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**Euthanasia Talk
Euthanasia Discourse, General Practice and End-of-Life Care in the Netherlands**

by

Frances Norwood

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Medical Anthropology

in the

GRADUATE DIVISIONS

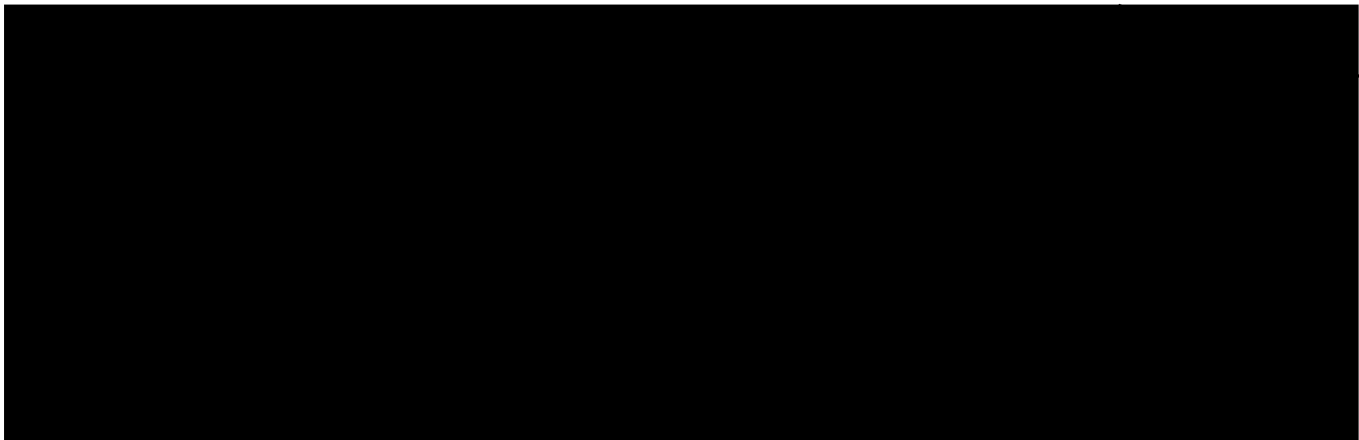
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Acknowledgements and Dedication

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This is dedicated in loving memory to my mother and all the other mothers and fathers, sisters and brothers, wives and husbands who gave us something really special before they died.

Abstract

In the Netherlands, nearly one-quarter of all people who die initiate a euthanasia request with their doctor, yet 9 in 10 of those who initiate a request, do not die by euthanasia. Nine in 10 die instead of natural causes. The Netherlands legalized euthanasia (killing a person at that person's explicit request) and assisted suicide (giving a person the means to kill themselves at that person's explicit request) by court decision in 1984 and again by legislation in 2001. With nearly a quarter of people who die in Holland (not to mention their family members and health practitioners) participating in this dialogue and so few participating in the act, it begs the questions: what are Dutch people talking about when they talk euthanasia and how does euthanasia talk impact the end of Dutch life?

After a 15-month ethnographic study of euthanasia and end-of-life care in the Netherlands with *huisartsen* (Dutch general practitioners), their end-of-life patients and their families, I found two things. First, in practice Dutch euthanasia is more often a discourse than it is a life-ending act, a discourse firmly embedded in the cultural and historical contexts that make Dutch people Dutch. Using a Foucauldian concept of discourse, I argue that the Dutch have created a script that teaches citizens how to think and feel about death, and ultimately how to die. Second, I found that euthanasia talk holds a wide array of meanings beyond the immediate, the obvious (planning for death). One of the most important is to affirm social bonds and social life at the end of Dutch life. People choose not to die euthanasia deaths because of the feeling of social

connection that engagement in euthanasia discourse fosters. Through engagement in euthanasia talk dying individuals maintain connection to family and society, giving them something they need to remain living. This dissertation is intended to provide ethnographic data not currently available on the modern-day practice of euthanasia and to add to a growing body of literature on death, dying and the role of the state.

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Prologue "Slaap Lekker" (Sleep Well)¹

I arrive at Dr. Maas' office a little after 2:00 p.m. He is in with someone, so I go to the waiting room until almost 3 o'clock. The Dutch are usually sticklers for time, so I am thinking that maybe she did cancel. Dr. Maas finally waves me into his office and I sit there as he does some last minute preparations. On his desk is a box, which I assume carry the drugs that will end Marike van der Horst's life. Dr. Maas comes back in and asks me how my day was. It was different, I said. For me too, he said. He sits down and opens the box to show me the drugs. He has more than he needs in case something goes wrong. In the box are two large bottles of Nesdonal (20 ml each) which will put her to sleep and six bottles of Pavulon (4 mg each) that, he says, are for "stopping her muscles." We head to the car and I ask why we are running late. He says that he spoke with Mr. van der Horst this morning and the family wanted to move it up to 3:30 p.m. Dr. Maas has already contacted the coroner, so they are all set for 3:30. Marike was "onrustig (restless, agitated)" last night. Why, I ask, does she still want it? Yes, he says, she still wants to go through with it.

We arrive and Maarten, her son, lets us in. The whole family is there: Joop --her husband-- and Marike; their grown children --Olv, Maarten and Frije -- and their spouses; and a couple - family friends from down the street. Dr. Maas goes around the

¹ Throughout the text (with the exception of the city of Amsterdam which is large enough a city to maintain participant anonymity) all identifying names, places, and descriptions of people have been altered to protect the identity of study participants.

room, shaking hands and saying hello to everyone and I follow suit. Mr. van der Horst tells us they have decided to have only immediate family by her bedside when the time comes, and the others will wait outside. Dr. Maas goes to Marike van der Horst in the bed and asks if she knows why he is here.

No, she says, confused then yes. (She's on large doses of morphine at this point.)

Are you sure, he asks.

Ja, zeker (Yes, certain), she replies. She is certain, Joop -- her husband -- echoes.

Dr. Maas, addressing everyone now, says all right, I will give you a needle and the first one will make you sleep and you won't wake up again. I'll prepare it in the kitchen, he says, and let you say goodbye while we do that.

We go to the kitchen and I hear family members sniffing, crying and saying goodbye. Dr. Maas prepares the syringes, fumbling a bit as he goes, showing me for the first time that he too is nervous. I look out the kitchen window and see the extended family milling around in the back yard now, hugging each other and crying, and some looking into the window to see what we are doing. Dr. Maas lines up the syringes -- one, two, three -- and we return to the living room, Dr. Maas with his black bag and syringes. Dr. Maas has Mr. van der Horst and the boys move the bed out from the wall so that everyone can have a place at her bedside. I feel nervous and numb, and very much like an intruder. Frije is really crying now, as she and her father take up positions at the head of her mother's bed. Olv and Maarten come to stand next to them, family on one side as Dr. Maas and I go to stand on the other side of the bed, Dr. Maas near her arm and I at her head. They are holding each other and Mr. van der Horst is holding his wife's hand, everyone is sniffing or crying softly as Marike van der Horst says, "Het is

best. Het is het beste zo. *(It is best. It is for the best).*” The family tells her to “slaap lekker, slaap lekker, mam *(sleep well, sleep well, mom).*” Dr. Maas tries for a vein on her arm and loses it, then has me go get his second bag from the kitchen. My tears clear as Dr. Maas gives me something to focus on; getting his bag, and quickly. He finds a second vein and I see her blood flow into the tube he places there to hold the vein. Marike van der Horst is still saying that it is for the best as Dr. Maas inserts the first syringe. He fumbles a bit as he attempts to remove the needle, which is no longer necessary because of the tube in her vein. “Slaap lekker, mam,” I hear again as I watch Dr. Maas push the plunger on the syringe and look up in time to see Joop van der Horst staring into his wife’s eyes, gently rubbing her face. Within seconds she closes her eyes and her mouth falls slightly open. She doesn’t move, blink, twitch or noticeably breathe again, and the cries get louder for a moment as she falls into asleep.

Seconds pass. Dr. Maas touches her eyelashes and she doesn’t move. He empties the contents of the second syringe. I hear Mr. van der Horst say as he does it, “it’s good” and “it is for the best.” Dr. Maas pushes the plunger on the third syringe as I hear Mr. van der Horst say, “It was enough;” and “It was too early, too early.” “Ja *(Yes),*” Dr. Maas says, agreeing with him.

We wait, watching her for any sign. Dr. Maas breaks the moment, sending me for his stethoscope, which I get and pass to him. He checks with his fingers on the inside of her wrist for her pulse and uses the stethoscope to listen to her heart. She isn’t breathing, he tells us, but her heart is still beating and I notice how the mood seems to lift when he explains things. We go back to watching and waiting, interrupted only by sniffling noses and family hugs. She doesn’t move. It’s a strange waiting that stretches

the somber mood, until it feels no longer real. She's not breathing, her heart still beats and yet she looks the same – asleep. We wait, probably not more than 4 or 5 minutes, then Dr. Maas checks her pupils by lifting her eyelids between forefinger and thumb. She is dilated, he tells us, and signals that it is over.

11/10/01 10:00

1. Euthanasia Death; Euthanasia Talk

In 2001, approximately 2.8 percent of those who died in the Netherlands that year died by euthanasia or assisted suicide (Wal, et al. 2003:46).² In no other country has euthanasia been legally practiced as long as in the Netherlands, which legalized euthanasia (killing a person at that person's explicit request) and assisted suicide (giving a person the means to kill themselves at that person's explicit request) by court decision in 1984 and again by legislation in 2001. Today, euthanasia is legally practiced in the Netherlands, Columbia and, most recently, Belgium. Assisted suicide is legally practiced in the Netherlands, Switzerland and the United States (Oregon State only) (Scherer and Simon 1999; van der Maas, et al. 1991; Wal, et al. 2003).³

Since 1984, Dutch citizens with "long lasting and unbearable suffering" have had the option to choose a government-sanctioned euthanasia death. Like Mrs. van der Horst, approximately 25 percent of those who died in 2001 made a request for euthanasia. Unlike Mrs. van der Horst, however, 9 in 10 who initiated a request for euthanasia did

² I have chosen to use the highest estimates of euthanasia and assisted suicide. Comparing interview data with a review of death certificate for 2001-2002, the estimated percentage of persons who chose euthanasia or assisted suicide ranges from 2.3 to 2.8 percent. See (Wal, et al. 2003:46).

³ There is a lot of play between law and practice. For example, euthanasia was legalized by the Japanese courts in 1962 and in Germany assisted suicide has been legal since 1751. In both countries, however, euthanasia and assisted suicide are rarely ever practiced due to strong societal and religious taboos. Conversely, in some of the Scandanavian countries, there are no laws allowing assisted suicide, yet it is a practice known to occur behind closed doors and, like in many countries, the sanctions against someone accused tend not to be severe. For this reason, I am choosing to use the term "legally practiced" to denote both legal precedent (by courts or legislation) and current practice (e.g., this would exclude a country where it is technically legal but not recognized as such in practice).

not die at the hand of their physician (Wal, et al. 2003:46).⁴ Nine in 10 who initiated a euthanasia request died due to natural causes. With nearly a quarter of people who die in Holland (not to mention their family members and health practitioners) participating in this dialogue and so few participating in the act, it begs the questions: what are Dutch people talking about when they talk euthanasia and how does euthanasia talk impact the end of Dutch life?

Framing Euthanasia

To answer these questions, I begin with a look at what is known about euthanasia. Consider Mrs. van der Horst's story. This is a story of the brief moments before a euthanasia death. What is missing from Mrs. van der Horst's story are the many discussions, relationships, cultural practices and histories that make up the context of her decision for euthanasia and her subsequent euthanasia death. Unfortunately, much of what we know about euthanasia and assisted suicide from around the world has – like this story I have presented to you – been artificially abbreviated (removed from its cultural context).

What do we know about euthanasia? Little empirical information exists about the modern, day-to-day practice of euthanasia. Much of what we know in the U.S. comes to us from popular literature and includes sensationalized media accounts (Richburg 2000; Smith 2001) and anecdotal or fictionalized testimonials by physicians and families

⁴ Using figures from the longitudinal study of euthanasia practices by van der Wal and van der Maas (2003), I can calculate that on average 9 in 10 people who make initial requests for euthanasia or assisted suicide, do not die a euthanasia or assisted suicide death. The van der Wal and van der Maas study finds that between 2.3 and 2.8 percent of all deaths in 2001 were a result of euthanasia or assisted suicide (3,229-3,931), divided by total initiated requests (34,700) equals 9 to 11 percent (on average 9 in 10). I can also calculate that 25 percent of those who are died in the year 2001, initiated the discussion (34,700 initiated requests / 140,377 total deaths). See (Wal, et al. 2003:46)

(Humphry 1978; Keizer 1996; Quill 1993; Quindlen 1994; Rollin 1987). Consider the most infamous of advocates for euthanasia and physician-assisted suicide in the United States, Dr. Jack Kevorkian (aka, Dr. Death). This pathologist turned right to die advocate performed a string of high profile assisted suicides, and finally, in November 1998, performed euthanasia on a televised broadcast of *60 Minutes*. Dr. Kevorkian is now serving a 10 to 25 year prison sentence for involvement in the 1998 euthanasia death (AP 1998; Garsten 1999; Kevorkian 1991). Is it any wonder that Americans are polarized on an issue that has Dr. Kevorkian as its best known advocate?

By contrast, the Dutch people have access to frequent, less polarized and less sensationalized accounts of euthanasia through their popular medias. During my stay in the Netherlands, I read about euthanasia in the newspapers on a weekly, and sometimes daily, basis. Like the U.S., the Dutch, too, have their controversial spokesperson, a *huisarts*, Dr. van Oijen, who performed the first televised euthanasia in 1994 (IKON 1994). Unlike Dr. Kevorkian, however, euthanasia was legal in the Netherlands at the time and so Dr. van Oijen only bore the brunt of exposing his actions (legal but still somewhat controversial) to the scrutiny of opponents and proponents at that time (BBC2 1995).

Within the Netherlands, much of the substantive literature on euthanasia comes from interview and literature review studies that focus on euthanasia as a policy. Much of what exists in this literature comes out of the work of Dr. van der Wal at the Free University in Amsterdam and Dr. van der Maas at Erasmus University in Rotterdam, researchers of the original Remmelink study commissioned by the Dutch government

(Maas, et al. 1991; Wal, et al. 1996; Wal, et al. 2003).⁵ Using data gathered during a longitudinal study using physician interviews and death certificates, a number of secondary studies have emerged over the years that focus on the incidence and prevalence of the euthanasia act (Maas, Delden et al. 1991; Wal, Maas et al. 1996; Wal, Heide et al. 2003), whether euthanasia practice adheres to Dutch policy guidelines (Haverkate 1999; Onwuteaka-Philipsen and Wal 1998; Onwuteaka-Philipsen 1999), and the relationship of opinion to practice by Dutch physicians (Pijnenborg 1995:99-106; van der Maas, et al. 1992; van der Maas, et al. 1991). In addition, a number of researchers from across the country have explored euthanasia policy in the context of the legal debates and practice (Griffiths, et al. 1998; Haverkate 1999; Hoogerwerf 1999; Klijn, et al. 2001; Koppedraijer 1999; Weyers 2002; Wils 2000).

With more than 20 years of experience behind them, it is surprising how little is known about the day-to-day practice of euthanasia in the Netherlands. Only two ethnographies of modern-day euthanasia currently exist (Pool 1996; The 1997), only one of which is available in the English language (Pool 2000). Both of these studies examine euthanasia practices in Dutch hospitals, offering rich ethnographic descriptions of how euthanasia and end-of-life care happens there. Robert Pool's ethnography focuses on the physician's view, examining how medical specialists in the Netherlands negotiate a path through issues of euthanasia and other medical behaviors that contributes to the end of life (Pool 1996; Pool 2000). Anne-Mei The [pronounced TE] focuses her study on the

⁵ The Rummelink study was first commissioned by the Dutch government in response to international criticism of the Dutch policy falling down the "slippery slope." In other words, the Dutch policy on euthanasia opening the doors to rampant voluntary and involuntary euthanasia practice. The first study of the prevalence of euthanasia practice was conducted in 1990, then again in 1995 and 2000. Originally nicknamed the "Rummelink study" after a politician who pushed for the research, the studies are now known as the "van der Wal and van der Maas" studies (Maas, et al. 1991; Wal, et al. 1996; Wal, et al. 2003).

tensions that arise between Dutch nurses and physicians as they attempt to care for their end-of-life patients. The suggests that nurses and the hands-on knowledge they bring to end-of-life care have been unfairly excluded from existing euthanasia policies (The 1997). Neither Pool nor The, however, examine euthanasia practices from the perspective of what is Dutch about the practice.

One researcher that does consider the "Dutch-ness" of the practice is American cultural historian, James Kennedy in *Een Wel-Overwogen Dood (A Well-Considered Death)* (Kennedy 2002). Limiting his study to the years 1968 to 1985, Kennedy finds that the cultural focus in the development of euthanasia policy was on bringing euthanasia practice into the realm of public debate. In Dutch, he calls it making euthanasia "*bespreekbaar*" (debatable, negotiable, talked about), a cultural practice that is used for virtually all Dutch bureaucratic and policy decision-making. Like similar policies on prostitution and soft drug use, Kennedy says, the Dutch bring a "back-room" practice into the light of the public domain by making it *bespreekbaar* (Kennedy 2002:18).

Much of the substantive research that exists outside of the Netherlands – done mostly by American researchers – tends to get bogged down arguing for or against what has been nicknamed the "slippery slope" debate (Battin, et al. 1998; Gomez 1991; Hendin 1997). The slippery slope debate suggests that allowing physicians to "assist in suicide, even in sympathetic cases, would lead to situations in which patients were killed against their will" (Battin 1996:182). Objectors counter that the evidence does not support a "slippery slope" argument and that it is possible to design a system that effectively regulates proper euthanasia practice. At the end of the day, however, this

debate inevitably results in a stalemate, neither side able to “prove” definitively their point because, only too frequently, neither side is arguing from the same theoretical or moral perspective. They are not speaking the same language.

A Study of Euthanasia

From 1999 to 2001, I conducted a 15-month ethnographic study of euthanasia and end-of-life care in the Netherlands with *huisartsen*,⁶ their end-of-life patients and their families.⁷ My goals were two-fold: (1) to provide data on a little known, but often talked about practice of modern-day euthanasia and (2) to contextualize the practice, by exploring how euthanasia is embedded in larger cultural and historical processes. I wanted to know, what is euthanasia and how is it experienced in the context of home? How might euthanasia reflect socially constructed, state-supported norms and ideals of what constitutes proper death?

⁶ I have chosen throughout this text to use the indigenous term, *huisarts* (*pl: huisartsen*), to refer to Dutch general practitioners. The term can be literally translated to mean, “specialist of the home” and as the readers moves deeper into this ethnography, I think they will find that Dutch *huisartsen* have an orientation to medicine and their patients that is strongly connected to concepts of family and home (see also Chapter 6). Dutch general practice is fundamentally different from much of U.S. general practice. To recognize this difference and to avoid falling into assumptions about what general practice is, I have chosen to use the term, *huisarts* and *huisartsen* throughout my text.

⁷ Data for this study was collected during a 15-month ethnography of euthanasia and home care in the Netherlands and relies predominantly on participant observation and interviews with patients, families and their *huisartsen* (Dutch general practitioners). In addition to tracking 10 *huisartsen* and 25 of their terminally ill patients at home as they considered their end-of-life options, I conducted observation or interviews with upwards of 650 patients, 30 Dutch physicians, home health care providers, and countless experts in the fields of euthanasia and Dutch culture. Research was done with persons on all sides of the debate and observation locations included homes, doctor’s offices, nursing homes (*verzorgingshuizen*), and acute care facilities (*verpleeghuizen*) in Amsterdam and in some of the surrounding townships of Amsterdam. A typical research day consisted of morning interviews at home with patients and their families and afternoons spent on house calls with one of the 10 *huisartsen* from the study. For more data my study sample of *huisartsen* and their end-of-life patients, see the Appendix.

After 15-months in the Netherlands, my research revealed two major findings that form the basis of my dissertation. *First, in practice Dutch euthanasia is more often a discussion than it is a life-ending act – a discussion grounded in a cultural discourse that shapes how Dutch people come to think, feel and practice the end of life.* What are the consequences of euthanasia discourse? What are Dutch people talking about when they talk euthanasia? My analysis begins in Chapter 2 where I define euthanasia discourse and describe euthanasia talk. The chapter starts with a more typical euthanasia experience than the one presented in the prologue, the experience of one woman as she explores in dialogue options and meanings at the end-of-life with her family and with her *huisarts*. In this chapter I focus on what I mean by the term, “discourse,” and how it applies to the practice of euthanasia talk. This chapter gives the reader an introduction to the framework of a euthanasia discourse – what it consists of, who participates, and how.

In Chapter 3, I recognize the importance of considering the development of a Dutch euthanasia discourse in the context of Dutch and non-Dutch cultural and historical practices. This chapter is about how history has impacted the development of current-day euthanasia policy and practices and just what makes euthanasia talk in the Netherlands distinctly Dutch. What is the current policy and what were the events and issues that shaped its development? How does history continue to influence the contemporary practice of euthanasia? Finally, what cultural forms might euthanasia talk be taking and how might a focus on euthanasia discourse provide further insight into what makes euthanasia talk distinctly Dutch?

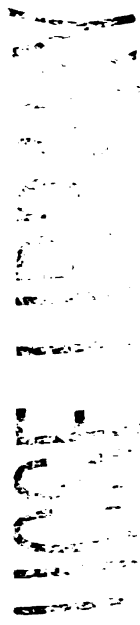
My second major finding reveals that euthanasia talk holds a wide array of meanings beyond the immediate, the obvious (planning for death). One of the most

important is to affirm social bonds and social life at the end of Dutch life. In talking euthanasia, dying individuals are provided with the social resources they need to remain connected through the difficult course of a final illness. This, I argue, is one reason why so many Dutch people talk about euthanasia, but then choose not to go through with it. In Chapters 4, 5 and 6, I examine euthanasia talk as a means for social affirmation and bonding via the roles that participants assume and anticipate in end-of-life discussions. Chapter 4 focuses on the role and perspective of the dying individual. The chapter begins with the story of one man with HIV/AIDS, reflecting on what it means to die in the context of his life, his upbringing and his marriage to an American man. What is the role of the dying individual at the end of life? How does illness and loss affect someone? What makes the individual feel connected and how does that play out in a euthanasia discussion?

Chapter 5 focuses on the role and perspective of the family, a group largely overlooked in the space between Dutch policy and practice. The chapter begins with the story of a husband who reflects on the life he shared with his wife before her euthanasia death. How do families deal with shifts in relationships as their loved ones approach death? What is their role in euthanasia talk and how does family in the context of home influence euthanasia discussions? What is the role of family in maintaining an individual's connection to Dutch society and what is the relationship of family and the state in this end-of-life discussion?

Finally, Chapter 6 looks at the role of *huisartsen* as agents of the Dutch state. This chapter begins with the reflections of one *huisarts* as he explores what it means to perform euthanasia. How do *huisartsen* think and feel about what they do? What do

they see as their role in euthanasia discussions and practices? And finally, how are *huisartsen* contributing to the maintenance of Dutch life by talking euthanasia with their patients and their patients' families?



2. Making a Discourse

Making the distinction between euthanasia (talk) and euthanasia (the life-ending act) is critical to understanding just what the Dutch are doing at the end-of-life. What is euthanasia talk? On one level, it is just what its main topic suggests, a discussion for the purpose of planning a person's euthanasia death. It is also, however, a product of a discourse, a cultural form that shapes the production, practice and interpretation of Dutch life and end-of-life. The focus of this chapter is on euthanasia discourse, the elements that comprise it and what it means to say that euthanasia talk (the focus of my dissertation) is a product of a discourse.

