious health and social consequences.[35-42] A recent study demonstrated how hospice services have positive benefits for family members as well as patients. Spouses of persons who died while receiving hospice services had a 5-8% reduction in the odds of their own mortality in the 18 months following the death of their spouse.[43] The authors conclude that we need to think more broadly about the costs and benefits of end-of-life care and recognize that "health care may have positive, group-level health externalities." Restricting access to home care may simply shift the care needs from the dying person to his or her family members in the months following death.

Results from the Insights into Hastened Death study also demonstrate how policies that use prognosis as an eligibility criterion for services can affect access to end-of-life care. "Terminal illness" is frequently defined as having a life expectancy of less than six months. The patients with an estimated prognosis of greater than 6

months shared many of the same concerns about quality of life and motivations to hasten their death as those with a prognosis of 1-6 months. Yet, because they were not recognized as having a terminal illness, they did not have access to hospice services nor would they have qualified for the Death with Dignity Act in Oregon. As it was, the three patients with more than 6 months of estimated life expectancy had difficulty acquiring counseling from advocacy organizations and lethal medications from their health care providers because they were not perceived to be dying.

Clinicians frequently over- or under-estimate prognosis, especially for patients with non-cancer diagnoses.[207-210] Our estimates of prognosis for these three patients matched their accounts of how their health care providers perceived their life expectancy. The lack of a terminal prognosis restricted their options for quality of end-of-life care and for realizing death on their terms, including opportunities to talk about dying and explore their hopes and fears. More generally, estimates of prognosis may frame where patients perceive themselves to be on the illness trajectory. This in turn may affect how they prioritize the activities for the time remaining in their lives, how they reflect on the meaning of life and death, and how they engage with closure tasks and saying good-bye to loved ones.[3]

The legal environment played a prominent role for family members who participated in hastening a loved one's death. Fears and concerns of legal consequences affected the range of options and expertise available to patients and families as they planned the death. The families from Washington operated in an illegal environment that created barriers to seeking information and assistance from health care providers and advocacy organizations. When families operated on their own without professional support, they felt vulnerable and worried, especially when they encountered complications during the dying process. They were concerned that they would not be able to facilitate the death their loved one hoped for and that they might suffer legal ramifications if they intervened. This did not prevent their involvement in hastened deaths, but often it affected the grief process afterwards.

Previous reports of complications have come from Oregon and the Netherlands where aid-in-dying is legal.[179, 200] The reports from Oregon document that 7 (4%) of the 171 cases between 1998 and 2003 had complications that were

primarily due to patients vomiting medications and thus ingesting a lower dose. These complications were all "near misses," with the longest period between when patients ingested medications to death time reported at 48 hours.[179] None of the reports detail how these complications were handled; apparently none of them required further intervention. In the Netherlands, clinicians are involved with the majority of hastened deaths and are often responsible for administering lethal injections. They also provide support and intervention in the event of complications. Data from two studies in 1990-1991 and 1995-1996 were pooled to examine complications that occurred during clinician-administrations (n=535) and patient-administrations of medications (n=114).[200] The overall complication rate was 7%, with near-misses occurring in 6% of the cases; patients woke up in 1% of cases. The complication rate was higher for patient-administered cases than clinician-administered ones (14% vs. 5%, respectively). In contrast to both Oregon and the Netherlands, six (23%) of the 26 hastened deaths in our study encountered complications; the four (15%) failed attempts required families to intervene. Three of four family members who were involved with administering drugs in these failed attempts experienced significant complicated grief.

Implications for practice

These data highlight several implications for practice. The patients in our study hastened their death at many points in time and expressed diverse thresholds of tolerance for different kinds of suffering. These data suggest that clinicians who are asked for aid-in-dying should not only screen for depression and other symptoms that could be addressed with palliative care. They should also explore their patients' perceptions of their illness trajectory, their fears about the future, and their thoughts about the timing of death and their comfort with the pace of dying. These other aspects of the dying process may uncover other opportunities for palliative interventions. If none are available, the dialogue will at least assure clinicians that they have explored all avenues and done their best to support their patients until the end of their lives. If clinicians are willing to participate in aid-in-dying, these data also suggest that they should be informed about lethal drugs, appropriate dosages, and the possibilities for complications. If they are uncomfortable with these details, they

should at least provide a referral to advocacy organizations such as the Hemlock Society or Compassion in Dying who can provide information and support to patients and their families. In addition, if they choose to comply with a patient's request, they should advocate that families be involved and present for discussions. Efforts to protect families from the details can back fire, leaving them unprepared in the event of complications or if the patient delegates responsibility to them, especially at the last minute with little time or support. Clinician involvement with families before the death establishes a relationship that should continue after death, to monitor the family members' bereavement, screen for complicated grief and provide support or referrals to help them deal with their loss.

Conclusions

The data from these studies underscore the complexity of organizing a death on one's own terms. True choices at the end of life require sophistication, organization and competence by dying persons, families and clinicians. The direction for my future work in this area will be to examine systems of care, financing mechanisms, and policy changes that foster continuity of care and supportive services for patients at the end of life and their families. Changing the health care system to incorporate seamless care across the trajectory of serious illness to death will require far more pressure from communities of patients and family members. Before we can change the health care system, we will need to change our expectations—or express them more clearly—of what it means to die on one's own terms.

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Vita

Helene Starks is a native of Seattle, Washington. She has had life-long interests in international travel and public health. She spent her junior year in high school in Lyon, France and her junior year in college in Florence, Italy. She graduated from the University of Washington in 1982 with an undergraduate degree in International Communications. She then spent three years in Mali (West Africa) as a Peace Corps volunteer working on maternal and child health and water and sanitation projects. Upon her return, she attended the University of California at Berkeley and completed a master's degree in health policy and administration in 1989. She subsequently came back to Seattle and began working as a research manager at the University of Washington. In 2001, she entered the doctoral program in health services research, while continuing to work at the UW. The focus of her research has been on clinician-patient relationships, medical decision making, medical ethics, quality of life assessments, quality improvement initiatives, and issues related to end-of-life care. She completed her doctoral dissertation in 2004.