Discourse is a concept that has gained increasing attention in anthropology following the work of Foucault (1972; 1981), Laclau and Mouffe (1985), Habermas (1992; 1996) and Bourdieu (1992). In a sense, much of what is produced today in anthropology is loosely inclusive of a concept of "discourse" as a medium linking knowledge, power, and practice (Andersen 2003:ix; Tyler 1986:125-26). As a consequence, a large portion of ethnography produced today focuses on language (e.g., medical, political, local, and transnational) and how cultural practice is shaped by emergent, discursive and hegemonic forms based in language (Brodwin 2000; Faubion 1993; Franklin and Lock 2003; Hogle 1999; Strathern 1992).

Probably one of the most influential theorists today on the topic of discourse is Michel Foucault. Foucault discusses discourse and its elements in a number of ways throughout his works (Mills 2003:53). My focus, however, is on the way he uses

discourse in relation to the production of knowledge and power in *The Archaeology of Knowledge* (1972) and in “Politics and the Study of Discourse” (1991). Foucault begins by defining discourse as a “an individualized group of statements” and as a “regulated practice that accounts for a certain number of statements” (Foucault 1972:79-80). Thus, discourse can initially be understood as both a grouping of statements (what I distinguish as “euthanasia talk”) and the rules by which those statements are formed (what I am distinguishing as “euthanasia discourse”). Discourse is not just about language or the structure of language, however, it is a discursive practice based on rules of exclusion. Discourse limits what is sayable, what is constituted as taboo, what is held in collective conscience, what is reconstituted from the past, and who in society has access (Foucault 1991:59-60).

Discourse, then, is a discursive formation that exists (1) as collections of statements, (2) as rules for the formulation of those statements and (3) as a practice of circulation and exclusion. The consequences of discourse are enormous. Foucault writes, “in every society the production of discourse is at once controlled, selected, organised and redistributed according to a certain number of procedures, whose role is to avert its power and its dangers, to cope with chance events, [and] to evade its ponderous, awesome materiality” (Foucault 1972:216). Discourse produces knowledge in forms that we come to think of as normative (as understood) and, in doing so, discourse obscures its very nature – that it is a cultural form constructed by and among people.

What might this mean for Dutch people engaged in euthanasia talk? I argue that a discourse has emerged that structures how Dutch people have come to think, feel and act at the end of Dutch life. I propose that this discourse functions on the basis of a certain

set of (mostly) unspoken rules and that the collection of statements that is euthanasia talk consists of certain inclusions and exclusions that shape who has access to this discourse, in what degree and how. My focus is not so much on how this discourse has come to be, nor on how it may or may not obscure social inequalities.⁸ My focus is instead on the existence and consequence of euthanasia discourse on the lives of Dutch people.

In the following sections, I will examine euthanasia talk in terms of its regularities. My method in this chapter is to use euthanasia talk as evidence for euthanasia discourse (Fairclough 1989:109-139; Foucault 1972:234). In the first section, I will introduce the reader to one woman, her family and her *huisarts* as they negotiate end-of-life through euthanasia talk. Next, I will discuss some of the rules of euthanasia talk that demonstrate evidence of a euthanasia discourse. I will examine what euthanasia talk consists of and how it typically progresses. Then, I will focus on the main roles that are assumed as individuals engage in this discourse. I will address how patients, families and *huisartsen* relate through euthanasia discussions and how participation is limited by what can and cannot be said and done. Finally, I will consider some of the consequences of euthanasia talk.

“Niks Meer Aan te Doen” (Nothing More to Be Done)⁹

Ms. Bosma was first diagnosed with rectal cancer in 1994. She was treated with radiation, then again in 1998 when a second mass was found in her lower intestine. By September 2000, at age 59, Ms. Bosma was told there was “niks meer aan te doen”

⁸ While a discussion of inequalities in the application of euthanasia discourse and euthanasia death is an important one, it is not the focus of this study. However, my findings do not support a “slippery slope” thesis that vulnerable populations (e.g., the elderly, disabled, etc.) are more likely to talk about and subsequently receive euthanasia death.

(=there was nothing more to be done) for her, her treatment phase was over. In September, Ms. Bosma came home from the hospital with the intent to die there.

Ms. Bosma was an independent woman, never married, but with a large circle of friends who visited often, a sister who came by daily and a elderly father who was fairly religious, sometimes confused and obviously distraut about losing his daughter. Ms. Bosma was a school teacher most of her life and told me she liked her life. I found her to be a matter-of-fact type person, direct and to the point when she was not talking about really difficult issues. Her huisarts saw her as a private person and, while he had a personable relationship with her, she tended to hold him at arm's length, maintaining a social distance that he found difficult at times. She was the first person that I interviewed in this study and I was nervous with her, scared to overstay my welcome or to ask questions that might upset her. At the end of our first interview she told me I needed to ask my questions, otherwise, she said, how would I ever get the answers? I liked her style.

I first met Ms. Bosma in September, during a planning meeting at her home scheduled by her huisarts, Dr. Muller. She was there, thin and tall with short brown hair and casual clothes, half sitting on the couch where she had been resting earlier as evidenced by a pillow and blanket. She sat with one hip raised and leaning on the arm rest so that she could sit sideways. The room was typical of Dutch homes, a small living room with a large picture window overlooking the back garden. With her were her sister, Janneke; her sister's wife; her father; Joeline, the nurse from the national home

⁹ With the exception of the Amsterdam location, all identifying names, places, and descriptions of people have been altered to protect the identity of study participants.

care service, Thuiszorg;¹⁰ myself and Dr. Muller. We shuffled chairs and people in this small space and negotiated the pouring of tea before Dr. Muller began the meeting. He asks if everyone knows what we are here for and reminds us that there is “niks meer te doen.” Ms. Bosma says yes and then someone asks her father if he understands. He says yes, she has cancer and she’s home now. Ms. Bosma says she’s here because she doesn’t want to be in the hospital anymore, the hospital tires her out. Dr. Muller says he understands and he and Joeline, from Thuiszorg, begin to lay out what types of services are now available to her, and the meeting meanders amongst issues of sleeping, eating and service options.

I didn’t see Ms. Bosma again until a housecall with her huisarts the following week. By then her living room had been transformed into the sick room that I got very used to seeing in the homes I visited. The couch had been replaced with an adjustable hospital bed overlooking the back garden and her side table was cluttered with tissues, untouched sandwich halves, medicine bottles and drinking cups with straws. During this visit, Ms. Bosma was having a lot of trouble with nausea – gagging while we talked to her – and I could smell a sickly sweet smell from the tube that drained the abcess in her lower intestines. Dr. Muller asks if she might want to go to the hospital and she says she doesn’t want to go, but she’s not sure. She is worried that her specialists are not treating her. She also says her friends don’t seem to know how to deal with her changes. They

¹⁰ *Thuiszorg* is literally translated to mean “Homecare.” It is the national organization which provides home care services free of charge or on a sliding scale fee to all Dutch citizens. Services include nursing and nurse assistance up to four times a day in the home, including an all-night overnight service. *Thuiszorg* employees set out meals, provide all manner of hygiene care, and even provide a weekly cleaning service for the home. While in the Netherlands, I also conducted participant observation with personal care assistants with Amsterdam Thuiszorg.

bring things she used to like and she knows they are just trying to be helpful, so she pretends she still likes it. She smiles a sweet shrugging smile and we smile back.

Three days later we have our first interview alone together and I find out that Ms. Bosma did decide to go the hospital, but there was nothing they could do for her. I asked if she would go to the hospital again in the future and she says “definitely no more.” Knowing my research topic, she offers that she has read information on euthanasia but knows it’s not for her. Like many others, however, Ms. Bosma has misconceptions about how euthanasia actually works. She thinks, for example, that there is a mandatory 5-day waiting period between deciding for euthanasia and receiving it.¹¹ How could you schedule something like that?, she asks. Also she has already experienced how bad it can get and she has morphine for the pain so she doesn’t need euthanasia. She tells me she isn’t scared about the future, because she’s had a good life.

At the end of October, Ms. Bosma again went to the hospital to have the drain to her intestines checked. At that time, and unbeknownst to us, her specialist raised euthanasia as a “treatment” option. This I came to find out was not done frequently in the Netherlands, but was also not unusual. The next day Dr. Muller and I pay a housecall and find Ms. Bosma propped up in bed facing the back garden and smoking a cigarette. Janneke, her sister, is there. Dr. Muller asks if she’s going to put the cigarette out and she does without turning to face us. Dr. Muller gets up to stand at the foot of her bed to better talk to her and she tells him she was in the hospital because the last five

¹¹ Ms. Bosma, like many Dutch people I met, seemed to be slightly confused about the regulations for lawful euthanasia. There is no mandatory five day waiting period, but doctor’s do attempt to stretch out the time between a request for euthanasia and a euthanasia death. I found the most common misunderstanding about euthanasia to be that once you decided you were ready for euthanasia, it was your decision alone to make and it could occur when you wanted it (e.g., that day). This was not the case.

days or so she's been having bad pain and can feel another tumor growing. She reaches down to her abdominal area to show us, coughs, and immediately cries out in pain.

"Ow, ow, ow," she says wincing and we all pause. She is quiet for awhile then apologizes, "sorry." "No, don't be sorry," Dr. Muller says looking concerned. She's scheduled to go back to the hospital on Monday, she says, but she thinks it is inoperable. Dr. Muller asks if they are going to change her drain. She doesn't know but she's had a fever.

"You have three options," Dr. Muller tells her, "one, they can change your drain; two..."

"Euthanasia," she interrupts. She's talked to the specialist about it and doesn't know if she can decide five days in advance but she has a lot of pain and good days and bad days, and....

Dr. Muller sits down in a chair at the foot of her bed and I look around to see her sister silent, sitting in a chair in the corner. Dr. Muller listens, pauses, then says yes, euthanasia is a possibility and she can have the specialist do it in the hospital or he can do it for her here at home. She should think about who she is most comfortable with and it won't make a difference with him. Ms. Bosma's sister says, no, they don't know the hospital doctor so well and Ms. Bosma adds that she doesn't want to go to the hospital. First, he says, she must have several discussions about it with him and also with her family. That is really important, he emphasizes, that you talk to your family. Does your father know you're thinking about this? No, she hasn't told him. He can help with that if she wants. He can, for example, schedule a family meeting to talk about it with him. Next, she must make her written euthanasia declaration, and make plans for it but that

does't mean she has to go through with it. Some patients just make the plan, then things progress and they don't choose euthanasia, he says. Her sister asks if they have to wait another five days if they cancel the euthanasia. No, that's not necessary. There is no five day waiting period, it's just that you have to plan it. Finally, a second doctor must come see her to talk to her about it. Dr. Muller asks if her sister has any questions. No. Ms. Bosma? Questions? No. He goes on to talk about medications, then asks Ms. Bosma if he should make a note that this is her official request for going forward with euthanasia planning? Yes, she says adamantly. We leave and before biking in different directions – he to his next appointment and me to mine, we share our surprise at the sudden request for euthanasia and Dr. Muller tells me that her father is really religious and she doesn't want to be a disappointment to him.

Two days later, I meet with Ms. Bosma again for an interview and we begin by talking about how she's feeling. We talk about pain and she says she hasn't had much pain in her life, and now she has some but she takes the pain killers and she doesn't mind them but it does make her fuzzy. We're talked about feeling good and the false optimism she gets, like when she felt good last week. She says she feels "akelig," it's a "yucky sick" feeling, not really pain, but yucky sick. She sleeps a lot and likes that because it makes her feel better when she wakes up. Things have been up and down, she says, fever at night and problems with the drain burning and feeling hot. The fever, she says, makes her feel sicker. I ask if she thinks that between Dr. Muller and the hospital they can fix that?

Ms. Bosma: I think so, yes. Tomorrow I have an appointment because I want to set in motion plans for euthanasia. The doctor from the hospital said that too, that

otherwise I'm pretty healthy and this could last a long time. So he said, we've done all we can do and I find this a good reason to say, now we can't cure you and you won't remain healthy, it can only get worse and worse.

Frances: So you choose for euthanasia on account of your talk with the hospital doctor and because it might last a long time?

Ms. Bosma: Yes, exactly. No, but I don't know when it will happen. That could be well down the road. It's dependent on the situation and how sick I feel or not. But if I really feel ill, then I can't keep going. Then it may be too late to bring it [euthanasia] up.

A month after our first interview together, Ms. Bosma explains to me that she is clear now on how euthanasia works. Before she thought that once you set a date, you had to go through with it. "But now I understand that you don't have to. It works another way. If you change your mind and say no, then you don't have to go through everything all over again to set a new date." She is still unsure, though, about being able to say okay, I'm going to die on this day. The fact that she can do it at home with her huisarts is also important. She doesn't want to go back to the hospital anymore. Why, I ask, why don't you want to go back to the hospital? She said, "It really repels me. No, I just can't go there. I've been there a lot and usually in the same hospital and let me tell you, this hospital is not a pleasant place. Sometimes when I go there, there are other people who are really sick there. Then you hear nothing but people with their big problems and I have my own problems, so I don't need to hear about everyone else's."

The following day, I am back at Ms. Bosma's for the family meeting that Dr. Muller has scheduled to discuss her euthanasia request. It is a typically wet Dutch day and I arrive soaked to the skin on my bicycle in spite of all the gear I wear regularly to

hold the water at bay. I wait for Dr. Muller outside Ms. Bosma's under an overhang and watch through blurry, wet glasses as he pulls up non-chalantly on his bicycle. He's wearing his leather today and somehow arrives rumpled but relatively unscathed by the rain. Janneke lets us in and I must peel wet layers off in the foyer. How do you do it, I ask him, how do you stay dry? Dr. Muller smiles at me that amused and sympathetic smile reserved for us foreigners.

Everyone is here: Ms. Bosma, her father, Janneke and her partner. The room feels a little tense this time, with Ms. Bosma smoking, propped up in her bed and us trying to arrange ourselves once again in chairs around the small, crowded room. Tea is poured and Dr. Muller begins the meeting by asking what the main complaint today is. Ms. Bosma starts to answer and then stops, staring out into the back garden. Dr. Muller prompts her by summarizing some things (not mentioning euthanasia yet) and she again she sits there, not responding. He asks if she has something she wants to say to everyone and she starts to speak, but it's broken speech, nothing about euthanasia, and again she falls quiet. I watch her and notice the glazed morphine stare of someone on high doses of pain killer and assume that her drugs are affecting things today. We wait. Dr. Muller starts again, explaining that he was here earlier this week and talked about the possibility of euthanasia, which is why everyone is assembled today. Mr. Bosma, tall and skinny like his daughter, speaks up, volunteering that they have talked about it. And how do you feel about it, Dr. Muller asks. Mr. Bosma starts to answer then begins to cry. He says he understands but would be more comfortable with it if he knew she only had a short time to live. Dr. Muller says it is important that he respect her decision, that is important. Mr. Bosma nods yes through his tears. The doctor says it is her decision but

it is also important to talk about it with family and friends. Janneke says she understands. Dr. Muller turns again to Ms. Bosma and asks her why does she want euthanasia? She stares. What is so terrible, he asks? No answer. Her sister offers that maybe it's because she is sick all day long. Ms. Bosma says no, that's not it. "Oh, I'm not right," she replies. Silence. Dr. Muller presses, asking her what makes it so difficult to talk about. No answer. Is it because we're all here, her sister's wife asks. No, she answers. Well, says Dr. Muller, you'll have to think about that because when the SCEA doctor¹² comes, that's what he'll need to know. Janneke agrees, yes, you'll have to think about that, and suggests that maybe the pain killers are a problem today. Dr. Muller – addressing everyone now – explains that the first step is to make a euthanasia declaration, which is from Ms. Bosma and states in writing that her decision is voluntary. The Dutch Voluntary Euthanasia Association (NVVE)¹³ can help them with that. Then a second doctor will come to talk to her. On the technical side, they must decide whether to have a drink or a needle but that is the technical side. Half of the people who talk about it don't do it because they choose not to or because sickness overtakes them. What we are talking about, he says, is just preparing for it. Outside, Dr. Muller tells me, "it is doubtful now."

¹² SCEA (*Steun en Consultatie bij Euthanasie in Amsterdam*) is an organization of and for doctors in the greater Amsterdam area who have questions about euthanasia or need to schedule an independent, second opinion for a euthanasia or assisted suicide case. It was created in 1997 in collaboration with the Royal Dutch Medical Association (KNMG) and the *Amsterdamse Huisarstenvereniging* (AHV) (Onwuteaka-Philipsen and Wal 1998).

¹³ The *Nederlandse Vrijwillege Vereniging Euthanasie* (NVVE) was formed in 1973 by a group of doctors in reaction to the *Postma* case. Today, the NVVE has a membership of over 100,000. The goals of the NVVE are to advance a "social acceptance of the existing legal possibilities towards a free choice on the end of life;" to advance a social acceptance of legal possibilities that are not currently within the scope of existing regulations; and to advance the "recognition of free choice [at] the end of life" as a human right (NVVE 2004).

On a housecall the next day, Dr. Muller receives a copy of the signed euthanasia declaration from Janneke with signatures from Ms. Bosma and the whole family.¹⁴ The next day, Ms. Bosma checks to see that her declaration is sufficient. It is and now, Dr. Muller states, the preparation has been done. Now you must tell me when you want to have it, when for you the time is near. Not until then, will the second doctor come. Well, she says, it will depend on what happens with the drain and that it is difficult to know. What about the pain, Dr. Muller asks, as they move on to other topics.

Two months after her terminal diagnosis and two weeks after her initial request for euthanasia, Ms. Bosma died of her disease. She didn't ask for euthanasia again, and in the last days before her death, Dr. Muller said he pretty much knew the euthanasia was not going to go through. She declined quickly at the end and was in some pain, high fever, benauwdheid,¹⁵ and in and out of consciousness. I asked Dr. Muller afterward what he felt was her main reason for requesting euthanasia. He said, to prepare for a future that might be worse. He was disturbed that she couldn't talk much about her request and thought (after initiating a consultation with Joeline from Thuiszorg) that it was because she wasn't ready to leave her family. If her request had gone further, he said, he would have needed her to talk more openly about why she wanted it. According to Joeline, it was a good experience for Thuiszorg employees. Ms. Bosma wanted to stay at home and with only her sister to help, Thuiszorg was able to grant her wish. Like Dr. Muller, Joeline was sceptical about her euthanasia request, saying that it seemed to come

¹⁴ All of the euthanasia declarations that I read were signed by family members as well as by the individual requesting the euthanasia.

¹⁵ *Benauwdheid* means either physical discomfort (a choking feeling) or emotional discomfort (anxiety) and was a word that I heard more than once by patients and physicians alike to describe that amorphous state between physical and emotional discomfort at the end of life.

more from the hospital doctor than from Ms. Bosma. Ms. Bosma, she said, was happy with life and wanted to live it.

Stages of Euthanasia Talk

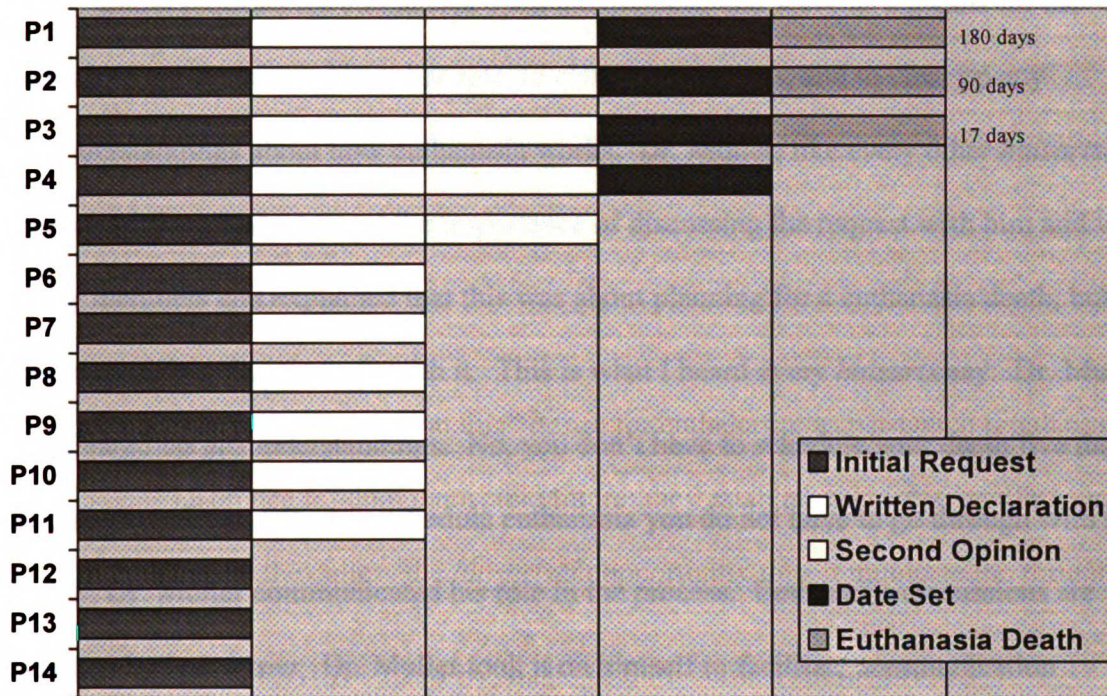
Compared with the story of euthanasia death from the prologue, Ms. Bosma's story (above) is the one more typical in the Netherlands. It is the story of euthanasia talk. Using participant observation data with 14 individuals with euthanasia requests (including Ms. Bosma) and countless testimonials by families and physicians throughout the study year, my research revealed a uniformity to euthanasia talk that conforms to at least five measurable stages. These stages make up the framework for euthanasia talk and include: (1) initial euthanasia requests, (2) written declarations, (3) second opinion appointment, (4) scheduling euthanasia, and (5) euthanasia death. These stages are represented by distinct sections within euthanasia discussions that are typically bound at the front end by the patient initiating a move forward in the planning process and at the back end by the *huisarts* pausing the discussion, leaving the onus on the patient to re-start the process.¹⁶ Figure 2.1 demonstrates the movement of 14 persons as they initiated and progressed through these five stages of euthanasia talk.

The five stages are as follows. First, there are initial verbal requests and written declarations that occur anywhere from years before death to weeks and days before death. These tend to be initiated at the first sign of serious illness, but can occur before that and well after that for a number of different reasons. Initial requests establish the first official

¹⁶ One argument could be made against a "slippery slope" in the Netherlands because of how the *huisarts* stalls the process at the end of each stage in the discussion. Because the onus is on the patient to re-start the process after the completion of each stage, the patient must be the on-going driving force behind a euthanasia request becoming a euthanasia death.

evidence necessary for a “long standing” desire for euthanasia (as per Dutch regulations); they serve as insurance for an unknowable future; they establish a *huisarts*’ willingness to perform euthanasia; they allow the *huisarts* an opportunity to communicate the formal

FIGURE 2.1. Five Stages of Euthanasia Talk (n=14)



and informal rules for euthanasia negotiations; and they allow the *huisarts* to clear up any misnomers about how euthanasia gets done. In Ms. Bosma’s case, her initial request came relatively late in relation to her illness. Prior to her request she made it clear that euthanasia was not something she was interested in and this was her stance after many years living with cancer. Her request for euthanasia came well into her terminal phase (which is not typical), raising some questions about the authenticity of her request with her *huisarts* and the home care team. The suggestion for euthanasia did not come from Ms. Bosma herself, it came from her hospital specialist who suggested euthanasia as an end-of-life option. This is something that does occur, though somewhat infrequently, in

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the Netherlands. Ms. Bosma knew that no discussion of euthanasia would proceed without an established official record of her request, so within days of her initial request, Ms. Bosma submitted her written declaration, confirming with her *huisarts* that it would be sufficient to proceed.

Initial requests for euthanasia open the dialogue and serve as a means for the *huisarts* to communicate his or her role, to clarify procedures, and to clear up any misunderstandings about how euthanasia works. Dr. Muller, like every other *huisartsen* with whom I worked, stressed the importance of discussing the request with him and with family members and explained that this was about planning for a euthanasia death, but not necessarily going through with it. This is what I heard every *huisarts* say. Dr. Muller also cleared up misunderstandings. No, you don't have to schedule your death five days in advance and, no, once you schedule euthanasia you do not have to go through with it. Finally, Dr. Muller communicated his role in the process. Euthanasia discussions are managed by *huisartsen*. Dr. Muller took it on himself to facilitate communication between Ms. Bosma and her father. It was he who called the family meeting and it was he who took charge of the content, speed, and trajectory of the discussions.

Requests (verbal and written) must be repeated and patients who do repeat their request are asked to explain why they want euthanasia over and over again. In Ms. Bosma's case, she was not able to articulate why she wanted it, causing her *huisarts* to pause the discussion after the written declaration and before the scheduling of a second opinion. The pause is critical. Like all other *huisartsen* with whom I worked, not one doctor said to a patient outright that they could not have a euthanasia death. Instead, *huisartsen* pause the process; they slow it down and wait it out. In Ms. Bosma's case,

these pauses (without outright rejection of her request) allowed her to relax, knowing that *if* she wanted to proceed the door was still open. From the perspective of her *huisarts*, however, it was clear that there would need to be firmer evidence that the request was genuine and met the proper legal requirements to proceed.

Initial requests, written declarations and subsequent repeated requests are typically as far as most patients go in the five stages of a euthanasia discussion. In my sample, only 5 of 14 initiated setting an appointment with a second doctor to confirm that the request for euthanasia met legal regulations. Once someone gets a second opinion, the likelihood of a euthanasia death occurring goes up considerably. Of 5 who received a second opinion, 4 scheduled a date for euthanasia and 3 died euthanasia deaths. Most second opinion appointments occur within 24 to 48 hours of the euthanasia death and all are arranged by the *huisarts*.¹⁷ For the *huisarts* to agree to schedule a second doctor, he or she must be sufficiently convinced that the request meets the policy regulations¹⁸ and his or her personal and professional limits of what constitutes a proper request. Once a second opinion is scheduled, however, there are still several events that can stop a euthanasia death from occurring. The patient must repeat their request to schedule a date for euthanasia (stage 4) and repeat their reason for their request the day the date is scheduled (stage 5). If the individual changes their mind, they must be able to tell the *huisarts* or a family member (or at least hesitate when asked why they want the process to

¹⁷ In the early years of legalized euthanasia, physicians would send their euthanasia patients to a colleague for the second opinion consultation. Some Amsterdam physicians argued that this did not constitute an “independent” second opinion and thus formed SCEA, a local organization that provides independent physicians for consultation on euthanasia cases. The model was well received, spawning a national organization, SCEN. Only recently, in January 2004, was SCEN de-funded leaving many physicians once again without an “independent” second consultation for euthanasia cases.

¹⁸ For more on euthanasia policy, see Chapter 3.

proceed causing the *huisarts* to once again halt the proceedings).¹⁹ Family holds the power to stop a euthanasia death by opposing it so strongly that the patient relents. Just as likely, however, the illness itself may stop a euthanasia death in these final stages by either proceeding so quickly that the patient dies or by going into some form of remission. Of 5 who reached the second opinion stage, one woman died in her sleep the day of her second opinion appointment and one woman cancelled her date with euthanasia due to pressure from her daughter.

If you decide that you want a euthanasia death in the Netherlands (if you meet the guidelines and know how to properly engage in euthanasia talk), then it is a matter of how much time it takes to get euthanasia. Verbal requests must occur repeatedly over a course of months and years, if time is available. As long as the illness is not progressing too quickly, forcing a shortened time frame, patients must discuss their choice for euthanasia with their *huisarts*, repeating their request and repeating why they want it over and over again. The timeframe from initial request (and one must determine which request to measure) and euthanasia death varies considerably, ranging anywhere from years to 4 or 5 days. Probably the most accurate measurement of how much time it takes to receive euthanasia in the Netherlands would be a measurement from the first verbal request made at the most recent illness episode to euthanasia death. In my small sample, that measurement ranged from 17 to 180 days.

¹⁹ Persons who are able to die home deaths, versus death in a hospital, *verpleeghuis* (acute care facility), or *verzorgingshuis* (nursing home), tend to be patients with the least complications in terms of care. This means that many of those who die home deaths tend to be more cognizant than those suffering and being treated for more complex conditions. Euthanasia-the-act can be a race against time when the illness or the treatment limits the patient's ability to be aware or communicate.

The reason some people make the choice to go through with euthanasia death and others do not is not easy to determine or communicate. To the *huisarts*, the patient often said, “*Ik wil het niet meer*” (“I don’t want it anymore” or “I’m through with it”) and offered simply – in the language of the policy guidelines – that their suffering was indeed “*ondraaglijk*” (“unbearable”). What many patients seemed to be asking for was an insurance policy of sorts; in the event of a future too horrible to bear, they wanted to know they had an option. Throughout the course of euthanasia discussions, patients would formulate plans around an uncertain future; a future filled with either too much suffering or too many limitations. Patients said if I can’t make my art anymore or if they remove another limb, I won’t want to go on. Many, however, change their mind when they arrive at that future point and realize that maybe their losses and suffering are bearable, at which time they formulate a new plan for a new day. When someone gets closer to choosing for euthanasia, it usually means that the uncertain future has come to meet his or her expectations. In other words, when future and reality meet – the future they have visualized becomes what they thought they could not bear – some make the choice to schedule death.

Of those who talked about euthanasia but did not die a euthanasia death, there were three reasons why they do not complete their plans for euthanasia: (1) they wanted to live the life they had left; (2) family opposition was enough to influence their choice to stop the euthanasia from going through; or (3) their illness was either not severe enough, in remission or progressing too quickly to allow time for a euthanasia death. Of 11 who initiated euthanasia requests but did not die by euthanasia, three decided they wanted to

go on living; three had family members who strongly opposed the euthanasia; and five had illnesses that interfered with the process.

Participants

While euthanasia talk is engaged in many different ways by different participants, there are norms that shape who engages in euthanasia talk and the roles they assume.

There are three main participants to euthanasia talk as it occurs in the context of home: patients, family members, and *huisartsen*. While there are a number of peripheral participants, including extended family; friends; *Thuiszorg* employees; hospital physicians and staff, etc. my focus will be on the three participants that were most prominent in euthanasia discussions. In this section, I will highlight the roles that these participants assumed.

The Patient. Consider Ms. Bosma's position in her euthanasia discussions. For her, the tension was between public rhetoric that euthanasia is an "individual's right to choose" and the practical reality of anyone considering euthanasia. The reality is that most people do not make decisions without consideration of and consultation with the people they care about.²⁰ Ms. Bosma, like most others included in this study, made her request in the context of family and societal relationships. Initially, Ms. Bosma was apprehensive about telling her father of her euthanasia request, worried what he might

²⁰ For this point, I am grateful to an audience member who spoke up at one of my first presentations of preliminary findings with an audience of physicians, social scientists and bioethicists at the Vrije Universiteit in Amsterdam in 2001. I had been talking about the role of the family and audience members were surprised to find them so involved in the practice of euthanasia (particularly considering how absent family members are from the policy). We brainstormed about what that might mean and one audience member suggested that, of course, family is involved because most decisions that get made in life, get made in the context of family, society and relationships. For more on the role of the family in euthanasia discussions, see Chapter 5.

think. By the time Dr. Muller convened the second family meeting (the one to discuss her euthanasia request), her father, though very distraught about losing his daughter, made it clear he was not going to oppose her choice for euthanasia.

The person who was not really prepared to go forward, however, was Ms. Bosma. All patients are required in this process to communicate their wishes. They must ask for euthanasia, explain why they want it and what is “unbearable” enough to warrant it. They must repeatedly initiate requests for euthanasia and they must be able to respond each time they are asked to explain the why and the what. Through her half-hearted euthanasia request, Ms. Bosma communicated to family and Dr. Muller her fear of dying in too much pain and suffering, and her fear of the unknown. At the same, she communicated her reluctance to go through with euthanasia. Euthanasia was not really something she had considered for herself previously and in the end, she really was not able to answer the question, why. Why the request? For her, her request for euthanasia was an insurance plan for an unpredictable future and not something that she would choose to do unless reality (and not a distant future) truly became “unbearable.”

Ms. Bosma was not going to receive euthanasia unless she changed how she answered the question, why. There are “red flags” that *huisartsen* look for and as red flags go, that was a big one. Other red flags, that occurred in other case studies, include asking for euthanasia the wrong way. For example, you cannot say “I want to die,” but you can ask for euthanasia by saying “*Ik wil niet meer*,” which means “I don’t want it anymore.” A wish for death signals possible suicidal thoughts or depression, both red flags for *huisartsen*. It is a subtle but distinctive difference to say you are tired and do not want to go on anymore versus wishing or wanting death to occur. Proper euthanasia

requests are not death wishes. Another red flag is when someone is estranged from family or does not have family involvement. *Huisartsen* attempt to demonstrate consensus around a request for euthanasia, which can be thwarted by a lack of participating family members. Individuals without family in the Netherlands (with the exception of elderly patients who have survived all of their living relatives) signal to the *huisarts* that something is wrong. In Ms. Bosma's case, she was not married and had no children, but she was well connected to her father and her sister, and had many friends that she had made during her years as a school teacher.

The Family. Ms. Bosma's family also played a prominent role in her care and in her euthanasia discussions. Her sister visited almost daily and her father was there at least every week. Without family involvement, most individuals who are dying in the Netherlands do not remain at home to die. Between the *huisarts* and *Thuiszorg* (the National Dutch Homecare organization), individuals can receive daily in the home: medical and nursing assistance, personal care (e.g., meals, bathing, and dressing wounds), housekeeping assistance, medical equipment, home modifications and overnight respite. A typical day in Dutch homecare might include a visit or two from the *huisarts*, a visit from a registered nurse, three hour-long visits from a personal attendant and an all-night stay by a personal attendant. Even so, most individuals with mobility or illness complications at the end of their life cannot stay home without additional (family) assistance. Ms. Bosma's family, then, were critical both in allowing her to stay at home and for their participation in her request for euthanasia. Once euthanasia requests have been initiated, family discussions was one of the main activities stressed by *huisartsen*.

Family must be included in euthanasia discussions and any potential conflicts (like how Ms. Bosma's father viewed her request) would need to be addressed.

Contrast that with family involvement in euthanasia discussions that occurs with individuals who live in nursing homes (*verzorgingshuizen*). Nursing homes are also the realm of the *huisarts*, and seven of my study participants lived in nursing homes.²¹ These were staged homes that ranged in the level of care available and included both efficiencies (without kitchens) located off a unit, much like a hospital floor, and one- and two-bedroom apartments (with kitchens) and access to nursing and personal care via a call button in the home. Nursing homes are where people go when they do not have families to aid with their care, when their illness is a little too complicated to care for at home, or (in the rare case) when they prefer the company or the security of such a home. Of those living in nursing homes that entered into a euthanasia discussion with their *huisarts*, family involvement was significantly less. Still, of the seven who lived in nursing homes, only two had absolutely no evidence of family involvement. One was a 91-year old woman, never married, and the other was not in the study long enough to determine family involvement.

The *Huisarts*. The irony of the phrase, "*niks meer aan te doen* (nothing more to do)" is never in sharper relief than it is when you look at what Dutch *huisartsen* consider as part of their everyday job as general practitioners, particularly once a euthanasia discussion has been initiated. Let us consider the position assumed by Dr. Muller at the end of Ms. Bosma's life. The initiation of euthanasia in end-of-life discussions signals a call to action for the *huisarts*. Now clearly there is something to do. *Huisartsen* must

orchestrate the planning of the euthanasia act, while evaluating whether the request meets societal (legal), professional (medical), and personal boundaries for proper euthanasia. For Dr. Muller, and most *huisartsen* with whom I worked, their roles involved establishing ground rules for euthanasia discussions, scheduling family meetings to discuss the request, adding a few extra housecalls to discuss the request, and managing the progression of the euthanasia discussion through the stages outlined previously in this chapter (each of which includes its own set of activities and rules for engagement).

Like other *huisartsen*, at the first mention of euthanasia Dr. Muller firmly established himself as the person in charge of the discussion. No *huisarts* with whom I worked (regardless of personality) failed to take a leadership role in this discussion. While Ms. Bosma could always re-start the dialogue, Dr. Muller took control of what topics were relevant to the discussion, how quickly the discussion progressed, and who was to be included.

According to Dr. Muller, family should be intimately involved, many discussions should take place, and within those discussions any serious oppositions to the request must be aired. Dr. Muller's role as facilitator of family discussions (e.g., making sure that the father understood what his daughter was requesting and accepted, or at least respected, her decision) was typical for nearly every *huisarts* with whom I worked. It was not unusual, for example, for *huisartsen* to initiate contact (not at the patient's request) with estranged family members in the hopes of facilitating a reunion before death.

²¹ Of 25 patient participants, 17 lived at home, 7 in *verzorgingshuizen* (nursing homes), and one lived at home until a sudden diagnosis of end-stage cancer put him first in the hospital, then in a *verpleeghuis* (an acute care facility), where he died a euthanasia death.

Huisartsen assume an integral position in relation to family in the Netherlands. Part of that may be because the style and structure of general practice in the Netherlands is unique. Many *huisartsen* have known their patients for many years, often treating them, their children, and their children's children. But it is not just about the length of the relationship, it is about the quality and the nature of it. Compared to other physicians, *huisartsen* generally consider themselves a different breed of doctor in the Netherlands. They pride themselves on being the doctor that treats the "whole" patient in the context of their illness, their daily stresses and their relationships (Groenewegen and Delnoij 1997; Muijsenbergh 2001). Changes have been occurring, however, that are impacting the nature of the *huisarts*-patient relationship; city *huisartsen*, especially, are feeling the impact as their patient populations grow to include more non-Dutch or non-English-speaking immigrants and more transitory groups. Dr. Muller (like a growing number of his city counterparts) had not known Ms. Bosma that long and, in fact, expressed regret that he and Ms. Bosma did not draw into a closer relationship as a result of their euthanasia discussions.

As will be discussed in greater detail in Chapter 6, *huisartsen* assume a very specific role in relation to patients and families in the dialogues that occur around euthanasia at the end of life. In spite of popular U.S.-based rhetoric which circulates in some degree in the Netherlands around an "individual's right to choose," in the Netherlands it is (in practice) the *physician's* right to manage euthanasia talk and (where needed) stall euthanasia death. *Huisartsen* are clearly in control of euthanasia talk and they see their role in these discussions as facilitators of the dying process, a process that is explicitly based in social relationships.

Consequences of a Discourse

Foucault claims that through discourses, death and dying have come to be regulated and normalized. What had previously been a random, unalterable event (death) has passed into “knowledge’s field of control and power’s sphere of intervention” (Foucault 1978:142). Euthanasia discourse serves an important function in Dutch life. By engaging in euthanasia talk, Dutch citizens (*huisartsen*, patients and families) affirm their roles (their bonds) within family and society. Following the work of Emile Durkheim (Durkheim 1912; Durkheim 1951), David Schneider suggests that categories, such as kinship, nationality and religion, all constitute the same ideological form; they all “provide for relationships of diffuse, enduring solidarity” (Schneider 1977:67). Maintaining unity and solidarity, he says, is what people do.

Maintaining social bonds is what I believe many Dutch people engaged in euthanasia talk are doing at the end of life. Euthanasia has become normalized within Dutch society; it is equated with end of life. When someone gets cancer, euthanasia (like radiation and palliative care) is considered an option. But it is *the talk* of euthanasia that is prominent at the end of life, and much less so *the act*. For *huisartsen*, talk of euthanasia gives them something to do when treatment has ended. *Huisartsen* control euthanasia discussions and the course of the stages leading up to a death by euthanasia or by natural causes, but their role is not limited to planning a euthanasia death. *Huisartsen* believe that their role is to manage family relationships and play their part in helping their patients die well. Families come to play a prominent role as well. By their presence and the aid they offer in the home, families help make it possible for their loved ones to die

there. By participating in euthanasia discussions, they help *huisartsen* feel comfortable about any decisions to go forward with a euthanasia request. And as a microcosm of society, families and homes offer dying individuals a web of relationships and a place where they can remain connected up to unconsciousness or death. For the dying person, euthanasia talk reaffirms their connection to self, family and society. Euthanasia talk gives individuals an active voice (control) at a time when action is increasingly thwarted by personal and social losses. Because of the emphasis by the *huisarts* on family involvement, it affirms the person's role and place within their family. Finally, because of the prominent role of *huisartsen* (almost a daily presence at the end of life), which is further facilitated by the initiation of a euthanasia request, Dutch people remain connected to their society. People who die at home in the Netherlands, engaged in euthanasia talk, do not die alone or sequestered. They die actively engaged in Dutch ways of living and dying.

I do not, however, want to suggest that Dutch death and Dutch engagement in euthanasia talk fosters only social cohesion and peaceful deaths. Social bonding is just one consequence of engagement in euthanasia talk. Discourse is not static; it is a discursive act, which means that individuals who engage in euthanasia talk are engaging in a fluid process that is not always perfect and does not always function to the benefit of participants. In the following chapters, I want to examine the elements that have influenced the production of euthanasia discourse and euthanasia talk (Chapter 3). I also want to explore in greater depth the main roles that participants in this discourse assume and when engagement in euthanasia talk does and does not foster social bonds (Chapters 4, 5 and 6).

3. Euthanasia in Culture and History

April 10th, 2001 was a crisp, sunny day in The Hague. The kind of day that we visitors to Holland look forward to after a long, wet winter with only rare glimpses of the sun. It was the same day that euthanasia was debated and passed by the First Chamber of the Dutch legislature, solidifying the Netherlands as the country with the longest-standing, legal practice of euthanasia. I arrived in The Hague by train and met my colleague and friend, Albert Klijn, a socio-legal researcher with the Ministry of Justice (WODC). It was 10 o'clock in the morning and by 10 o'clock that night members of the First Chamber were expected to vote on whether or not to pass euthanasia into law. It was a symbolic gesture by a liberal majority made up of the Labor Party (PvdA), the People's Party for Freedom and Democracy (VVD), and Democrats '66 (D66). The "Purple Cabinet" as they were popularly called, with the Green Party (GL), would move the much-debated practice of euthanasia sanctioned by court decision in 1984 into the realm of legislation.

Albert and I find the public viewing room located one building over from the First Chamber. This is where people without tickets can sit and view history being made by satellite feed. There are surprisingly few people here. Outside, only a handful of protestors – one group of four standing around a van with the back doors opened to reveal a large statue of the Virgin Mary and another group of about 20 assembled around a priest in robes. The priest was speaking quietly to the crowd. Both groups are decidedly tame, even by Dutch standards. Inside, the viewing room is stark with a line of

mostly empty folding chairs facing a large television screen. Maybe 20 to 30 people are scattered around the room.

Albert fills me in. He says the Chamber convened last night at 7:00 p.m. with opening statements by the spokespersons of each political party. The Termination of Life on Request and Assisted Suicide (Review Procedures) Act, as it is called, passed the Second Chamber in November 2000 and with the current liberal coalition in place, Albert says, there is no question that the law will pass the First Chamber today.²² I've read something about the Dutch system. It is an interesting one based on a multiple party system that regularly sees as many as 12 or more parties winning seats in both the First (Upper) and Second (Lower) Chambers. This means that no one party wins a majority, but there are a few who tend to come out on top. Once elections are completed, those with the most seats and similar politics will band together to form a coalition. In 2001, PvdA, VVD, D66, and the Green Party formed the majority coalition supporting the euthanasia law, which was opposed most vocally by the Christian Democrat Party (CDA), the Reformatorische Politieke Federatie (RFP), Gereformeerd Politiek Verbond (GPV) and the Socialist Party (SP).²³ According to Albert, the liberal majority formed out of the elections of 1994, taking over the majority position from a more conservative Christian-right coalition. The Purple Cabinet, he thought, saw their time in office as a

²² The Dutch Parliament, like ours, is made up of two houses: the First Chamber (equivalent to our Senate) and the Second Chamber (equivalent to our House of Representatives). Legislation must begin in the Second Chamber where members have the ability to amend proposals and then must be either accepted or rejected by the First Chamber.

²³ The majority parties in opposition over the proposed euthanasia law were as follows. The majority in favor of the law were PvdA (the labor party), VVD (known as the traditional liberal party), D66 (liberals thought to be left of VVD), and GL (the swing party made up of the former Communist Party, environmentalists and former Catholic politicians). Parties opposing the law included CDA (the Christian Democrats), SP (the left-leaning socialist party), RPF and GPV (two orthodox religious parties, both represented by one speaker in the debates, Mr. Schuurman).

“window of opportunity” to turn away from more conservative, religious right policies and to pass, instead, policies that support what they believed were popularly held beliefs around social life in the Netherlands. Since their election, the Purple Cabinet had passed laws supporting late stage abortion, homosexual marriage, and today on the agenda – euthanasia.

This morning it is time for the Ministers of Justice (Korthals) and Health, Welfare and Sport (Borst) to speak, to reply to comments made last night by Chamber members. First the Ministers will speak; Chamber members can reply; the Ministers will speak again; and then the members will vote. We watch the television screen and Albert tells that the First Chamber is known as a “chamber of reflection.” Members must say either yes or no, but they cannot make amendments or changes to the law. They can, however, offer suggestions and hope that their suggestions get incorporated. Unlike the Second Chamber, the First is arranged so that all party members are seated mixed throughout the room, instead of allowing party affiliates to sit together. This, he thinks, facilitates the “reflection” aspect.

I focus in on the screen and hear Timmerman-Buck (CDA) ask about the reporting procedure for physicians performing euthanasia. What, she asks, happens when we normalize euthanasia, as opposed to having euthanasia be an exception to the law? Minister Korthals talks about reporting frequencies (how often doctors are reporting euthanasia) and mentions the van der Wal and van der Maas studies (originally called the Rammelink Study, commissioned by the government to study Dutch euthanasia prevalence and practices). Timmerman-Buck pushes, saying we want more doctors to report when they are performing euthanasia; that is the goal of the euthanasia

law, right? Minister Korthals agrees and says they will prosecute doctors if they fail to report.

Next, Minister Borst begins her speech. She says that the proposed law reflects a “respect for life” and she reminds us that the world is watching. In our system, she says, you can have care until the “bitter end” and mentions the role of nurses who give patients the time and space to talk about what they want at the end of their life.

Schuurman (RPF/GPV) interrupts, says that he is worried that euthanasia will become an obligation. There are shortages in available care, which might make euthanasia too easy an option. Minister Borst counters, saying “a euthanasia request is not euthanasia” and that “no one is obliged to ask for euthanasia.” Schuurman interrupts again to talk about the “toetsingscommissies,” the regional assessment committees set up in 1998 to monitor the “requirements of careful practice” as outlined by the Royal Dutch Medical Association. Are they doing their job, Schuurman asks. Minister Borst continues, reflecting on the importance of palliative care. “Good palliative care,” she says, “is integral to good healthcare.”

I ask Albert, what’s up with all the interruptions? He tells me that that is how it works. Members can interrupt at any time, with no acknowledgement from the chairman (the moderator) or the speaker. Members must only walk up to the podium and speak into the microphone. Borst and Chamber members continue in this pattern, “reflecting” on the role of the regional assessment committees, the role of the doctors, nurses, religion and government.

We break for lunch and Albert scores two passes to sit in the chamber for the remainder of the day. At one o’clock the First Chamber reconvenes to talk briefly about

the Constantijn marriage (they are voting on whether to approve the marriage of the Queen's son), with plans to continue with euthanasia discussions at 3:30 p.m. We enter the First Chamber by the second floor balcony; visitor seating that overlooks the chamber on two sides. It is a room befitting such an occasion. It is a large hall arranged similarly to a Dutch church with half of the main room facing the other half at a slight angle, seated in small, two-seater pews arranged in rows. Overlooking the chamber are balconies on opposite sides of the room, where visitors can observe each other and the events below. By the top of the room is the chairman's table and at the bottom, the Minister's table. The four sides arranged like a trapezoid, with everyone facing inward. The chairman is dwarfed by a large painting of King Willem I, the first king of an independent Netherlands after the signing of the first Dutch constitution in 1814. The ceiling, too, speaks in history, covered by murals depicting a building with windows and people from various cultures looking in. I see what appears to be Dutch people in the dress of the 17th century, Indonesian and African people, and interspersed throughout cherubs supporting the frames of the building, all observing the proceedings from their place on high. Below this, the wall is lined with portraits of elderly, white Dutch men, probably original chamber members is my guess. Albert tells me the building is a new building, which they decided to keep in the "old style."

The euthanasia debates get started again and Timmerman-Buck from CDA is running through all the elements of current euthanasia practice that may throw the law into question: What about passive euthanasia? What is the role of the regional assessment committees? How can we say that reporting will increase under the new law? And what about dementia and euthanasia? Kohnstam from D66 says there is a

history to euthanasia, but that voluntary euthanasia “has totally nothing to do with Nazi Germany.” He disagrees with Schuurman and Timmerman-Buck. Schuurman says he feels misunderstood, says there is a break in society and reads a passage (in English) about dying with dignity. Chamber members, I note, are starting to look bored. Several look like they are sleeping off lunch, propping their heads politely off their tables using hands and elbows. Schuurman makes a motion asking for more support and training for palliative care. The chairman reads the motion then asks for comments for and against. De Wolff from the Green Party says euthanasia will not be normalized by this law and cites a recent newspaper article by a foreigner who said that the Dutch have figured out their moral society. She agrees and will favor this law today. Le Poole from the Labor Party (PvdA) says that doctors stuck their neck out for this and this is for them and their patients who have thought about what they want. She too mentions Nazi Germany and outsider reactions. Dees from VVD starts to quote an English text regarding right to choice and is interrupted, reminded that the text was not originally in English, therefore he should paraphrase it in Dutch. Ruers from the Socialist Party (SP) wonders who is controlling the regional assessment (toetsing) committees. Nobody, he says.

I lean in closer to Albert to ask how many will speak on this motion and he tells me seven – seven parties, seven spokespersons. The remaining chamber members speak, then the chairman reminds speakers the rules for using other languages in the chamber. If a text is available in Dutch, even if it has been translated from another language, members must use the Dutch version. The chamber breaks for an hour, with plans to reconvene at 6:00 p.m. Outside there are only a few news cameras and one new set of protestors: two men in black ski masks and white lab coats with over-sized syringes in

their pockets and a larger banner that reads "Euthanasie blijft moord, 293 294 WvSr," which translates to "Euthanasia is still murder" and sites the main articles of the criminal code that will be altered by the passage of the law today. Below that they have the familiar red circle with a slash through the Dutch words for "constitutional state" and "civilization." Over beers at a local pub, I ask about the protestors and the media. Where are they? I ask. Albert says it is a done deal so most of the protestors stayed home and much of the media presence are probably foreign. It was not until the next day that I found out that a crowd of protestors did gather to stage a rally, but they did it in a courtyard across the street and out of sight of the First Chamber building at the request of officials. A polite Dutch protest, I think to myself.

The chamber reconvenes at 6:00 p.m. The chairman calls the room to order and Minister Korthals begins reading from some typed notes. He is responding to Timmerman's position on the regional assessment committees. Timmerman-Buck interrupts. She is starting to get emotional. Minister Borst reads from her typed notes on palliative care. She says palliative care is not separate from other care at the end of life in the sense that it is offered as a package deal through Thuiszorg (the government-subsidized, national homecare organization). Borst thinks Schuurman's motion is unnecessary. Schuurman says he wants to keep his motion. The chairman suggests a 20-minute break so that CDA and their coalition can meet. The chamber reconvenes at 7:20 and I note that the mood in the chamber has shifted somewhat. The seats on the chamber floor are full, the balcony is overflowing and the mood is one of excitement. I assume we are getting close to a vote. Albert points out some of the members of the Second

Chamber who have joined us on the balcony to watch. We are all leaning forward in our seats now.

The chairman says we will take a vote on the motion and asks if someone wants to speak to the motion. Timmerman-Buck steps up to do so, saying only a few brief words. Turn by turn, one member from each party gets up to speak to the motion. They are all brief. Next, the chairman calls for a vote on the euthanasia law, members must say for or against when their name is called. He begins calling names. Albert tells me that only a simple majority is needed to pass (38 of 75 members "for" will pass the law). The vote comes in – it is 46 for, 28 against, and 1 not present. The law passes to silence; no clapping, no noise. Next there is a vote on the motion and members are asked to stand to vote for it. Motion fails and then everyone is up out of their seats, shaking hands and congratulating their neighbors. I, too, receive handshakes and congratulations. On the floor of the chamber, I see one young member, who I didn't hear from all day put his head on his desk. He appears to be crying. Several members join him, one leaning in to offer words of comfort and a hand on the back.

On April 10, 2001, the Dutch parliament passed the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* making the 1984 court-sanctioned practice of euthanasia (killing a person at that person's explicit request) and assisted suicide (giving a person the means to kill themselves at that person's explicit request)

legal by law in the Netherlands.²⁴ After 30 some years of national debate and 17 years of legal practice, the Netherlands is the country with the longest-standing legal practice of euthanasia or assisted suicide in the world. This chapter is about the history of current-day euthanasia discourses and practices, and just what makes the discourse and practice of euthanasia in the Netherlands distinctly Dutch.

The Parliament debates on April 10, 2001 tell us a story about Dutch process and transnational history. We, the reader, arrive in the middle of the story to find that euthanasia law in the Netherlands is a done deal. It seems a symbolic gesture capping 17 years of mainstream practice. We meet the political players – proponents of the law (Ministers Borst and Korthals, and spokespersons from VVD, D66, PvdA, and GL) and opponents of the law (CDA, RFP, GPV, and SP). And we hear tell of current and pressing issues – Dutch doctors are not always reporting euthanasia cases, the power of regional assessment (*toetsing*) committees to regulate “careful practice” by physicians is unclear, and not enough is known about the current state of Dutch palliative care in the context of euthanasia requests.

This isn't just a Dutch story, however, because the Dutch are concerned with the legacy of euthanasia and how their story will impact history and culture. As Minister Borst and other participants remind us, “the world is watching.” They know they are the model (both for and against) euthanasia policy around the world and they are aware of the burden of history, both the history that they are making and the history that they must

²⁴ The Dutch distinguish between euthanasia and assisted suicide. Euthanasia occurs more often than assisted suicide for reasons that include a general trust in physicians, a long-standing policy of social medicine, and the belief that euthanasia is safer (quicker and more dependable) than assisted suicide. In 2001, between 2.2 and 2.6 percent of all deaths were attributed to euthanasia, while only 0.1 to 0.2 percent of all deaths were attributed to assisted suicide (Wal, et al. 2003:46).

re-make in order to support and defend their stance on end-of-life. The mass eugenics programs of Nazi Germany occurred not so long ago, as several members point out in their attempts to both acknowledge and distance themselves from the past. Finally, this is a Dutch story that speaks to Dutch processes and cultural forms. How First Chamber members debate policy, how they and the public protest, debate, and compromise is steeped in norms of Dutch cultural practice.

In this chapter I will attempt to chart the history of Dutch euthanasia practices, which culminated in the April 10th passing of euthanasia law in the Netherlands. I will describe the current policy and some of the events that led up to the development of that policy.. Next, I want to look at euthanasia in the context of history and culture to examine how an end-of-life discourse has emerged from the long-standing practice of euthanasia. Finally, I want to consider how euthanasia talk is distinctly Dutch and how it has come to exist as an end-of-life practice in the Netherlands.

Dutch Euthanasia Policy

The Dutch policy on euthanasia and assisted suicide, like many of their more controversial policies, is not altogether clear. In the 1994 film, *Pulp Fiction*, John Travolta's character reminisces about a trip to Amsterdam. Referring to the Dutch policy on soft drugs, he says, "It's legal, but it's not 100% legal" (Tarantino 1994). That is a good description of Dutch policy in practice. In 1984, the Dutch legalized euthanasia and assisted suicide by court ruling, finding that as long as physicians followed certain requirements for due care established by the Royal Dutch Medical Association (*KNMG*), they would not be prosecuted for what was technically an *illegal* act. Euthanasia and

assisted suicide from 1984 to 2002 was illegal, but could (and was) “legally practiced,” my own term which I think best captures the contradictory stance Dutch law and Dutch courts have in regard to euthanasia, soft drugs, and prostitution.²⁵

With the passing of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (the 2001 Act), the Dutch partially de-criminalized euthanasia and assisted suicide by making the following changes to their Criminal Code. Euthanasia and assisted suicide, which was technically illegal in Articles 293 and 294 of the Criminal Code, are (still) technically illegal, but remain a practice (now sanctioned by law) that will not be prosecuted as long as certain requirements are met. Prior to the 2001 changes, Articles 293 and 294 read,

Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth-category fine (Article 293).

Any person who intentionally incites another to commit suicide shall, if suicide follows, be liable to a term of imprisonment not exceeding three years or a fourth-category fine (Article 294).

After April 1, 2002, the Criminal Code was revised to read,

1. Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth-category fine;

2. The act referred to in the first paragraph shall not be an offense if committed by a physician who fulfills the due care criteria set out in Article 2 of the Act, and if the physician notifies the municipal pathologist of this action accordance with the provisions of Article 7, paragraph 2 of the Burial and Cremation Act (Article 293, The Act 2001); and

Any person who intentionally incites another to commit suicide shall, if suicide follows, be liable to a term of imprisonment not exceeding three years or a fourth-category fine (Article 294, The Act 2001).

²⁵ The policy of not prosecuting activities that are technically illegal in the Netherlands is one that has been labeled “forebearance” or a “policy of tolerance.” Weyers explains, “[f]orbearance (*gedogen*) is an accepted legal practice in the Netherlands. It is one of several possible official reactions to a violation of the law and it consists of refraining, on policy grounds, from initiating a prosecution. See (Weyers 2001:21) According to Article 40 of the Dutch Legal Code, forbearance could be supported under circumstances of “*force majeure*” or a “defense of necessity”.

The Requirements of Due Care state that persons as young as 12 years old may request euthanasia or assisted suicide.²⁶ Persons 16 or older may receive euthanasia even if they are "no longer capable of expressing [their] will" as long as there is a written statement containing a request for termination of life prior to loss of communication.²⁷ Euthanasia and assisted suicide must always be performed by a physician who:

- a. holds the conviction that the request by the patient was voluntary and well-considered,
- b. holds the conviction that the patient's suffering was lasting and unbearable,
- c. has informed the patient about the situation he was in and about his prospects,
- d. and the patient holds the conviction that there was no other reasonable solution for the situation he was in,
- e. has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a - d, and
- f. has terminated a life or assisted in a suicide with due care (Requirements for Due Care, Article 2, The Act 2001b).²⁸

Effective April 1, 2002, the Act changed little in terms of daily practice.

Physicians in the Netherlands still follow virtually the same requirements of due care (outlined prior to the 2001 Act) and government debates still center around palliative care, euthanasia reporting frequencies, and iterant cases that define the borders of a

²⁶ According to Article 2 of Chapter II. Requirements for Due Care of the Act, "if the minor patient is aged between twelve and sixteen years and may be deemed to have a reasonable understanding of his interests, the physician may carry out the patient's request, provided always that the parent or the parents exercising parental authority and/or his guardian agree with the termination of life or the assisted suicide" (Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001).

²⁷ There are at least three different types of living wills in the Netherlands: (1) the euthanasia declaration, (2) the refusal of treatment document and (3) the do not resuscitate document (NVVE 2004).

²⁸ Over the almost 20 years of legal practice, the Dutch produced and made changes and refinements to their requirements of due care. Prior to the 2001 Act, the requirements stated: (a) the patient makes a voluntary request, either vocal or written, (b) the request must be well-considered and durable, (c) the patient suffers without any hope of recovering, (d) the physician consults a colleague who agrees that the above mentioned criteria are met, and (e) the physician performing euthanasia or assisted suicide does not issue a declaration of natural death, but informs the local medical examiner of the circumstances (NVVE 2004).

slippery slope. The shift was probably more symbolic than anything else, marking the culmination of euthanasia practice in the realm of medicine and law, but offering little in the way of changes to the current practice. The changes in policy capped the end of a liberal majority in Congress, which has since shifted back to the middle right. It was a political statement of a liberal majority whose agenda was to pass laws that they believed reflected the majority of the Dutch people. It was also the culmination of at least 30 years of physician debates around end-of-life care. It marked the pinnacle of a physician-led movement, fueled by physicians frustrated at being caught between medical advances that allowed them to keep the bodies of their patient's alive and a belief that proper care did not always entail preserving life at all costs. The 2001 Act was the culmination of a discourse that shaped the emergence of Dutch euthanasia policy and practice (euthanasia talk); a discourse steeped in the language of medicine and law.

American policy analyst, John Griffiths and colleagues at the University of Groningen, have studied the Dutch policy on euthanasia, characterizing its development in four phases (Griffiths, et al. 1998:9-88). The first phase lasted from 1945 to 1970 and prepared the groundwork for the development of euthanasia policy. In 1952, a doctor from Eindhoven was found guilty of killing his brother on request. His brother was dying of tuberculosis. Although he could have received a jail sentence, the doctor was granted one year probation "because, as far as the Court is aware, this is the first time that a case of euthanasia has been subject to the ruling of a Dutch judge" (Griffiths, et al. 1998:44). In 1967, the Dutch public was presented with their first case of long-time coma and euthanasia. Twenty-one year old Mia Versluis had been in a coma with severe and irreversible brain damage after cardiac arrest during a foot operation. A year later,

Versluis' anesthesiologist wanted to remove her feeding tube with the intention of ending her life. Her father fought this in court and the doctor was found guilty of "behavior that undermines confidence in the medical profession" (Griffiths, et al. 1998:48). He was fined 1000 guilders (roughly equivalent at that time to US \$1500) and the court suggested that termination of life support should only be done if colleagues and family have been consulted. Phase one included a popularly received book by psychiatrist and neurologist J. H. van den Berg in 1969. Van den Berg confronted questions around the Versluis case, for example, patient disclosure and patient's rights, and more general questions, such as those raised by the increased ability of physicians to sustain life with the artificial respirator in the face of the moral ethics of doing so. He argued that medical ethics must change with times. What was a duty to preserve life at all costs, now must be a duty to preserve life whenever doing so makes sense. Meanwhile the cultural and legal climate in Holland was changing. By the 1970s, the Dutch reacted to a growing public liberalism against antiquated morality laws, by legalizing abortion (1971) and the sale of contraceptives (1970), and by repealing the crime of adultery (1971) and a restrictive provision on homosexuality (1971) (Griffiths, et al. 1998:45-49).

The public attention paid to doctors working at the end-of-life coupled with a growing liberalization and legalization of certain social behaviors laid the groundwork for the second phase in the Dutch debate, which lasted from 1970 to 1982 (Griffiths, et al. 1998:50-61). Phase two is marked by increasing public debates by physicians frustrated by the inadequacy of existing policies around end-of-life and the refinement of euthanasia as a concept for end-of-life practice. Physicians began admitting publicly that they were providing their patients with assistance in the dying process, exposing a long-understood

bedside practice to the scrutiny of public debate.

In the beginning of this phase, “euthanasia” was used broadly to define a wide range of behaviors that shortened life. Debates around physician testimonials and euthanasia courts cases helped refine definitions, distinguishing Dutch “euthanasia” from other medical practices that end life.²⁹ In 1973, the *Postma* case helped define the limits of Dutch euthanasia. In this case, Dr. Postma, a physician, terminated the life of her mother at her request by giving her an injection of morphine. The court found that giving increased doses of medication for pain relief, even if it is likely to cause death, does not constitute a violation of Article 293 of the Dutch Criminal Code. In 1981, the *Wertheim* case further delineated acceptable boundaries for euthanasia practice. In this case, a 67-year old woman was helped to die by a voluntary euthanasia activist. The activist was found guilty of assisted suicide and given a sentence of six months subject to one year probation (due to Ms. Wertheim’s age and limited physical condition). The court held that the decision to assist in a suicide must be done by a doctor and the doctor must not make the decision alone (Griffiths, et al. 1998:50-61).

The third phase (from 1982 to 1986) is characterized as the phase when euthanasia entered what I term the realm of “legal practice.” In other words, euthanasia remained technically illegal, but physicians could perform euthanasia or assisted suicide and not be prosecuted as long as they followed the Requirements of Due Care (Griffiths, et al. 1998:61-73). In the landmark *Schoonheim* case (1982), a physician, convicted for

²⁹ As of Phase two, euthanasia came to be defined as voluntary (at the patient’s explicit request) and direct (an explicit act by the physician with intent to end life). Passive euthanasia has become known as “medical behavior that contributes to the end of life” and includes both withdrawing and withholding care as well as unintentional (indirect) death as a result of increased pain relief (e.g., death due to increased doses of morphine). See (Griffiths, et al. 1998:60).

killing his 95-year old patient at her request, was acquitted. Dr. Schoonheim performed euthanasia on a woman in the presence of her son, daughter-in-law and the doctor's assistant. The woman had a broken hip and was physically unable to walk, but mentally intact and had repeatedly asked her doctor to help her die. Dr. Schoonheim was acquitted on grounds of "force majeure" which meant that the doctor was justified on the basis that it was a "situation of necessity" in the face of unbearable suffering and in spite of conflicting duties (Griffiths, et al. 1998:62-63). This led to the report of the Royal Dutch Medical Association (*KNMG*) in 1984, which outlined the "requirements for due care" and opened the way for legalized practice of euthanasia and assisted suicide by Dutch physicians. In 1982, the State Commission on Euthanasia was formed to report on emerging euthanasia and assisted suicide policies and in 1985 the Commission refined the definition of euthanasia to be "intentionally terminating another person's life at the person's request (quoted in Griffiths, et al. 1998:67-70).

In the fourth phase (spanning 1986 to 1997), the debate shifts from questioning the legitimacy of the practice to methods of regulating the practice. Griffiths and his colleagues think that this phase concluded with the unsuccessful efforts to write euthanasia practice into law. I would argue, given the unfair advantage of perspective since their publication in 1998 that the fourth phase perhaps lasted from 1986 to 2001 and did culminate in the legalization of euthanasia in the Dutch Criminal Code. The 1980s and 1990s saw several failed attempts at a euthanasia bill (e.g., the *Wessel-Tuinstra* bill). The government also formed a commission, the Rummelink Commission, to study the current practice of euthanasia. The first report of the Commission, conducted by researchers van der Wal and van der Maas, attempted to squelch national and

international rumors that Dutch euthanasia was headed down a “slippery slope.”³⁰ The van der Wal and van der Maas study found that 1.7 percent and 0.2 percent of all deaths in 1990 were attributed to euthanasia or assisted suicide, respectively (Griffiths, et al. 1998:78). However, an additional 0.8 percent of all deaths were attributed to medical behavior that ends life without an explicit request by the patient. This figure was not counted as “euthanasia” by the researchers and it was this figure that continues to raise concern for opponents of the practice around the world.

Euthanasia and Other End-of-Life Practices in History

As Minister Borst and several others on the Chamber floor pointed out the day euthanasia was passed into law, Dutch policies and practices around euthanasia did not develop without influence from other nations, past and present. The Netherlands is one of the more porous European societies, situated on the edge of Europe between the North Sea, Germany and Belgium, with a long history of embracing foreign people and their material culture. Most Dutch people today are conversant in several languages (i.e., Dutch, English, German and French), and the import of foreign food, businesses, and cultural ways – particularly in cities like Amsterdam – is met with little tangible resistance (Claval 2000). A walk up the Damrak or through the Leidseplein reveals McDonald’s and Burger King alongside vendors of *satée*, gyros, Belgian fries and native croquette sandwiches. Indeed, Stockholm professor of anthropology and visitor to

³⁰ Battin characterizes the “slippery slope” argument as “permitting physicians to assist in suicide, even in sympathetic cases, would lead to situations in which patients were killed against their will.” In other words, you open the way for euthanasia and widespread abuse will occur, ergo the “slippery slope”. For more on the slippery slope and other popular arguments for and against euthanasia, see (Battin 1996:180-183)

Amsterdam, Ulf Hannerz characterizes Amsterdam as a global mosaic, where past and present, local and global merge; where Indonesian *rijstafels* overtake traditional pea soup in official tourist brochures of things “Dutch” (Hannerz 2000a:187). Euthanasia discourse has emerged at the intersection of a variety of Dutch experiences, both foreign and domestic. In this section, I will explore what elements of history and culture the Dutch have inherited, rejected and embraced to formulate their own distinctive version of euthanasia policy and practice.

A glance back in time reveals that euthanasia (and its frequent counterpart, suicide)³¹ have existed in practice throughout recorded history (Lam 1997). Japan has a long history of suicide for reasons of honor, including *hara-kiri* or *seppuku*, as it is called. In *hara-kiri*, the most typical method of suicide, a man will run himself through with a sword to the gut or through the main artery in the neck. Motives varied. It could be done to show allegiance for a superior (*Junshi*), as an offer (*Gisei-shi*), to free oneself of hate or to express disappointment (*Funshi* or *Munenbara*), to pay the penalty for a mistake (*Kashitsu-shi* or *Sokotsu-bara*), or as a form of protest (*Kanshi* or *Kangenshi*) (Lam 1997:99).

Ethnographic studies in the early and mid 20th century with the Dinka of the Sudan reveal the practice of assisted suicide. According to Maurice Lienhardt, the Dinka master-of-the-fishing-spear will ask to be buried alive near the end of his life in order to preserve the *wei*, or life force, of the tribe (Lam 1997:57). According to his source, Lienhardt, “he will not be afraid of death; he will be put in the earth while singing his

³¹ For the purposes of clarity, I will distinguish between historical practices around suicide, assisted suicide and euthanasia. Suicide I will define as the act of a person taking his or her own life; assisted suicide, as the act of a person assisting another to take his or her own life; and euthanasia, as the act of a person taking another person’s life at that person’s request.

songs. Nobody among his people will wail or cry because their man has died. They will be joyful because their master of the fishing-spear will give them life (*wei*) so that they shall live untroubled by any evil” (quoted in Lam 1997:57). As late as 1962, elderly Inuits in Canada have been reported to kill themselves or have their children assist them in death when they become sick or no longer useful to their tribe (Lam 1997:143). According to his source, De Poncins, “[b]owed over his hole in the ice, he brooded. If he had been able to kill several seals in a row, he would have resumed his place as the great hunter of the clan, and it would have been his privilege to speak mockingly to the younger man. But fate was against him. He missed seal after seal... He was too old to kill”(quoted in Lam 1997:142-143).

While euthanasia has long been linked to historical examples of euthanasia (as described above), rarely is the connection made between on-going euthanasia practices and the current Dutch policy of euthanasia. History demonstrates that euthanasia and other related life-ending practices have existed as long as there has been oral and written history and family and physician testimonials tells us that euthanasia *continues* to exist in countries where it is not legal today. Until only recently, euthanasia had been practiced at the bedside of physicians, families and friends around the world without the scrutiny of laws and courts. The early days of the AIDS epidemic saw partners and friends sharing tips of how to assist in the suicide of their loved ones dying of AIDS. Physicians in countries around the world have admitted to a long-standing practice of aiding in the death of their patients (Glascok 1990); there have been popular books on self-deliverance (Guillon 1982; Humphry 1991); and numerous associations around the world who advocate help in dying.

The question becomes, then, why the move towards medicalization and legalization of euthanasia practice? The answer can be found in the history of euthanasia and other related practices. The following discussion traces the history of euthanasia that has culminated in a Dutch euthanasia discourse that manages the end of Dutch life using the language of medicine and law.

Rational Suicide and the Greeks. In the earliest written records from Greece, euthanasia and its counterpart, suicide, existed only as concepts, not as specific words. Before "euthanasia" and "suicide" entered the lexicon, there was "self-murder," "self-destruction," "self-killer," "self-homicide," and "self-slaughter" (Alvarez 1971:49). The word, "euthanasia," first appears in ancient Greece as *euthanatos*, literally translated to mean, the "good death." The Ancient Greeks coined the term, euthanasia, and solidified the concept of a voluntary death justified on the basis of rational process. Typically contrasted with "non-rational" reasons for suicide, such as madness, despair, or moral weakness, early Greek philosophers agreed that some forms of self-murder, e.g., euthanasia and suicide for reasons of preserving honor, were justifiable when committed after proper reflection and for the right reasons. Philosophers of the Cyrenaic school, the Cynics, the Epicureans, and the Stoics all recognized the supreme worth of the individual, while at the same time arguing that the individual should have the right to choose between a life worth living and death. Diogenes, of the Cynics, argued that death should not be feared and individuals *should* kill themselves if they cannot live well (Minois 1999:44). Stoics viewed suicide as a wise and honorable choice, arguing that it is the wise man who gives his life for his country, his friends or in the event of serious pain or incurable illness (Battin 1996:7; Minois 1999:44).

Reacting to the widespread beliefs of these early philosophers, Plato and Aristotle spoke in opposition to suicide. Plato opposed most forms of suicide on the basis that man is the property of God, and to take God's property is to commit an injustice. In the *Phaedo*, he sets forth his position, obscuring it somewhat with a long passage by Socrates on the desirability of suicide. Taken as a whole, Plato is attributed with opposing suicide, except in the case of: (1) death that has been legally ordered by the State, (2) a painful and incurable illness, and (3) misery or compulsion sent by God (Battin 1996:31-33; Minois 1999:45-46). Compared to that of Plato, Aristotle's position is more clearly in opposition to suicide. Aristotle is attributed with the first theory that looks at suicide in relation to society (Battin 1996:66). In *Nicomachean Ethics*, he condemns suicide as an act against the state, arguing that the individual has a responsibility to the state. Suicide is a cowardly and unjust act, even though he admits that "the great-souled man holds that life is not worth having at every price" (quoted in Minois 1999:46).

The Economics of Suicide and Roman Law. Like the Greeks, the Romans were divided in their stance towards suicide, but were the first to take the debate on suicide from philosophy to law, using an argument based in economics. Under Roman law, suicide was forbidden for slaves and soldiers only. The Roman State based their suicide law on a property argument, stating that slaves did not have the right to destroy private property and, likewise, soldiers did not have the right to destroy property of the State. Historian Georges Minois suggests that an aging Roman Empire instated the law for simple economic reasons to preserve their Roman workforce (Minois 1999:29). There was no legal prohibition against suicide for the free Roman citizen, however, and ancient Rome is infamous for its suicides: Cato, Zeno, Lucretius, Seneca, and the tens of

thousands of Christian martyrs who offered their bodies for dismemberment in Roman coliseums in exchange for honor in this life and salvation in the next (Battin 1996:57-61).

Christianity: Ambivalence to Prohibition. Early Christianity was marked by ambivalence towards suicide and it was not until the late 4th and early 5th centuries that the Catholic Church set forth a cohesive position prohibiting most forms of suicide. Early interpreters of the New Testament found frequent references to suicide, which they interpreted as scorn for worldly life and yearning for a better life in the eternal thereafter. Passages in Paul, James, Peter, Luke and John offered early Biblical scholars passages glorifying certain forms of voluntary death. In John, "There is no greater love than this; to lay down one's life for one's friends" (John 15:35 quoted in Minois 1999:25). Taken literally, early Christian martyrs offered themselves up in increasing numbers for gruesome deaths in Roman gladiator events fueled by encouragement from the Donatists of the period. Early years of martyrdom in which tens of thousands offered themselves up for death was seen more than just a release from this life, but also a release from sin and an embracing of salvation. Battin explains, "By killing oneself to avoid the sins that one will inevitably commit in this world, one secures one's hopes of heaven. Death is not an evil; it is merely a gateway, as it were, to the world beyond" (Battin 1996:59).

Not all forms of voluntary death were interpreted so favorably by early Christians. Suicide from despair or flight from sin was viewed by many early Christian scholars as unacceptable and shameful. Minois writes, "Christian death must testify to faith in God, however; it is not to be sought for itself or out of despair. The joyful death of the martyr was contrasted to the death of the despairing sinner" (Minois 1999:25).

It was not until the influence of St. Augustine that the Church came to adopt a more cohesive stance against suicide and other forms of self-annihilation. Following on Plato's argument in *Phaedo* and in reaction to the Donatists who defended Christian martyrdom, St. Augustine based his argument on the Sixth Commandment, "thou shall not kill." In *City of God*, St. Augustine argues that no man has the right to end his life, no matter the motivation. St. Augustine argued that man is created in His image and life is the gift of God, thus a rejection of life is a rejection of God.(Alvarez 1971:50; Minois 1999:27-28). By mid century, Christian law followed suit with a series of prohibitions, solidifying the Church's stance against all forms of suicide. In 452, the Council of Arles, forbade suicide of slaves and domestic servants and in 533 the Council of Orléans forbade suicide of accused criminals. In 563 and 578, the Councils of Braga and Auxerre, respectively, forbade all forms of suicide, making it an offense against God which resulted in damnation in the hereafter and punishment both in terms of the suicide's possessions and corpse, punishments that exceeded the punishment for murder, which resulted in only a fine (Minois 1999:29-30).

Punishing the Corpse. The concept of punishing the suicide's corpse became prevalent in Elizabethan Europe up through the early 19th century, where suicides were viewed as the lowest of the low and the suicide's body received treatment akin a criminal. It was not unusual for the suicide's body to be drawn by horses through the streets, dismembered, impaled and left to warn others at crossroads. Author of *The Savage God* (1971), Alvarez explains,

Apparently the terror of suicides lasted longer than the fear of vampires and witches: the last recorded degradation of the corpse of a suicide in England took place in 1823, when a man called Griffiths was buried at the intersection of Grosvenor Place and the King's Road, Chelsea. But even then self-murderers were not left in peace: for the next fifty years the bodies of unclaimed and destitute suicides went to the schools of anatomy for dissection (Alvarez 1971:44).

Prohibitions against suicide included benefits to the State and economic punishment to the surviving family, as well. In France and England, a suicide's property reverted to the State. In France, a suicide's property were turned over to the King, their name was defamed, any titles were reversed and the remainder of their possessions destroyed. This practice was legislated through the French Revolution, disappearing from the penal code by 1791 (Alvarez 1971:45-46).

Contemplating Euthanasia in the Renaissance. More than ever before, the Enlightenment brought euthanasia and suicide into the realm of public debate and analytical inquiry. What had become taboo under the growing power of Christianity was drawn into the light of discussion in the Renaissance. Rather than defending suicide, Renaissance thinkers and philosophers began to explore systematically what suicide and its many-nuanced forms meant. In 1515, Thomas More published *Utopia*, a fictional account of a society which allows suicide in the case of incurable illness or suffering (Minois 1999:66-67). In 1544, Martin Luther suggested that the victim of suicide was not to blame, that suicide is clearly the work of the devil (Minois 1999:72-73). Montaigne dissected the debate in terms of rational, religious, social, moral and philosophical arguments for and against suicide, eventually siding with suicide only in the event of extremity, "in cases of intense and incurable physical pain, or to avoid a

death by torture” (Minois 1999:89-92). John Donne took a religious argument in his, *Biathanatos*, arguing the more radical position that maybe suicide is not a sin (Minois 1999:94-96). Finally, Robert Burton formalized the concept that suicide may be a result of a physical malady, a melancholia, as opposed to a sin (Minois 1999:98-102). Meanwhile, suicide was gaining considerable notoriety as a topic in literature and the stage. In the plays of William Shakespeare, alone, there were 52 suicides, the most famous suicide of all previewed by Hamlet’s soliloquy, “To be or not to be? That is the question” (Minois 1999:86-115).

Medicalization of Euthanasia. Capitalizing on advances in antisepsis and germ theory and the decrease in power of the Roman Catholic Church, physicians made great strides in the 18th and 19th centuries consolidating their authority and expanding their purview. Physicians replaced the priest at the bedside of the dying individual. Prior to the Renaissance, hospitals were predominantly religious and charitable institutions designed to sequester and care long-term for the chronically sick and the poor. After the Renaissance, hospitals became the fortress of physicians as they transformed medicine from a social welfare system to an institution of medicine designed to cure the sick and house the dying (Starr 1982:145-162).

Euthanasia and dying entered the realm of medicine and doctors. Death became a medical concern. People no longer died at home surrounded by family and accompanied by their local priest or minister. People came to die in hospitals surrounded by machines and doctors that could no longer keep the body alive. Death became the failure of medicine (Aries 1974:87-89). By the late 20th century, doctors around the Western world began to express their frustrations with advances in technology that allowed them to

maintain the life of the body without regard to the life of the person. Physicians also began to admit publicly to a common practice of intentionally ending the life of some of their patients who they felt were suffering needlessly at the end of their life (Glascok 1990). Around the world, euthanasia and other "death-accelerating behavior" by doctors came into the realm of public scrutiny and legal debate.

Legalization of Euthanasia and Assisted Suicide. The modern era also brought euthanasia and assisted suicide back into the realm of law for the first time since the Roman era and the prohibitions of late Christianity. The most infamous case of "euthanasia" occurred in Hitler Germany. Adolph Hitler's program began under the code name, *Aktion T4*. In 1920, Alfred Hoche, M.D., professor of psychiatry at the University of Freiburg and Karl Binding, professor of law at the University of Leipzig, published a book that gained popular attention. In *The Permission to Destroy Life Unworthy of Life*, Hoche and Binding argued that patients should be allowed to ask for "death assistance" from their physician under certain conditions that included the ability to withdraw the request at any time in the process. Hoche and Binding went on to say that death assistance should also be afforded to those with brain damage, psychiatric illness or mental retardation so that public money could be better spent for those who were not living a "meaningless life" (King 1996). In 1933, after some years of public debate, the German Ministry of Justice responded, stating that they agreed that physicians should have the ability to end the life of those who are disabled, incurably ill, or "on the threshold of old age" and that such a program would result in savings to the state (King 1996).

Aktion T4 began as a program focused on sick and disabled infants and children. Disabled infants were given what was then called a "mercy death," by injection or starvation. In July 1933, Hitler came out with his Law for the Prevention of Progeny with Hereditary Diseases, legalizing involuntary sterilization and abortion of fetuses in order to prevent the economic burden of disability on the State. In 1939, Hitler's euthanasia program expanded to including "the mentally ill, the handicapped, those suffering from incurable illnesses, the aged and imperfect newborns" (Scherer and Simon 1999:67). From there, the program went on to include other races and groups that the regime deemed to be "defective," including Jews, Communists, Czechs, Greeks, Gypsies, Russians, Poles, Serbs, Ukrainians, Yugoslavians and homosexuals; which ultimately resulting in the involuntary deaths of over 15 million people men, women and children (Silverstrim n.d.). Today in Germany, suicide has been legal since 1751 and physician-assisted suicide is technically legal, according to guidelines that state that the request must be made by a person exercising his or her own free will (Scherer and Simon 1999:67). The practice, however, rarely occurs in a country that is living only decades removed from the legacy of Hitler.

Since 1937, Switzerland has allowed assisted suicide under Articles 114 and 115 of the Swiss Penal Code, which state that it is not a criminal offense if assistance in dying is carried out for "pure and noble" reasons (Scherer and Simon 1999:69-70). In Switzerland, individuals can receive assistance in dying from one of three right to die organizations, one of which, *Dignitas*, also offers assistance to non-citizens. None of the Scandinavian countries offer legal sanctions for euthanasia or assisted suicide, even so the few who do get prosecuted for the offense in these countries typically receive light

sentences (Humphry 2003). In 2002, a liberal coalition in an otherwise Catholic-dominated Belgium passed their own euthanasia law, arguing (like the Dutch) that since euthanasia is known to occur, it is better to regulate the practice in the public domain, rather than allow it to occur without public and legal scrutiny (Southern Cross Bioethical Institute 2002). By the close of 2003, 259 Belgians have died by euthanasia (ERGO 2004).

Most European nations, however, continue to prohibit euthanasia and assisted suicide. Countries with strong Roman Catholic roots have not surprisingly remained opposed to the practice, including Italy, Spain, Portugal and France. France, for example, bans any publication that offers advice on suicide, notably Derek Humphry's, *Final Exit* (1991). In the United Kingdom, euthanasia has undergone probably the longest-standing public-legal debate. In 1935, the United Kingdom formed the British Voluntary Euthanasia Society and introduced legislation in the House of Lords, the Voluntary Euthanasia bill, to legalize euthanasia in the event of terminal illness or suffering. The bill was easily defeated in 1936 and again in 1969, when a similar bill was defeated. While Britain has had a heated debate over euthanasia and assisted suicide since the 1930s and continues to have court cases that make the popular media regularly, theirs has been a debate that has not found legal precedent for a "right to die." In Britain, the emphasis has been on palliative care and Hospice, an organization founded by British nurse turned physician, Dr. Cicely Saunders, to care specifically for people who are dying (Scherer and Simon 1999:60-67).

In the United States, the debate about euthanasia has fallen mostly to patient's rights advocates and religious conservatives. In 1973, the American Hospital Association

drew up the first Patient's Bill of Rights, which outlined patient's rights to informed consent and refusal of treatment. In 1976, the case of Karen Ann Quinlan raised public concern for patients caught in a persistent vegetative state and the doctor's requirement to continue treatment. Karen Quinlan's family fought for years for the right to withdraw her from the life-sustaining treatment, and in their public struggle, they gave voice to a growing, patient-based "Right to Die" movement. In 1980, the Hemlock Society was formed by Derek Humphry, a journalist and husband who helped his wife die, then wrote a book about it (Humphry 1978). In 1989, the Nancy Cruzan case was heard by the U.S. Supreme Court, which ruled that the Constitution supports a right to refuse treatment. In 1991, Derek Humphry published *Final Exit*, a how-to on suicide which shot to the best-seller list, and is now available in many languages around the world (Humphry 1991). In 1994, the state of Oregon in the United States passed the first U.S. law legalizing physician-assisted suicide, which went into effect in 1997 and continues to this day despite frequent attacks from conservative and religious-based groups (Scherer and Simon 1999:27-47).

Elsewhere around the world, euthanasia and assisted suicide have entered the legal domain in only a few countries. In 1962, voluntary euthanasia for medical reasons was approved by the Japanese high court, yet the practice of euthanasia did not follow. In Japan, euthanasia is more often associated with the withdrawing or withholding of unnecessary supports. Scherer and Simon write, "*songen-shi* refers to a dignified death after the loss of reasoning capabilities or faculties and the onset of severe pain. This is usually thought of as a death occurring without taking extraordinary measures. *Anraku-shi* is a direct translation of euthanasia, meaning a good death" (Scherer and Simon

1999:86). Avoiding pain and suffering is not promoted within Japanese Buddhism, which places value on an individual's ability to process through meditation and Buddhist practice suffering, thereby creating good karma from bad. Additionally, Japan's strong social network, rooted in family, does not promote individual choice in such matters (Scherer and Simon 1999:86-89). Thus while euthanasia is *technically* legal in Japan, it is typically not practiced.

In 1995, the Northern Territory in Australia wrote and passed the first law legalizing euthanasia. Conservative religious reaction was strong and swift, however. Enacted in July 1996, a total of four persons died euthanasia deaths before the law was overturned in March of 1997. That same year, a constitutional court in Colombia, South America overturned a law, which stated "that when an individual killed another for pity, to end the other's intense suffering from a corporal wound or incurable illness, a prison sentence of six months to three years would result" (Scherer and Simon 1999:93). The Colombian Congress is now set with the task of providing guidelines for euthanasia, and as of yet, has failed to do so. The public backlash in Colombia has been strong, especially by the Roman Catholic majority, making euthanasia technically legal in Colombia, but rarely practiced.

The Dutch Experience in History. The 20th century has seen the emergence in the Netherlands (and around the world) of euthanasia practices. The Dutch experience is based on the legacy of Greek rationalization. In the Dutch experience, certain forms of intentional death have become rationalized and justified. Assistance in death is deemed legally justifiable as long as the request comes from the patient, is made explicitly verbally and in writing, is made after long consideration and in light of unbearable and

irreversible suffering, and is performed by a physician who follows all the requirements for due care. Talking about euthanasia is deemed socially acceptable as long as participants follow the unspoken rules for engaging in euthanasia talk, and ultimately, patients need not complete a euthanasia death in order to die properly Dutch.

Engaging in euthanasia talk within the context of the public domain speaks to the legacy of the Renaissance where philosophers engaged the topic of suicide, assisted suicide and euthanasia in an attempt to better understand it. This, too, is what the Dutch have done in regard to making euthanasia a matter of public debate. By exposing the most controversial of practices to public scrutiny, they re-make euthanasia into a form that is manageable and acceptable. In the Dutch Senate debates of 2001, the Dutch also play homage to the legacy of Hitler Germany. To move forward in the legalization of euthanasia policy without mentioning Hitler's eugenics program would send red flags for much of the world who is watching what the Dutch say and do. But a mention is all it gets, because the Dutch believe that their policy is nothing like Hitler's program.

Irrelevant to the Dutch experience is mention of economics as per the Roman era. In an age when health care costs of a welfare state are increasing exponentially, potential savings of a euthanasia death (versus a long-drawn out hospital death, for example) are surprisingly not topics for Dutch debate. Neither is the topic of premature death as taboo attributable to the late Christian and Elizabeth periods. Euthanasia (talk or the act) is not taboo in the Netherlands. In fact, through proper engagement in euthanasia talk, Dutch people affirm their role in society, proudly dying (by euthanasia or more likely by natural causes) like rational-minded, society-bound Dutch citizens.

Minister Borst, in her speech to the First Chamber, said “a euthanasia request is not euthanasia.” While I am not clear whether she had considered the many nuances of what that statement might imply, I have to say I agree with her. A euthanasia request does not equal euthanasia death. A euthanasia request, in practice, is how Dutch people have come to initiate talk that guides Dutch people to die Dutch deaths.

Euthanasia Talk as Dutch Cultural Practice

In this final section, I examine some of the prominent Dutch cultural traits that may be impacting how euthanasia discourse has manifested in the form of euthanasia talk. These are traits alluded to in the 2001 Senate debates on euthanasia and examined in greater detail by historians and other students of Dutch culture.

Traits from the Golden Age. The Dutch Golden Age is often attributed as the precursor for many current Dutch practices. In the 17th century, the Netherlands rose to power as an independent nation in what they call their “Golden Age,” which culminated in Dutch freedom from occupation by Spain in 1815. The Dutch have long been attributed with a strong merchant mentality (based on their rise to power as international traders), conservative Calvinist views, and a respect for artistic and intellectual freedom. The Netherlands was home to those escaping religious or intellectual persecution during the Reformation in Europe. They provided refuge to such greats (native and non-native) as John Calvin; Rembrandt, Vermeer, Vondel, Cuypers, Berlage, Spinoza, Descartes and

Erasmus (Beenakker, et al. 1997; Mak 2000; Nijman 2000; Schama 1987; Zumthor 1994)³².

British historian, Simon Schama, characterizes the Netherlands of the 17th century as a culture based in contradiction (Schama 1987). The rise of the Dutch nation, he says, was certainly founded on trade, but trade in the face of strongly Calvinistic views, creating a people balanced between what he called the abundance created by their mastery of trade and shame that came with the Calvinist emphasis on avoiding indulgences. Schama explains,

As in so many other departments of Dutch culture, opposite impulses were harmoniously reconciled in practice. The incorrigible habits of material self-indulgence, and the spur of risky venture that were ingrained into the Dutch commercial economy themselves prompted all those warning clucks and solemn judgments from the appointed guardians of the old orthodoxy. It was their task to protect the Dutch from the consequences of their own economic success, just as it was the job of the people to make sure there was enough of a success in the first place to be protected from (Schama 1987:371).

Flexibility (and creativity) in the face of contradiction became key to cultural survival.

Schama writes,

The retaining membrane that held Dutch culture together for more than a century was a marvel of elasticity. Responding to appropriate external stimuli, it could expand or contract as the conditions of its survival altered. Under pressure, it could tighten to compress the Dutch into a sense of their indissoluble unity. In more expansive times it could relax and well, allowing for internal differentiation and the absorption of the whole gamut of beliefs, faiths, and even tongues (Schama 1987:596).

³² The years of the Reformation saw the persecution of many great thinkers. The Netherlands rose as a free haven for those fleeing persecution in other European cities. Geert Mak writes, “[a]fter the toppling of the last medieval regents, the city [of Amsterdam] paradoxically grew into a realization of a medieval utopia: the safe, enclosed space in which the non-citizen could cast off the yoke of serfdom. ‘This church consecrated to God knows not enforced beliefs, nor torture, nor death,’ the Jewish immigrants, full of trust, wrote above the door of their Portuguese Synagogue. They called Amsterdam the Jerusalem of the West.” See (Mak 2000, p. 108)

Having a policy, like their euthanasia policy, that is at the same time legal and *illegal* is an example of how the Dutch continue to balance contradiction. In the Netherlands, policy tends to follow practice. In other words, euthanasia always existed and it was not until doctors spoke up publicly that euthanasia entered the realm of legal discourse. Practices are by their nature inherently contradictory. One doctor may do it this way, another that way. So it seems not such a stretch that Dutch policy, based on current practices, also embodies contradiction. The Dutch are also merchants with a long history of embracing foreign ways, initially for the purpose of facilitating business. Today, they are proud to be a melting pot of original ideas and social experimentation, and have a long history of embracing what is too radical for the rest of Europe. In the past, this meant offering refuge to the radical thinkers of their day (e.g., Calvin and Descartes). Today, it means offering refuge to such practices as smoking hash, engaging in prostitution, and participating in assisted death.

Euthanasia talk as I came to see it is based most securely in an ironic contradiction. On the one hand, you would think that all the talk of euthanasia would encourage Dutch people to die by euthanasia. That is the fear of the “slippery slope” that once you allow one euthanasia death that more will follow that may not conform to the original parameters for euthanasia. While this will always be something important to monitor, I do not believe that this is occurring in the Netherlands. This is because euthanasia talk tends to keep people connected to family and to society, thus making euthanasia death less attractive, less necessary. The irony and the contradiction lay in the consequences of euthanasia talk. Talking about euthanasia is actually talking about what

you want at the end of your life with the people you love under the guidance of your society.

Tolerance or Faith in Society. Some researchers suggest that the more radical social policies of the Dutch may have their origin in practices of tolerance (Horst 2001; Shetter 1987). One popular argument is that with over 16 billion people on a piece of land approximately twice the size of New Jersey (CIA 2003), one-third of which was reclaimed from beneath the North and Zuider Seas, the Dutch have to be tolerant of each other's different views and needs in order to function and survive in such close proximity to each other and to the sea. This argument is embodied in the age-old image of the Dutch boy with his finger in the dyke. Everyone is responsible for the welfare of the town, thus even a small boy can save the town with just a finger in the dyke. A more recent version of this argument points to the fragmentation that occurred in response to World War II, which resulted in "pillarization," or pluralization, of Dutch people by religious and ideological groups (Shetter 1987:178-183). People from the same religion or political affiliation had their own schools, sports clubs, unions, newspapers, radio and television programming. This required a policy of tolerance or a "compromise culture," to facilitate conflict resolution among competing concerns.

But can an ideology of tolerance alone account for such long-standing practices of regulating prostitution, soft drugs, and euthanasia? Geographer, Jan Nijman, suggests that the concept of Dutch tolerance has perhaps run its course in the Netherlands, evolving into something that no longer resembles tolerance. Nijman explains,

[t]olerance, perhaps Amsterdam's most prized commodity, is increasingly packaged and labeled to meet the demands of mass tourism and instant gratification. In the process it has become something of a perversion, in the sense that it turned into a commercially motivated permissiveness that is in fact contrary to the city's Calvinistic roots (Nijman 2000:41).

I would argue that tolerance does not seem to capture what Dutch people do. If the Dutch do not approve of something, they let you know quietly but unequivocally. It is quite powerful, for example, the social reaction if you show up late for a meeting or speak out-of-line in a social group. The line between what is done and not done is not unclear. While the Dutch people seem to pride themselves on an idea of tolerance, I would argue that the Dutch seem more committed to order and process.

Indeed, one of the more compelling explanations for euthanasia that I encountered while in the Netherlands, is the idea that the Dutch willingness to control water (nature) is linked to their willingness to control death (nature) by euthanasia policy (Kennedy 2002; Rutenfrans 1997). Many anthropologists have argued that concepts of nature result from cultural interpretation rather than objectified fact (Cronon 1996; Strathern 1992; Yanagisako and Delaney 1995). The Dutch relationship to things natural is indeed a unique one. As far back as 500 B.C., the Dutch were building *terpen* (earthen mounds) to hold the waters back from their settlements and by the mid 20th century they had reclaimed one-third of their country from underneath the sea by a massive series of

dykes, canals and polders.³³ I would argue that what began as an adversarial relationship with nature (when rains or high tides wore dykes away destroying people, livestock, land and homes), emerged as a relationship based on mutual respect and division of labor. The Dutch have a word that engineers use to refer to locks, bridges, tunnels and the like. The word is "*kunstwerk*," which also is used to refer to any "work of art." Shetter suggests that this word carries these two meanings not because the Dutch have difficulty distinguishing art from a bridge, but because to the Dutch "manmade modifications of [the] environment" are "works of art" (Shetter 1987:31). Nature provides Dutch people with raw materials (water; land; and Dutch life) and the Dutch shape these things to meet their needs (reclaiming land from the sea and orchestrating death). It seems little wonder that the Dutch are willing to help nature along in death. If they can make land, they can certainly (through talk of euthanasia) make death.

In the Netherlands, the beauty of nature is in the hands-on relationship that the Dutch have with it. It is what I would call an "aesthetic of co-construction" that is particular to the Dutch people; an "aesthetics of existence" that emphasizes human control in relation to natural boundaries and definitions (Foucault 1978). Schama argued that the Dutch perceive themselves to have Divine authority to co-construct existence. He explains,

³³ A polder, or section of dry land, is created when dykes are built surrounding a body of water. Windmills were then used to pump out the water into canals that surrounded the polder. To keep the polder dry, and inhabitable, windmills continued to pump water from the polder. From 1927 to 1968, Dutch engineers drained large sections of the Zuiderzee and other sections around the country resulting in one-third more useable land. Over the years, there were periodic floods that destroyed large sections of polder, the most recent was the flood of 1953 in which 1,800 people lost their lives. The Dutch response was to engage in the most ambitious project to date, the Delta Project. A large, moveable dam designed to protect the southern delta regions from North Sea storms (Meijer n.d.:6-17; Shetter 1987:31-39, 233).

[T]he act of separating dry land from wet was laden with scriptural significance. 'The making of new land belongs to God alone,' wrote the great sixteenth-century hydraulic engineer Andries Vierlingh, '[b]ut He gives to some people the wit and the strength to do it.' In other words, the special favor of the Almighty had delegated to the Dutch a kind of license in the act of territorial creation (Schama 1987:35).

Today, nature, for many Dutch people, is no longer bounded by religion. In the 1970s, Europe experienced sharp rates of decline in church attendance and affiliation, and the Netherlands, in particular, experienced some of the highest rates of secularization (Becker and Vink 1994). According to most recent figures, only 40 percent of Dutch people are affiliated with a church and as many as 20 percent of the population describe themselves as humanists, believing in human values over divinity (SCR 2001a:156; Shetter 1987:174). The vacuum left by the rather abrupt move away from the Catholic and Protestant establishments may have provided the Dutch with the opportunity to replace God at the helm of nature by society itself. What was once a stronghold of Catholic and later Calvinist belief has become a nation that believes instead in the power of *their society* to take care of their own.

Look at what Dutch society has done. They have reclaimed land from the sea. I once asked a Dutch water engineer if another flood (like the 1953 flood that killed 1,800 Dutch people and destroyed livestock, land and homes) was possible. "*Was het mogelijk?*" I asked. In the U.S., this would have almost been a blasphemous question. Of course floods are possible. It is nature and nature is unpredictable. You tempt it and it can even be wrathful. The Dutch answer was "no", a future flood that breaks through

Dutch dykes is not possible. Why, I asked. The answer – because Dutch people have controlled for every contingency. They have it all worked out.

The combination of the Dutch relationship to nature and the hole left by secularization in the Netherlands has led to a belief, a faith, in Dutch society. Managing death by euthanasia is not a stretch for a society that believes themselves to be on par with nature and with God. Euthanasia is simply an extension of what the Dutch already do with water and land. In euthanasia, the Dutch use what they are given by nature, the dying Dutch body, and they improve upon it – making death an orderly process that corresponds to their aesthetic of good and proper death.

An Orderly Process. Order and control seem to play an important role in the Dutch aesthetic. Cultural historian James Kennedy suggests that Dutch concern with euthanasia comes down to a matter of social control. The Dutch exert social control by employing a long-standing practice they call "*overleggen*," a term that means "to consider, consult, or confer" (Hannay and Schrama 1996:609) or "*bespreekbaar*," a term that means "debatable or negotiable" (Hannay and Schrama 1996:90). By making euthanasia debatable, Kennedy says, the Dutch have imposed order on the hidden, taboo or otherwise chaotic by bringing these practices into the light of public scrutiny and debate (Kennedy 2002:16-18). *Overleggen* is a very specific process of bureaucratic decision-making that is applied in many different realms of practice from deciding who in the workplace is responsible for cleaning the kitchen this week to deciding euthanasia policy on the floor of the First and Second Chambers.

Overleg is a process by which consensus-building occurs and decisions get made in politics, in business and in many other realms of social life in the Netherlands.

Information is shared, superiors do not act superior, tempers and passions are kept in check, and in the end, a decision is made, diluted by compromise and majority rule. Van der Horst explains,

The literal translation 'consultation' does not embrace the full meaning of the term in Dutch. [*Overleggen*] is a form of group communication which aims not so much at reaching a decision as giving the parties involved the opportunity to exchange information. The Dutch spend many of their working hours in *overleg*. This means that they are discussing the state of affairs with their colleagues. They describe in detail the activities they are engaged in and the rest of the group are, in principle, entitled to make comments or ask questions (Horst 2001:170).

Van der Horst links a term, *gezelligheid* (which has no satisfying English equivalent) with the Dutch propensity for *overleg* (consultation). Van der Horst explains,

[*Gezelligheid*] describes an atmosphere that the Dutch proudly believe is unique to them. The word itself is closely related to *gezelschap*, company. It is a form of behaviour, of communication, which keeps the people involved together because they appreciate it and it makes them feel good. *Ongezellig* behaviour on the part of one of the participants can ruin the atmosphere entirely. And the chance is always there because in a café or at a party, it is no longer necessary to search for a consensus. People are there for fun. They can and do stand up for their opinions. Controversial statements can be heard from all corners. The danger then is that the *gezelligheid* will be disrupted if someone does not permit another to voice their opinions and attacks them personally (Horst 2001:257-8).

To maintain *gezelligheid*, van der Horst suggests, people must be heard and the process for deliberation must play out.

I argue that what the Dutch seem to favor is a *process* of decision-making that is based on an aesthetic of order and control. Discussing something is quite different than acting on it and proper Dutch citizens have choices, but that does not mean that they should act in ways that communicate excess. The Dutch have a popular saying, "*Doe maar gewoon, dan doe je al gek genoeg*," which is translated to mean, "Be normal, that is crazy enough" (Horst 2001:214). From the Queen down to the prosperous businessman,

Dutch citizens are encouraged to downplay extravagance and individual achievement, be it in wealth, dress or manner. They are encouraged to show restraint. This is not to say that Dutch people do not know extravagance. Any visitor to Amsterdam can see the wild side of Dutch life played out by the orange-clad fans at an Ajax soccer match, in the Amsterdam Canal Pride (a gay pride event along the *Prinsengracht*), or in the wild streets of Amsterdam and other cities on Queen's Day. As per their ability to embrace contradiction, typical Dutch citizens know when and how to demonstrate excess (Schama 1987:371). Proper Dutch citizens are encouraged to conform to normative standards that do not include overindulgence. Soft drugs are "legal" in the Netherlands, but that does not mean that everyone should smoke to excess. Euthanasia is "legal" in the Netherlands, but that does not mean that everyone should die that way.

What the Dutch seem to be embracing in their euthanasia discussions is the process of making death orderly. The goal of euthanasia talk, like any good example of *overleggen*, is not about the end result. It is not about dying euthanasia deaths, but about living the remainder of your life in proper Dutch ways. Euthanasia talk – not euthanasia death – creates the order that the Dutch are striving to achieve. The Dutch ability to manage contradiction, to balance between indulgence and restraint, provides them with the necessary resources to engage in euthanasia talk, without the focus being on euthanasia death.

In the Senate debates of April 2001, euthanasia was a rational choice for a society bound (not by religion) but by its responsibility to its own society. Steeped in history and the Dutch familiar, euthanasia talk finds form. Borrowing from the historical past, it is a rational choice (e.g., ancient Greece) made after 30 years of public debate (e.g., the

Renaissance). It is a choice made in recognition of certain historical events (e.g., Hitler Germany) and not others (e.g., late Christianity suicide taboos). And it is a choice made in an era in which medicine and law have come to dominate public discourse, in which medicalization and legalization of human behavior have proliferated. Borrowing from the Dutch past, euthanasia talk (and the discourse on which it is based) is steeped in contradiction, penchants for control, a unique relationship with nature, and in well-worn practices of Dutch decision-making.

4. Window to the Garden: Euthanasia Talk and the Dying Individual

The Dutch have a special connection to their gardens and during my stay in the Netherlands, I came to see the garden as an expression of Dutch individuality. Any Dutch home or ground floor apartment has a garden out back with a 6 to 8 foot fence typically high enough to keep the eyes – but not the ears – of their neighbors at bay. With the premium on space in the Netherlands, gardens are small, but packed with personality. A few are tended to give the impression of nature in the wild, many others, however, are more controlled, more sculpted – showcasing exotic plants, tiny walkways and benches nestled among neatly manicured rows of flowers and plants. Visitors to 17th century Holland also noted the unique status that Dutch gardens held. According to architectural historian, Wytold Rybczynski, “the Dutch prized three things above all else: first their children, second their homes, and third their gardens” (Rybczynski 1986:60). Dutch gardens were different from other European gardens, which tended to be public spaces, shared by several townhouses. The introduction of the Dutch garden coincided with the shift from a communal big house to individual family homes in the Netherlands and these gardens were constructed to be private and orderly with “precisely clipped hedges, geometrically shaped box trees, and colored gravel walks [echoing] the orderliness of the interiors” (Rybczynski 1986:60).

Today, Dutch people continue to covet the back garden. Gardens are a status symbol and when Dutch people talk gardens, they talk about the size of the garden (slightly larger is better) and how well kept it is. As Han van der Horst emphasizes, gardens “must be as strictly controlled as possible” (Horst 2001:115). An overgrown

garden is akin to a dirty front stoop or dirty window panes; it is not the sign of proper Dutch living (Horst 2001:115, 245-249). I mention the Dutch garden because it was something that figured prominently at the end of Dutch life and seemed to hold great comfort for those who were dying. Many who were sick or dying at home (and who lived on the coveted ground floor), typically placed their bed in the living room next to the large picture window that overlooked the back garden. Having spent time as a Hospice volunteer in the United States, I cannot help but to compare that with the more typical scene in American homes, in which the dying individual is situated in front of a television screen that is rarely ever turned off. Watching television is not how most Dutch people (living or dying) spend their time.

This chapter explores what it means to engage in euthanasia talk from the perspective of dying individuals (the first of three main participants which will be the focus of Chapters 4, 5 and 6). I want to describe what it feels like to experience life at the end of life and I will examine some of the consequences of dying and how euthanasia talk impacts that experience. I will explore the role of the individual in euthanasia discussions and how they interact with family and *huisartsen*. I will explore how euthanasia talk keeps people connected to family and society and I will explore when it does not. Finally, I want to talk about what is distinctly Dutch about this way of dying and what it means to want to die overlooking your own garden.

The chapter begins with the story of a gay man who was diagnosed HIV+ in the mid-eighties. A month before I met him, he came very close to dying due to complications from AIDS. When we met, he had a euthanasia request in writing with his *huisarts* and had had multiple conversations with his *huisarts*, his partner and his family

about his request. This is the story of what it was like to come so close to death and why he chose to initiate a request for euthanasia.

"Into the Garden"

I met Matthijs [pronounced Ma-TAIS] and his American partner, David, on a cold, clear day in February 2001. They live not far from the center of Amsterdam in a Dutch flat on the coveted ground floor. (Unlike the other apartments in a multi-story building, only ground floor apartments have the desired private garden in the back). It is a typical city apartment with small, narrow rooms and large, bare picture windows overlooking the street in the front and the garden in the back. David and Matthijs welcomed me in and after settling in the living room over tea and cigarettes, we began what would become a series of intense discussions about life and death, love, religion, and society.

I took to them both immediately. David, the more boisterous of the two, is an American man, cute and boyish looking even in his mid-forties. He is the kind of guy I love to be around, the kind of guy who talks with his hands and marks his speech with big theatrical pauses and expansive looks that bring everyone around into his conversation. Matthijs, tall with the Dutch angular jaw and dark curls around his face, clearly loved David's outgoing style, complimenting it with his own quiet, yet thoughtful responses. I asked how they met and David told me they met at a sauna in the early 1990s. A week later, they were sitting around David's apartment after dinner and a movie, and Matthijs dropped that he would probably die before his mother. David, who had already lost one partner to AIDS, picked up on that, asking outright, "Are you HIV+?" Matthijs replied,

"yes." David reacted immediately, jumping up from his seat to go over and put his arms around Matthijs. "It just makes me love you all the more," he said hugging him. "We've been together ever since," David tells me, with a long sideways glance at Matthijs who had obviously heard this story before.

Matthijs was diagnosed HIV+ in 1986 when he initiated an HIV test because "everyone else was getting one." The results were wholly unexpected and he remembered reflecting on how healthy he felt at the time. He remained asymptomatic until 1994, when he had minor health complications. In 1996, he started with protease inhibitors even though he was not sick. I asked why and he said they were popular at the time, touted as the miracle cure, he said. Matthijs experienced serious liver problems in 1997 and more complications in 1999. By summer 2000, Matthijs found he was resistant to many of the protease inhibitor combinations and stopped taking them.

AIDS dementia was the next health scare, complicated by a long lag time in diagnosis. For David, a former nurse in the United States, this was just one of a long series of frustrations with what he described as the sluggish and at times non-responsive Dutch medical system. By January 2001, Matthijs was so ill that he and his doctors believed that he had only days or weeks to live. He rallied, however, and fueled by David's willingness to question the system and against his family's wishes, Matthijs stopped all medical treatments in February 2001. Now, he tells me, he doesn't want to know whether his viral lode is high or his T-cell count is low; he just wants to live the life he has left.

Matthijs has a euthanasia request on file with his huisarts, Dr. de Boers, and has continued to maintain somewhat of a relationship with her even though he has stopped

all treatment with his specialists. I asked Matthijs and David whether they had talked the request over with Dr. de Boers and they said they had. They had several discussions with her and both came away feeling that Dr. de Boers would help them at the end if they needed it. This is what they had to say:

David: She couldn't promise me that he wouldn't have pain, but you know if she had said that I wouldn't have believed her. She said she would do her best to make sure he didn't suffer unnecessary pain. She said when there are breathing problems, for example, it is often more difficult for the family than it is for the individual. It is traumatic to watch. But she can come here four times a day if it's necessary, as much for the family as for Matthijs. I've had so many difficult experiences with the doctors here. The first couple of times I spoke with Dr. de Boer, I had the impression that she didn't want to listen to me. After that I took her aside and made it clear how important it was for me that she be direct but also sensitive to where I was coming from. Now I know that I can say what I want to her and that [we're clear].

Frances: And for you, Matthijs, how did that decision come about?

Matthijs: Well [big pause], I always felt, I'm not afraid of dying, but of dying worried. I've seen both my parents die and in their cases there was no. They were... The whole idea of euthanasia was abhorrent to them but what happened by the time they couldn't really breathe anymore, they got a shot of morphine. And of course it wasn't euthanasia, and yet the effect is more or less the same.

Frances: It did end their life?

Matthijs: It did end their life within 10 minutes of the shot, but of course you can't go by the government definition of euthanasia because they'll get upset. "Of course,

I don't do that." I was talking about it with Dr. de Boer when I was trying to figure out my feelings about euthanasia. She said, "I've done euthanasia, but I'd rather not." [and I told her what had happened to my parents and] she said "no, no, no, that is NOT euthanasia. That's not what we're talking about." But to me it comes down to the same thing, except in my case, I don't know how to say ... some people say, "Ik ben zo benauwd"³⁴ (I am so anxious/I have tightness in my chest)" or somebody else says, "Hij is zo benauwd, is er iets tegen benauwdheid, dokter? (He has tightness in his chest, is there something for [that], doctor?)." Ja, as long as you don't call it euthanasia.

At this point in the conversation, David who was already late for an appointment had to leave, but he and Matthijs suggested that I stay a little longer. We continued our interview.

Frances: So why euthanasia?

Matthijs: I'd rather die, uh, but if you can't control your future and another factor is because David's other partner suffered quite badly and it was a real strain on him. It was made worse because the doctor [at that time] advised not to let the patient know it was a terminal situation.

Frances: What did David's last partner die of?

Matthijs: AIDS.

Frances: But they didn't know that it was terminal?

³⁴ *Benauwdheid* is used by patients and physicians to describe a symptom that has both physical and mental attributes. It is translated to mean "tightness of the chest," "closeness, stuffiness," "fear, anxiety," and "distress" (Hannay and Schrama 1996:81). In end-of-life care, it signals an acceptable term of suffering that can warrant an increase in morphine. Its use marks one of the liminal areas in euthanasia and end-of-life care.

Matthijs: Everybody around him knew, but he didn't. He didn't know. He knew that he had AIDS, but only they knew that he was dying.

Frances: Was this in the U.S. or here?

Matthijs: That was in the U.S. And David was quite young and it was a real situation. Especially at the end when he was losing his mind and obviously in a lot of pain and there was no help. To take the anxiety away I wanted to have a euthanasieverklaring (written euthanasia declaration). Although for euthanasia, this is just a piece of paper, it states what you want but it doesn't have much [pause] -- you don't have any right to euthanasia when you give them this. And we had a couple of negotiations with Dr. de Boer about her euthanasia attitude, so at the moment we feel, how would you say, optimistic? Good?

Frances: So she has agreed that she will do it for you if it is necessary.

Matthijs: [She has agreed] that she is not opposed to it per se – to be here, to perform the procedure. Which I think is a good thing. I talked to some other doctors before who were easy about it, but [that] didn't make me feel comfortable. Like they would say, "Yeah, no problem at all. No problem at all. It's so far, so you just tell me." I think when it's that easy I don't really trust it. Because, ja, when you are in the medical profession, basically you want to keep people alive. In some situations it's nearly impossible to save somebody and I'm sure for the doctor that must be a really frustrating and pressing thing to perform a euthanasia, because otherwise, you wouldn't have wanted to become a doctor. So I feel pretty [content] with Dr. de Boer, but I do hope when the time comes that I'll either die in my sleep or die staring outside into the garden. We don't know. The way my parents died. They were sick and got sicker and that's how

I might die. When I was really sick I was thinking a lot about something, at the moment, I was really... When you get sick you feel different about a lot of things. You get much more emotional, less rational; not just about your own life, but about relationships as well. [phone interruption]

Frances: You were talking about what you think when you are feeling sick.

Matthijs: Oh [pause]. Like you want to make up stuff. You realize you don't want any bad feelings anymore... Feelings become so important. When you start feeling better, you kind of get back to your old self.

Frances: Is that good [laughing]?

Matthijs: On the one hand yes, on the other hand, no. I had the kind of education where you don't show those kinds of emotions, men don't cry, that kind of thing. When I felt that I was dying, I didn't mind about crying or being emotional or making a fool of myself. Those kinds of things I don't remember anymore... I hadn't expected that the feeling would go away with the return of my health. But it is logical, of course, a lifetime of conditioning. That doesn't leave you all of the sudden.

Frances: What kind of treatment do you want to have at the end of your life?

Matthijs: For me, I have no need for medical interventions to remain living.

Frances: Do you have a living will that states that?

Matthijs: Ja.

Frances: And your plan is to stay home or will you go to the hospital if you need to?

Matthijs: Under no circumstances do I want to die in the hospital. I hate hospitals. You have no privacy. And you have no control over when to sleep and when to

bathe.

Frances: It's too regulated?

Matthijs: Ja, it's regulated and you are totally powerless. You lie in a ward with all these people, but of course when you're dying you get your own room, but even then it is strange. I don't know if you've ever been laid up in a hospital. It's not comfortable. The mattress and the pillows are plastic with only a sheet over them. At home you have your comfortable bed and down-filled pillows. When you sweat in a hospital bed, it's terrible. [Everything is wet]. At home, you're in your own surroundings; you have your cat and your partner, but I do understand it is a luxury to want to die at home. And at home you do have to be dependent on someone to care for you.

Frances: If you could paint an ideal picture, what kind of care would you want to have?

Matthijs: That is a difficult question to answer. In my ideal world no one would get sick and no one would die. But preferably, ja, the ideal care is the kind of care that you receive from your mother, who is constantly around and always ready to help. In that regard I've been very lucky. You can't always control whether you will have a partner in your life or not. And I don't think I'd still be here if I was alone in the world. Alone? Naturally you always have friends and family, but someone who really cares for you. Cares for you in practical and material ways, but also in spiritual ways as well, someone you can go deep with. I've been really sick a few times and few times I came to the point where I thought, if I wanted, I could let my life slip away. But if there is a reason to go another day, then I could do that too. I think when you have someone who cares for you and loves you, then you can say I want to go another day or another week.

Which gives me the idea, my ideal situation would be to stay healthy, to be able to remain standing seven hours a day, and to go to work. Then I could complain about that instead.

Matthijs' story is a little different than some that I witnessed while in the Netherlands. First, he was the only person with whom I worked who had HIV. While ten years ago HIV and cancer made up the majority of euthanasia cases in the Netherlands, changes in the efficacy of AIDS treatments seems to have brought about a sharp decline in the number of persons with euthanasia requests dying of AIDS related illnesses (Pool 2000:241; Wal, et al. 2003:49).³⁵ He was also one of the few who had come to the brink of death and returned able to express to me in words what it felt like to experience dying. Matthijs' story is in many ways, however, similar to the other stories that I heard and experienced in the Netherlands. His story (and theirs) reflect common themes. In the following sections, I will focus on how euthanasia talk is used: (1) as an ideal scenario that empowers individuals who are dying and provides them with a venue for processing meaning and emotion; (2) as a mechanism for exerting control and order in the face of bodily disruption; and (3) as a mechanism for staying connected with family and society at the end of Dutch life.

Making Death Ideal. At one point Matthijs talks about his request for euthanasia and he said he was content in knowing it was an option, but his hope was to die in his sleep or staring out into his garden. He followed that with the description of his parents' deaths, how they got sicker and sicker, until they couldn't breathe anymore. He

³⁵ In 2001, 77 percent of all euthanasia cases were persons with cancer. Four percent had heart or blood diseases, 4 percent had diseases of the nervous system, 5 percent had lung diseases, and 10 percent had other illnesses that were life threatening (Wal, et al. 2003:49). For more on the main illnesses impacting patients in my study sample, see the Appendix.

described their deaths as messy and disorderly, eased only by increases in morphine, which finally took both their lives. The Dutch ideal is to die at home, surrounded by loved ones, dying peacefully staring out into your own garden. The next best choice is euthanasia.

Euthanasia talk provides dying individuals with an idealistic and *realistic* option for death. By talking about it, individuals invoke their ideal scenario; an ideal in which they may be situated in the bed overlooking the garden, surrounded by loved ones (not gasping for air, doubled in pain, sick or incontinent). The caring *huisarts* arrives, administers the shots and the person drifts off held by his loved ones. By talking about euthanasia and having their ideal death be a real possibility, they get to live that ideal in the days they have left. If events begin to turn and their suffering actually becomes something they dread, they know that euthanasia can change that and often it is the knowledge (the idea) of euthanasia that makes what does come bearable.

Matthijs came close to dying in a hospital a month before I met him. That and many other hospital experiences made him adamant that he did not want to die in the hospital. In the hospital he felt powerless, a thought expressed by many who have encountered hospitals in Holland and outside of it (Glaser and Strauss 1968; Kaufman 2005; Pool 2000). By engaging in euthanasia discussions, individuals who are dying are able to exert more control over their life than when euthanasia is not considered an option. Anthropologists Anne-Mei The (1997) and Robert Pool (2000) both conducted research on euthanasia in Dutch hospitals, describing how patients in orchestrating their own deaths, were able to exert control in an otherwise largely disempowering situation.

Some researchers suggest that ideal death is thwarted because in certain venues (particularly hospitals), dying individuals are not allowed room for processing meaning (Kaufman 2002) or emotion (Mamo 1999). Sharon Kaufman (2002) looks at how meaning is negotiated in the American hospital and finds that time for contemplating meaning is largely missing from the typical hospital experience. She writes,

A "time for dying " – with all that idea implies for responding to the humane, facilitating closure of a life, and allowing a space for finitude and the transcendent – is difficult to create for the majority of persons who actually are near death, especially within the existing culture and structure of the American acute care facility (Kaufman: 35).

Meaning, she argues, when it does find space in the hospital experience, is not something fixed or clearly shared. Meaning is something "embedded in and made through intersubjective relations, cultural worlds, and structures of power" (Kaufman 2002:35), and too often the power of the hospital to structure and limit those negotiations is underestimated.

At home and in the context of euthanasia discussions, dying individuals are encouraged to process what it means to die (their emotions and their thoughts) in the company of their family and their *huisarts*. This is because through euthanasia discussions, the structure exists for processing what it means to die. Processing emotions is particularly important in the time before death. Kirsten Hastrup (1995) argues that emotion is a largely a cultural construction that people use in their motivation to communicate and connect with others. She explains,

Emotions are part of social practice, not outside of it. The affective registers may vary from one culture or one situation to the next, but emotion as such is located in a community, not in the individual. Emotion is a relation, not a substance (Hastrup 1995:94-95).

Emotions are a big part of dying and in euthanasia talk, fear and uncertainty – two emotions frequently expressed by those who are dying – can be socially processed and culturally managed because emotion work and the processing of meaning is a large part of what constitutes euthanasia talk. The *huisarts* must know why you want euthanasia; why your suffering is unbearable; and that you have talked your choice over with your family.

Euthanasia talk also gives dying individuals a way to re-exert some *control* over the course of the remainder of their life, to process fear, uncertainty, and loss; and to create their own ideal of how they would prefer their life to end. Many Dutch people had similar ideas about what constituted “good” or ideal death. If it couldn’t happen “naturally” (slipping away while staring into one’s garden), then euthanasia was the next best thing. The idea of euthanasia death was orderly, controlled, planned, peaceful, clean, and envisioned with a parting scene conducted by the *huisarts* and surrounded by loved ones. Compare that with “bad” death, which individuals described as uncertain, uncontrollable, messy, painful, and drawn out, an event that occurred without loved ones present. The fact that so many people in my study invoked similar notions of what constitutes “good” and “bad” death in the course of their euthanasia discussions suggests that euthanasia talk is where shared cultural ideas about life and death that are embedded in euthanasia discourse finds expression. Euthanasia talk provides the semantic framework that allows dying individuals the space to negotiate and express certain acceptable ways of knowing, feeling and acting at the end of Dutch life.

Orderly Death. At the core of euthanasia talk and Dutch notions of what makes death ideal, is a tension between cultural striving for order and the (oftentimes)

unpredictability of illness and death. When the body is failing, people experience bodily losses and depending on the dying trajectory created by the illness, those losses can occur unexpectedly or stretched out over a period of time. How does that affect the person who is dying? Arguing from the perspective of Merleau-Ponty and Bryan Turner, anthropologist Gay Becker states,

Order begins with the body. That is, our understanding of ourselves and the world begins with our reliance on the orderly functioning of our bodies. This bodily knowledge informs what we do and say in the course of daily life (Becker 1997:12).

Bodily distress disrupts the order of the body; it disrupts a sense of self; and it disrupts the stories that people use to make sense of themselves and the world in which they live. According to Becker, people cope by using narrative (stories that people create about themselves) to maintain continuity. Narratives are similar to euthanasia talk, framed by cultural discourses of what it means to participate in different stages of cultural life as we age, grow old and die. But while narratives offer a wide array of cultural choices in terms of how stories can be framed, euthanasia talk, I argue, is one way (one popular way) in which Dutch ideas about death have been channelled. Euthanasia talk is not a narrative, but people who engage in this talk employ narratives of continuity to aid them in maintaining identities of self and other.

Becker suggests that in the U.S., there is a pervasive ideology towards continuity. Americans strive to maintain continuity in their life stories and they use narratives to do that – narratives mediate disruption and disorder. I would argue that continuity is not just an American motivation, Dutch people strive for continuity as well. Narratives of continuity help Dutch people maintain order and re-negotiate sense of self at a time in life when present and future are becoming increasingly tentative.

I suggest that euthanasia discourse, and consequently euthanasia talk, is based on an ideal that favors continuity and control over disruption and disorder. This Dutch concept of continuity manifests in at least two ways in the form of euthanasia talk: (1) as an attempt to anticipate, plan and create orderly death and (2) as an attempt to maintain personhood by maintaining social relationships as death approaches. Matthijs talked about issues of uncertainty and control at several different points in our interviews. It was one of the reasons he initiated his euthanasia request. When I asked Matthijs, "why euthanasia," he gave me two answers: (1) for use in the event that the future might be uncontrollable and (2) because if it got really bad, he wanted to spare his partner from having to go through that with him. No one knew what suffering the future might hold for Matthijs. His hope was to die in his sleep or staring out into his garden. The best he knew, however, was that he did not want to die the deaths his parents died. Taking control through euthanasia talks was the middle ground between these two extremes.

During the year I knew Matthijs, he had, with David's help, come to exert quite a bit of control over the direction of the remainder of his life. He had chosen to stop all treatment, with some friction from his family. He was able to remain living at home, predominantly with the help of David and from assistance provided by the Dutch government. He received financial assistance from the government, since leaving employed work, had had some assistance provided by Hospice and was on the wait list for home care.

In the face of an uncertain future, Matthijs initiated a euthanasia request with his *huisarts*. If his hopes for an ideal death did not occur and his fears of a difficult death became real (based on what he knew had occurred for his parents and David's ex-

partner), Matthijs had at his disposal the choice of having his life end early. When I asked Matthijs how he came to initiate his request for euthanasia and he said it was not because he was afraid of dying; it was because he was afraid of dying “worried” like his parents died. At the end both of them couldn’t breathe and both received a shot of morphine that helped end their life. Matthijs thought this was the same as euthanasia, but I disagree. They may have had a death similar to a euthanasia death, but unlike Matthijs what they did not have was the advantage of *talking* about euthanasia, of planning for an ideal and experiencing comfort in knowing that someone would help you prevent what you fear most. Euthanasia talk gave Matthijs a framework for taking back some control over the course that the rest of his life would take, control that he had lost due to his illness and in his hospital experiences.

Staying Connected. For Matthijs and nearly every other participant in my study, family relationships played a very prominent role at the end of life. When someone was dying, relationships were what they valued most. Families made dying at home possible (by providing the round-the-clock care that *Thuiszorg* could not) and were integral participants in euthanasia discussions. In *Constructing Death* (1998), sociologist Clive Seale argues that attempts to maintain social bonds are fundamental to social beings, particularly at the end of life. He writes,

The maintenance of the human social bond is ‘the most crucial human motive’ (Scheff 1990:4), yet dying is a severance of this. In spite of symbolic attempts to transform death into hopes of immortality, to create a sheltering canopy of culture against nature, for people facing death these human constructions appear fragile. Disruption of the social bond occurs as the body fails, self-identity becomes harder to hold together and the normal expectations of human relations cannot be fulfilled (Seale 1998:149).

Those who are dying must deal with a series of social losses particularly when decline is stretched out over time. For the people in my study, this often meant that they could no longer get out on the bicycle or do their shopping and errands. They became homebound and eventually bed-bound. They stopped being able to cook and share meals, clean the house, work in the garden, and as time went on, more and more of their daily self care (bathing, toileting, etc.) had to be done by others.

Extended family and close friends may continue to visit, but as time goes on and their bodies grow weaker people who are dying no longer have the energy to host visitors. What is different in the Netherlands, however, is that the social world of the dying individual is not limited to the family. It is a social world supported by the government in the form of extensive home care that includes *huisartsen*, *Thuiszorg*, and a host of other financial and social supports. In the U.S., for those lucky enough to be able to die at home, there are few supports for home care, so there is typically few to no visits from health care professionals (with the exception of Hospice and those who can afford to pay for home health nursing). In the U.S., one's social world usually shrinks to family or friends who have committed to taking care of you. Like in the U.S., the Dutch social world near the end of life also shrinks to include mostly those close friends and family who have committed to your care. In addition, however, the Dutch dying experience includes a large team of home health professionals who are typically in and out of the home several times a day. Matthijs was not yet in need of home care, but he was on the waitlist for *Thuiszorg* and when and if that time came, he would have access to nursing assistance up to four times daily (including overnight respite). Nursing assistance would include setting out meals, self care (bathing, dressing, toileting), and help with

medications or wound care. Matthijs would be assigned a registered nurse who would be responsible for integrating his daily care in consultation with the *huisarts*. This person may visit the home daily or several times a week. *Huisartsen* visit the home weekly, daily and sometimes several times in a given day if necessary. In addition, there is someone who will come weekly to clean your house. Even without euthanasia, Dutch people who die at home are surrounded by people; they are surrounded by their family, close friends, and by a host of health care professionals.³⁶

Maintaining social bonds is not, however, simply about who is around. Social bonds are maintained by a person's ability to participate in relationships and by the emotional connection that is shared. In the time I knew Matthijs, he was able to participate fairly well in his life and in his relationships. He was able to cook and eat, to get out of bed, to read and host visitors even though at times his energy was low and (due to his earlier brush with dementia), he had promised David that he would not leave the home alone. A month earlier, however, Matthijs was in a very different situation when he was hospitalized and eventually isolated in a private room where doctors expected him to die. I asked what that felt like and Matthijs said that at the time he thought, if he wanted, he could let his life go, but he didn't because his relationships were what mattered when death was close. He said his orientation to the world became an emotional one – emotion over rationality – and what was most important was having someone who cared for him and loved him. Being able to express love and caring even when most social activities are no longer possible keeps people connected.

³⁶ Ironically, one of the main complaints by those receiving *Thuiszorg* assistance in the home is the presence of so many "strangers." What started as a program based on neighborhood nurses (where one nurse took care of a neighborhood), has since expanded to meet growing demand and longer waitlists.

I argue that even without euthanasia, dying in the Netherlands is a uniquely Dutch experience. This is because, *even without euthanasia*, Dutch society does not let its citizens go it alone. The Netherlands has a long history as a welfare-based state, a society concerned with the care of their citizens. It is a society that is based on compromise, a critical element of the common practice of bureaucratic decision-making (*overleg*) in which everyone participates. And it is a society that fosters collective (over individual) achievement. What makes the Netherlands remarkable is not Van Gogh or Queen Beatrix. It is what Dutch *society*, what the Dutch collective, has accomplished. It is a society that fosters intellectual and social freedom; it is a society where the poor need not be homeless or hungry; where prostitutes have health care; and where those wishing to end their life early have state assistance to do so.

By invoking euthanasia, dying individuals tap into a deeply ingrained Dutch discourse that has grown out of and, when invoked, in turn fosters a Dutch way of life; a collective way of life. Thus when dying individuals enter euthanasia talks, they engage a discourse that heightens and focuses the cultural experience of dying according to a culturally-shared and patterned dialogue that fosters familial and societal relationships. Part of this social network of relationships includes *huisartsen* in a way we do not see in the U.S. Matthijs and David had had several talks with Dr. de Boers about euthanasia and both were comfortable that they had found the right *huisarts* to help them if the time came. For both David and Matthijs, this belief was important. The relationships that Matthijs and David had with his other specialists and their last *huisarts* had been difficult. David, as an American outsider and a former nurse, tended to clash with the Dutch system, questioning Matthijs' doctors in ways they were unaccustomed to. By the time I

met them, Matthijs had stopped all treatment with his other specialists, David had asked Hospice not to return to the house, and Dr. de Boers was the only connection they still had with the Dutch healthcare system. While I am not certain that this relationship would stand the test of time, at that point it seemed to be offering what was needed. From David's perspective, euthanasia talk tapped into American narratives of freedom. According to David, euthanasia talk offered Matthijs independence and freedom of choice, freedom to make up his own mind about how he would die. From Matthijs' perspective, this tapped familiar Dutch narratives. Euthanasia is an end-of-life option to Dutch people. You get a terminal prognosis and you talk about euthanasia. And in the Netherlands, euthanasia is a social experience, managed by the *huisarts* and engaged in consultation with your *huisarts* and your family.

I am suggesting that euthanasia talk is based on an ideal that favors continuity in personhood and in relationships. Engaging in euthanasia talk gives individuals who are dying an active role that binds them to their families and their society. Seale states that social death will occur before biological death when one's connections to self and society have been irreparably severed (Seale 1998:7). In the Netherlands, I argue that a euthanasia discourse exists to prevent that from happening. Social death need not occur or can be staved off until nearly the end as individuals take active roles in planning their death.

Individuals Excluded

It is important to point out that engaging in euthanasia talk does not always facilitate ideal deaths, empower individuals, or facilitate social bonds at the end of life.

As described in Chapter 2, there are informal and mostly unspoken rules for engaging in euthanasia talk, rules that favor certain people over others, rules that can be broken and those that cannot. From the position of the person making the euthanasia request, there are a number of informal rules that apply. First, you must have the right kind of illness or disease. Engagement in euthanasia talk favors dying trajectories that have somewhat predictable levels of future suffering and decline. In other words, it is helpful to have a disease that is known for horrible death, to know that complications due to cancer or AIDS will in time cause X, Y and Z, as opposed to decline caused by old age, for example. Getting old is not a good reason for euthanasia. Illnesses must also have some level of predictability in terms of timeframe. Risk of stroke is not a good reason for a euthanasia request, because it can occur at any time in the unknown future. Engagement in euthanasia talk favors illnesses that have longer, more predictable and drawn out timeframes. Finally, engagement in euthanasia talk favors physical illness over mental illness or emotional distress. While one of the more controversial sides to the Dutch law allows for persons with any kind of illness, not necessarily somatic or terminal, to legally receive euthanasia, in practice these are the cases that doctors prefer to avoid.

Second, in order to maintain euthanasia discussions, you must know what you can and cannot say. Dying individuals who want to engage in euthanasia talk must not ask to be killed; but they can be *benauwd* (anxious or short of breath). They should not be severely depressed; they must suffer in appropriate ways (stoically or with pain medication); and they must remain surrounded by family, not isolated from society. In Matthijs' case, it was not appropriate from the *huisarts* perspective to equate his parents' deaths by morphine with today's euthanasia death. According to the legal definition,

increasing morphine doses is not euthanasia. And while David's participation in this dialogue is supposed to be an active one, it was likely that his manner as a Dutch outsider might be cause for future discord if euthanasia discussions progressed. Euthanasia is for Dutch citizens who act in Dutch ways. Matthijs and David's earlier experiences challenging the former *huisarts* and withdrawing from all treatment were behaviors on the borderline of Dutch etiquette. Conflict the Dutch way is supposed to be negotiated and worked out. Conflict the Dutch way ends in compromise.

Not all persons stay connected to social life through euthanasia talk, making a smooth transition from life to death. Certain people have difficulty engaging in euthanasia talk. Recent immigrants, non-Dutch speakers, Dutch people who break the rules by outrageous behavior or by isolating themselves socially are typically excluded from (or have difficulty engaging in) these discussions. There was, for example, one elderly man from Suriname who went to his *huisarts*, asking in broken English for euthanasia. "Kill me," he said, "I want to die." "Why?" she asked. "For the pain," he said. She continued talking about his pain and sleeplessness when he asked again for her to kill him. That won't be necessary, she replied, writing him a prescription for more sleeping pills. To me, she explained he was depressive. I suggest that this man, and others I met, simply did not fit the informal and unspoken requirements for engaging euthanasia talk.

Being capable of engaging in euthanasia talk does not guarantee a smooth transition to death. Dying is still hard and while euthanasia talk seems to make it somewhat more manageable, more controlled and the burden more shared, it does not take away from the gravity of this time. Matthijs did not want to die. David certainly

didn't want to lose him. And Dr. de Boer, who had already performed two euthanasia deaths that year, was not thrilled at the prospect of another. But for Matthijs, the thought of going into the uncertainty of the end-of-life without a plan was worse than going into it with this contract between them. However tenuous euthanasia plans are, they are at least something that binds patients, families and *huisartsen* until death occurs either by euthanasia or by other means.

Window to the Garden

Over time I came to see a transition that occurs when Dutch people die at home. It is a transition from watching and being watched from their front windows to contemplating their gardens from a hospital bed positioned at their back window. I return to the theme of Dutch windows and gardens because it strikes me as a metaphor for transitioning from health to disease, from life to death, and from active participants in public space to winding down in Dutch privacy.

Any new visitor to the Netherlands has noticed the large, curtainless windows of the typical Dutch home in the city and in the country. When I first came to live in the Netherlands, I was surprised that I could walk the streets and have an unobstructed view of people eating dinner, watching the nightly news, or just sitting around their living room. As I entered these Dutch homes in the course of my work, however, I also noted how the front windows were used by those within. It is the pastime of some Dutch people, particularly as they grow older, to sit in their front windows, watching the people and the happenings of the street go by. Swedish anthropologist Ulf Hannerz (and visitor to Amsterdam) suggests that the Dutch window is a device that allows culture to flow

from private to public and vice versa (Hannerz 2000b:176).³⁷ Private space does not begin at the door of Dutch homes, it begins in rooms at the back of the house, where neighbors and passersby cannot see you. According to popular legend, leaving windows open to the public is a cultural practice that originated at least as early as the 17th century when people left their windows (and their nightly lives) exposed in response to strong Calvinist views that favored proper Dutch behavior. By exposing their nightly routines to the street, who of their neighbors could question their propriety? Legend tells a different story, however, of people disguising alcohol in tea cups for the benefit of their nosy neighbors. Things were not always what they seemed.

Today, when Dutch people get sick a shift often occurs from the front rooms to the back. Before someone grows too weak to get out of bed, they are included in the activities of the living room, watching the street and being watched by the street. When someone who is dying grows weaker, however, *Thuiszorg* comes in and provides them with a hospital bed that is typically situated in a room (usually a dining room or den) on the first floor at the back of the house overlooking (if they have one) the back garden. This is private space, intimate space, space reserved for family and close friends. This is not space on display to the public. It is a metaphor that comes to rest in Dutch ideals of death – a good Dutch life winding down, coming home to die in the warmth of first floor family life, and in private contemplation of the garden that nature and they together had a hand in making.

Dutch private is not entirely private, however, and the “public” enters even this space in the form of homecare and euthanasia talk. With sometimes daily visits from the

³⁷ For more on sociocultural practices of Dutch windows, see Hernan Vera (1989).

huisarts and with *Thuiszorg* nurses and nursing aides coming and going up to four times a day to clean, prepare meals, change linens and dressings, provide respite, and give medications, etc. the Dutch sick home is far from private. Matthijs was not yet at the stage where he needed *Thuiszorg*, so for him his euthanasia request with Dr. de Boers was the only thing currently keeping him connected with the health care system.

Consider, though, what that standing request means. It means that if Matthijs gets sicker and cannot achieve a peaceful death on his own, his *huisarts* will come into his home and take him into death the next best way. This is because Dutch death and the time leading up to it are “public” concerns in the Netherlands.

5. A Family Matter: Euthanasia in Families and Homes

The meaning of home and the relation of home to family has played a central role in cultural practices in the Netherlands and, in particular, in how euthanasia talk occurs at home and with the *huisarts*. Euthanasia talk is not a practice that occurs in social isolation between dying individuals and their *huisartsen*. It is a practice that occurs within families and within the context of home. Euthanasia is a family matter.

The Dutch have created a particular style of “home” that impacts how families have come to relate to Dutch society. The concept of home has a long and particular history in the Netherlands. According to historian Witold Rybczynski, it was in Dutch cities and towns that the home first evolved from the combination live-work space of the Middle Ages to the more intimate, individualized, and family-oriented space that we still see today (Rybczynski 1986:15-75). Rybczynski writes,

[S]ince the Middle Ages, many people no longer lived “over the store,” there was a growing number of bourgeois – builders, lawyers, notaries, civil servants – for whom the home was exclusively a residence. The result of this separation was that – as far as the outside world was concerned – the house was becoming a more *private* place. Together with this privatization of the home arose a growing sense of intimacy, of identifying the house exclusively with family life (Rybczynski 1986:39).

The appearance of intimacy in the home, Rybczynski argues, was a result of the changing relationships within the family, in particular the relationship of parents to their children. In most families across Europe during the Middle Ages, children were sent away from the home often by the age of seven. Children of the working poor were sent to wage jobs; bourgeois children were sent for apprenticeships; and children from higher classes were often sent to serve as pages in noble homes. By the 16th and 17th centuries, with the

growing affluence of the Dutch nation, the numbers of bourgeois increased and local schools emerged to replace apprenticeship away from home, resulting in the presence of children at home for a greater part of childhood. Children and home, under the care of the female head of house, became the focal point of Dutch family life.

According to Rybczynski, home was not just a physical space, but also a state of being in the family. Home helped define family and vice versa. The Dutch have two words for the English equivalent, "family." *Familie* refers to the extended family, which could be any combination of parents, children, grandparents, aunts, uncles, cousins, etc. These are family who may, but more likely do not, share the same household. *Gezin*, on the other hand, refers to one's immediate family, bounded typically by the home that they share. Children remain in their parent's *gezin* until they grow up, move out and started a *gezin* (and a home) of their own.

Today's *gezin* plays a central role at the end of Dutch life in spite of smaller than average household sizes and the limited composition of many Dutch homes, which typically do not include aging parents (SCP 2001a:83). Even though children grow up and leave their *gezin*, the Netherlands is a small country and children often stay in regular contact with their parents. It is not unusual for several generations to live in the same town or to return home frequently for family functions and visits. So while those who are aging prefer to live "independent" of their children, children will often be close enough in proximity to provide on-going support when someone becomes sick or incapacitated at the end of life.

This chapter looks at the consequences of euthanasia talk and the role of family in the context of home and the Dutch state. On the one hand, family has maintained an important (and defining) role in what it means to participate in Dutch life. Families and the home they share continue to shape how people live and die in the Netherlands. While the *gezin* may have shrunk in size and composition, the role that families play at the end of life and the power that they can exert in euthanasia discussions is considerable. On the other hand, the state has had an increasingly powerful role in end-of-life discourse, literally entering the Dutch home to take responsibility for how people die. This chapter is about what it means from the family's perspective to participate in euthanasia talk given these tensions between state and home, and public and private concerns.

In the following excerpt, I talk with a man who cared for his wife until her euthanasia death. His is the story of a family, how they participate in euthanasia discussions and how they are affected by euthanasia deaths.

“Already Gone”

I remember Mr. Veenstra [pronounced VAYN-stra] three months after his wife's euthanasia death, a tall man with white hair and kind, sad eyes. He missed his wife. Mr. Veenstra, in his 70s, is one of those large, but gentle men, who talks softly and walks with a slight stoop to the shoulders, which had the unintended effect of making me feel not so small. I first met Mr. and Mrs. Veenstra in the spring of 2000. After her death that summer, I met with Mr. Veenstra regularly over the course of a year and he told me the story of his life, his marriage, and his wife's death.

They were one of those couples that makes you feel good to be around. Through

50 years of marriage, three kids, cancer treatments and remissions, they remained in love with each other. Watching them together and hearing Mr. Veenstra describe their relationship, it was truly as if they were perpetual newlyweds. One day after her death, Mr. Veenstra and I talked about what made their relationship so special.

Frances: I'm glad that I got to meet her.

Mr. Veenstra: Ja, I had a really special woman.

Frances: I think so too. I don't know her so well, but she seemed like a sweet and interesting woman.

Mr. Veenstra: There was once a psychology professor in Amsterdam and he said at the start of his class, there are two kinds of people: cuddlers and those who don't cuddle. Cuddling is for those who find it nice to touch, hold each other and to do things for each other. Some people find it nice to do for each other, others don't. Others prefer to have their own space and to live their own life, more independent. This professor said that if you get married, it is important for cuddlers to marry cuddlers and non-cuddlers to marry non-cuddlers, otherwise it won't work out. Then he asked all the cuddlers to raise their hand. I didn't that day, but I remember the story.

Frances: Let me guess, you were one of the cuddlers?

Mr. Veenstra: Ja, my wife and I were both cuddlers. We loved to be near each other.

Mrs. Veenstra was diagnosed with cancer of the intestines in 1980. She had a piece of her lower intestine removed and received chemotherapy treatment, which helped her stay in remission for ten years. In 1990, she was diagnosed with a tumor in her brain, which was successfully treated. In December 1998, once again she felt discomfort

in her bowels. She got really sick this time and was in and out of the hospital, but they couldn't find anything wrong with her. Finally, in September 1999, they discovered what was wrong this time – the cancer was back, this time in her intestines and her liver. After almost 20 years struggling with cancer, she was told there was “niks meer aan te doen (nothing more to do).” Her doctors thought she had anywhere from a few weeks to maybe three months to live, so she discontinued treatment and came home from the hospital with the intention to die there.

She didn't die when they expected her to and I got to meet her and Mr. Veenstra in March 2000 on a house call with their huisarts, Dr. de Vries [pronounced da VREES]. On the way over, Dr. de Vries fills me in on her case. He tells me that Mrs. Veenstra has a written request for euthanasia on file with him. They discussed it two or three months ago, but she hasn't mentioned it since then. He thinks she might be changing her mind about going through with it, so he's not going to bring the subject up with her today. We knock on the door and Mr. Veenstra lets us in. Mrs. Veenstra is lying in a hospital bed in the living room overlooking the back garden. As we walk over, she jumps up, energetically trying to get into a sitting position. She's dressed in t-shirt and pajama pants. We say hello and shake hands and sit down at a table that is pulled up next to her bed. The table is covered with clippings from magazines of beautiful flowers and colorful things. She is an artist and making collages is her art.

She asks for a shirt to cover up, which her husband goes to get for her and I notice the skin hanging loosely on her arms and her distended stomach. You can see the tumor is a large one, underneath the skin on the right side of her abdomen as Mr. Veenstra helps her slide her arms into a second shirt. Dr. de Vries asks how she is doing.

They talk about what she's eating and what her specialists at the hospital have told her. She is eating okay, but seems to have different likes and dislikes than she used to. Dr. de Vries says that sometimes happens with cancer. She says her heart has been beating fast. Dr. de Vries wants to listen to her heart, so Mr. Veenstra helps her take her top shirt off slowly, one arm at a time. Dr. de Vries listens through his stethoscope as she breathes in and out for him. Then he uses the fingers of his hand to push in and around her stomach region. "Does that give you pain?" he asks. It does, particularly on the right side. Dr. de Vries helps her put her shirt back on and sits down again. He thinks it is the cancer, not the medication, making her heart beat fast. He asks if she's up and around at all. "Ja," she says, and she's been outside too. She says her hospital doctor suggested that she do collages because she can't do her other art anymore. "I do it because I like to," she says. They continue chatting, then she gets up to go somewhere. Mr. Veenstra says, "where are you going?" "Oh," she says and sits back down, obviously confused. Dr. de Vries makes an appointment for the following week and we go. In the car he says it is interesting that she didn't mention euthanasia at all this time.

For many months after that, euthanasia did not come up. Mr. Veenstra cared for his wife at home, and as she got sicker he did more and more. They had decided that as long as they were able, they would rather do it without the help of home health nurses. While they did receive supplies (the bed, etc.) from Thuiszorg, Mr. Veenstra wanted to care for her himself as long as he was able. He cooked for her, bathed her, changed her, and got up with her throughout the night. Near the end, he said, she was taking 28 pills a day and had increasing difficulty with pain, nausea, vomiting and diarrhea. The vomiting and diarrhea became uncontrollable and when she could no longer sit up in bed

to do her artwork, they agreed it was time for euthanasia. Ten months after she was told there was "niks meer aan te doen," she was ready. I asked Mr. Veenstra when her decision to live became a decision for euthanasia.

Frances: When did it change?

Mr. Veenstra: Well, that changed slowly. She was so sick, she couldn't paint anymore, then she did collages with clippings. When she couldn't do that anymore, she began writing haikus. See, she was always busy and when she couldn't do that anymore, she wanted to die. Ja, she had written a euthanasia declaration. She'd written that before so we asked Dr. de Vries what we could do about that. Then we had to wait another two weeks, because Dr. de Vries couldn't just do it the next day, he had to prepare.

Frances: And how was that for you? Was it good that he took the time?

Mr. Veenstra: Well, my wife wanted it to be as soon as possible, she wondered why it took so long. But Dr. de Vries had to do it by the regulations and even on the last day, the day of her euthanasia death, she had to sign her declaration for euthanasia again, but she couldn't because she was so weak.

Frances: Did she use morphine?

Mr. Veenstra: Ja, not the patches but the pills and later when she couldn't do the pills anymore, she used suppositories. She didn't want to use the morphine though because it made it hard to think. Then we didn't have good contact with each other anymore and she said she would always prefer pain over being out of her senses. We did use it when it was bad. When she had so much pain and she was so sick, then it was necessary. But that was something we could always discuss and decide together.

Frances: And what did you do with her in this time?

Mr. Veenstra: I just cared for her. She had so much pain, so she slept a lot. I was really busy. She took something to prevent constipation, which gave her constant diarrhea. Her bed was often wet with it, the floor too. So I was always doing the washing, cleaning the floor and the toilet. She was ashamed of that – that was so sad, because she no longer had control. She often vomited.

Frances: I remember in March when I talked to you both, I asked her why euthanasia and she said that she had her art and as long as she could do her art, that's what she would do.

Mr. Veenstra: Ja.

Frances: When did that change?

Mr. Veenstra: Ja, we were both ready. We were ready two weeks before. I could always talk really well with my wife. We had a good marriage. We loved each other very much and the children too. We have wonderful children and good contact among us. But the last two weeks, I had the idea that something in her was gone. My contact with her was lost. Not just because of the morphine, it was the same when she took no morphine. It was like a small part of her was already dead.

Frances: I understand.

Mr. Veenstra: It's like she withdrew and I no longer had that spiritual connection with her. That went slowly away.

Frances: So you mean a piece of her was already gone?

Mr. Veenstra: Ja. And in regards to euthanasia, that is very important. I think euthanasia is a good solution. You have everything in your own hands. When my father

died, he lived up north and we went every weekend (150 kilometers). But he didn't die. And we would get phone calls to come immediately because it's going to happen and we came and he kept on living. Six or seven times we came back because we thought, "now this is it," but then nothing happened. With euthanasia you have that in hand. It's organized. The kids were there, because I know how terrible it is to keep coming back, to wait and nothing happens. In the end, my father died without us there. My father was very sick, and he too wanted to die, but in his time euthanasia was not possible.

Frances: Do you think euthanasia is a natural death?

Mr. Veenstra: No, it's no natural death, but it is a good death. It is ultimately the end of your life. If you can organize that with others, it is better than if you let it run out. That way you don't know how it might go. I could care for my wife up until the last moment, but if I didn't know how much longer it would be then maybe I would need help. That is important too.

Frances: You mean that the best scenario is to be able to plan?

Mr. Veenstra: Ja, we wanted to take care of it ourselves. We wanted to be able to regulate it ourselves, to be able to say we want it this way and that, because this is obviously an important moment. We were lucky that we could always organize our own lives, like we wanted.

In the weeks and months following his wife's death, Mr. Veenstra had to find new ways to relate to his friends and his world now that he was a widower and no longer a couple. The house became quiet. Slowly the hospital bed and the left-over equipment disappeared. The kids visited regularly and his days were marked by errands out on the bicycle, reading books, and sending e-mails. We talked a little about what it was like.

Mr. Veenstra: Ja, well when you wife dies, you begin a new future. You must see what you can do with your future. I don't know how long it's going to last, but you can't sit around crying. That doesn't help me and it doesn't help my wife either. I know people who do that, people who pity themselves, but I don't want to be pitied. I want a normal life.

Frances: So did your wife say to you that you must do something with your life after she died?

Mr. Veenstra: No, she didn't tell me what to do, she was sensible enough not to do that, but we did talk about what I would do. At the time I didn't know what I would do and it just didn't interest me. When my wife was alive, I was really busy. The last month I slept on the couch and got up with her 4 to 5 times each night and was with her all during the day. When she slept, I slept. Any errands I did really fast and came home as quickly as possible. Three times a week, I bathed her. I looked after everything, but it wasn't bad.

Frances: And now, how is it?

Mr. Veenstra: Well, I cook everyday. I set the table. I eat still on the same side of the table. I want to keep doing that, it's important I think. But, ja, the goal? I sometimes say, "what am I doing it for?" that feeling sometimes overtakes me.

One of my last visits with Mr. Veenstra, he surprised me with a story about his wife's ashes. We had been talking about her funeral and how they had organized it to be reflective of her personality, then Mr. Veenstra jumped in with this story.

Mr. Veenstra: I went with the kids to distribute her ashes not long ago. When she was alive, we found a little piece of land in the country where we planned to throw our

ashes. This place is really beautiful, with gentle hills and trees everywhere.

Frances: So you were going to distribute her ashes there?

Mr. Veenstra: That's what we wanted, ja. My wife and I picked the place together. But when I went to go pick up the ashes, the funeral company had them a long time, so when I could finally pick them up, I was so happy, that I couldn't get rid of them. So I'm keeping them here, in the house.

Frances: And you didn't throw some of them in the place you picked?

Mr. Veenstra: No, because it is sealed, so I can't get them out. If you open the seal then I'll have to empty the whole thing. I talked to the kids and told them I wanted to keep them safe with me. And when I go, then we can be distributed together.

Frances: So if you die then your kids will distribute your ashes together.

Mr. Veenstra: Ja, and having the ashes here has been a relief. I feel like she's with me now, because before I would come home and the house was empty. Now it's not.

Frances: She's here?

Mr. Veenstra: Ja, [he said pointing to a jar on the bookshelf].

Frances: [Looking around] I think with her art she is also here, but the ashes maybe that is something else.

Mr. Veenstra: Ja, maybe the art is the spirit and the ashes are the body.

Mr. Veenstra's is a love story about a man who cared for his wife up through, into and after death. In many ways, Mr. Veenstra's story is similar to others in my study. Family relationships are important to people at the end of life. Family members were prominent in nearly all euthanasia discussions that I encountered and family support was instrumental in keeping someone at home to die. In the following sections, I will

consider several themes that arise from Mr. Veenstra's story (and the story of others that I experienced while in the Netherlands). I will consider (1) how euthanasia talk and end-of-life care is embedded in the context of family and home; (2) how family and the state seem to work largely in cooperation with each other within the context of euthanasia talk and end-of-life care; and (3) how euthanasia talk is used by families to manage memories and relationships at the end of life. I will explore when euthanasia talk by family members does not facilitate ideal death. And finally, I want to examine the context of home and how euthanasia talk may be impacted by the venue in which these discussions occur.

A Family Matter. Like most participants in this study, family played a key role in caring for persons who were dying and participating in their euthanasia discussions. Mr. Veenstra made it possible for Mrs. Veenstra to die at home, caring for her around the clock particularly in the last few months of her life. I conducted participant observation with *Thuiszorg* and found that while their services are extensive,³⁸ even they cannot care for people in the home who are seriously ill without at least some support from another caregiver and typically this means family members. Mrs. Veenstra, like 12 of 14 dying individuals who participated in my study,³⁹ was able to die at home because she had at least one family member to aid in her care. The more complex the illness and treatments, the more important family become in caring for loved ones at the end of life.

³⁸ *Thuiszorg* can provide home care up to four times a day. Primary services include nursing (dressing wounds, etc.), assistance with toileting and self-care, assistance with meals and housework, and overnight respite for the family.

³⁹ Of 17 patients who were terminal or actively dying, 14 were able to stay at home to die (12 of whom had at least one family member giving daily care). Only one patient was able to stay at home with only the support of home care services. One patient's family situation was not known. For more information on the entire sample of patients and families, see the Appendix.

From Mr. Veenstra's perspective, his wife's end of life choices (e.g., pain management and euthanasia) was a family matter. They had been a couple for 50 years and it was as a couple that they considered when and how much morphine to use, where their ashes would be spread when they died, and if euthanasia was right for them and for her. Recall what Mr. Veenstra said about how they worked as couple to manage her use of morphine. She did not want to take morphine because it made it "hard to think." When that happened, then they did not have good contact with each, something that both of them wanted to have. He said she preferred pain over the dulling effects of morphine and that that was something that they discussed and decided together.

Ultimately, it is up to the dying person to make the decision to die by euthanasia, but in the discussions prior to death it is a choice that is made in consultation with and consideration of family members. Mrs. Veenstra initiated a euthanasia request after talking to her husband and her family about it. She proceeded through the discussions (at the urging of her *huisarts*) in consultation with her family, but it seems that even without urging she would have consulted her husband and her children. She did it for all of her other healthcare choices, why wouldn't she for the most important decision she might make in the last months of life – a decision to end her life prematurely. Mrs. Veenstra chose for euthanasia when she could no longer make her art. Mr. Veenstra was ready for her euthanasia death when the connection that they had no longer came through, when he said it was like something in her was already gone. Together, they discussed, considered, planned and ultimately chose euthanasia as the manner in which they would part.

Medical anthropologists and sociologists have paid considerable attention to conflict that arises between family and the medical establishment as patients and families

negotiate end-of-life choices (Anspach 1993; Glaser and Strauss 1968; Kaufman 1998), but less attention on the instrumental role of family in end-of-life care (Hasselkus 1994; Johnson, et al. 2000; Kaufman 2002). Sharon Kaufman suggests that end-of-life choices and the meaning that has for people involved is something that is shared. She writes “[m]eaning’ not only is located in the patient, but also resides in the family, in the health care provider, and in the communication among them as well” (Kaufman 2002:38).

Like other healthcare choices, the choice for euthanasia is not made in social isolation. Social bonds are what hold people to life and in euthanasia talk social bonds are what continue to hold people to life remaining. Ultimately Mrs. Veenstra chose to die a euthanasia death, but that was after 20 years of living with cancer and 10 months after she was told she had a few weeks to a few months left to live. Mrs. Veenstra lived well beyond the time her specialists expected her to die. It is not possible to say what makes some people live longer than others in spite the odds, but it is clear that Mr. and Mrs. Veenstra chose a course of palliative care that maximized what they found most important (her ability to create art and their ability to connect with each other) at the expense of minimal management of pain and nausea. She lived an active member of her family and it was only in the last two weeks when she could no longer maintain her relationships that she (and her family) chose for euthanasia.

In Cooperation With the State. Much of the reason that family can play such an important role as caregivers at the end-of-life is because of the safety nets that exist in the Dutch welfare system. Remember that Mrs. Veenstra had been treated for cancer off and on for over 20 years. She had been sick a lot, Mr. Veenstra told me, and each time he cared for her, supported by the vast system of social welfare that is available in the

Netherlands. Dutch people have numerous supports that can be used when someone in the family is ill. The Dutch Health Insurance fund (*ziekenfonds*) is available on a sliding scale fee to anyone who makes below a certain wage and free-of-charge for those who cannot afford to pay. The Sickness Benefit pays 100 percent of an employee's wages for the first six weeks of illness and up to 70 percent for the remaining 52 weeks. According to the Disablement Benefits Act (WAO), after the first year (if someone is still not able to return to work) sick employees, if eligible, can receive up to 70 percent of their former income. The Dutch unemployment benefit system also covers those who are eligible at 70 percent of former wages for up to six months and there are provisions for employed workers to take what is called "care leave" to care for sick family members (de Vries 1998:206-210; Palriwala 2001).

Even though the Netherlands has one of the most extensive social welfare systems in the world, the state has come to exist in cooperation with the family in caring for its citizens. What was a system that largely displaced the family in terms of caring for the most vulnerable groups (e.g., nursing homes for the elderly) has since shifted towards supporting families to provide home-based care at the end of life. Indian anthropologist Rajni Palriwala and several of her colleagues conducted research in the Netherlands regarding the recent impact of the Dutch social welfare system on relations within marriage, family and other social networks. Palriwala suggests that while the Dutch social welfare state grew over the last 50 years to the extent that state came to bypass family in terms of social responsibility, recent shifts in the system have occurred with the aim to "strengthen 'social connectedness' and revive 'family values'"(Palriwala 2000).

I agree with the changes that Palriwala has noted in the relationship between family and the Dutch state and suggest that euthanasia talk is another way that the state has to foster family involvement at the end of life. While family is absent in the actual language of the policy that regulates euthanasia, families have, at the urging of the *huisarts*, come to play an instrumental role in the practice of euthanasia talk.⁴⁰ Mr. and Mrs. Veenstra both worked for much of their lives and without the Dutch welfare system that supported Mrs. Veenstra (when she could no longer work) and Mr. Veenstra (when he needed to care for his wife), it would have been difficult to continue to care for her at home. Mrs. Veenstra needed the input and support of her husband and her children as she contemplated euthanasia and Dr. de Vries also needed her family's input and support in order to help confirm for him that the choice was a good one. Dr. de Vries needed the family in order to establish consensus around her decision for euthanasia, because when family members object to euthanasia it is often taken as an indication by *huisartsen* that all may not be right with the request. Consensus-building through the common Dutch practice of *overleg* is what Dutch people do when faced with a decision. In Mrs. Veenstra's case, no one in her family objected to her choice for euthanasia. However, in 13 other cases of persons with euthanasia requests in my study sample, three were cancelled because family members objected and family member objections was one of three main reasons why a euthanasia request did not go through.⁴¹ Family and the state have come to co-exist within euthanasia discourse. Families receive assistance from the

⁴⁰ Considering that euthanasia policy does not mention family involvement at all, it is striking the extent to which family are involved in euthanasia discussions in practice. For more on the absence of family in euthanasia policy, see Chapter 2.

⁴¹ For more on the role of family in the rest of the study sample, see the Appendix.

state to keep their loved ones at home and to facilitate ideal Dutch deaths and the Dutch state earns legitimacy as a humane entity, kept in check by the participation of family.

Managing Memories and Relationships. Euthanasia talk facilitates ideal Dutch deaths and is used as a means to manage social (familial) memories and relationships at a time when otherwise relationships and personhood are slipping. Recall Mr. Veenstra's story. I asked him when the decision had been made to go through with euthanasia and he said it was when his wife could no longer do her art. He also said that when that happened "it was like a small part of her was already dead." I had heard these words before. I remember well one woman who had lost her husband to an accidental fall three weeks previous. After the fall she said it was not the same. "My husband wasn't there. My husband, he's there in the photo," she said pointing the picture. What Mr. Veenstra's and this woman's stories speak to is how identities change when people are dying and how family members who are left behind perceive these changes. When does a photograph become more real than a person? It happens when a person can no longer participate in a relationship and when the memory of that person from the photograph overtakes the personhood of the body in the bed. There is something about people that sometimes dies before they do (Seale 1998). Conversely, there is something that can linger as well. I was really touched by Mr. Veenstra's need to hold on to his wife's ashes. When he brought her ashes home, he said it was like the house was no longer empty. This is because Mr. Veenstra was able to re-assign personhood (the memory of her person) to what was left of her body after death.

We know that Dutch families are intimately involved in practices at the end of life, but then how specifically are they involved in euthanasia talk? Clive Seale (1998)

argues that in the face of social death, like that described by Mr. Veenstra, one of two things can happen. People either create narratives that re-interpret bodily losses (negotiating identity and reaffirming social bonds) or they attempt to have social death coincide with death of the body by controlling the manner and timing of death, e.g., through euthanasia (Seale 1998:7-8). I would argue that euthanasia talk in the Netherlands encompasses a little bit of both these activities. Within this discourse there is room for family members to negotiate shifting identities, personhood and relationships as losses occur. Euthanasia talk allows family members to manage their memories of a person. There is also room, however, for families to manage death through participation in euthanasia talk, even in the absence of a euthanasia death. Euthanasia talk provides families with a semblance of control, a script for how ideal death could occur. Families use this ideal to negotiate and manage the losses that occur as someone is dying.

Euthanasia talk manages memories and relationships by invoking an ideal death scenario, maintaining the personhood of dying persons up through death and maintaining the memory of the person and the person's relationships after death. In a review of conceptions of "good" and "bad" death across cultures (and including the Netherlands), South African anthropologist Robert Pool (2004) found that "good" death shares a number of commonalities around the world. First, good death is often defined by the patient's experience of dying, whether it is "mild, painless, peaceful, dignified," or "brief." Second, good death is grounded in a social context, which includes positive family involvement. Good family involvement includes communication, positive relationships, and resolution of any major conflicts. Finally, Pool found that good death includes patient autonomy and the ability to control the dying process (Pool 2004:960).

At several points in my interviews with Mr. Veenstra, he kept returning to his father's death. Something about that haunted him. Recall, we were talking about how his wife withdrew near the end and how he "no longer had that spiritual connection with her." Mr. Veenstra suggested that euthanasia was a "good solution" for that. Why? [Because] "you have everything in your own hands" and he proceeded to tell me about what didn't go right in his father's death. His father's death was not well scripted because his death was long, painful and drawn-out; it was unpredictable and ultimately occurred without family present. Most people who talked about euthanasia compared it to a worst case scenario from their past. Like others with whom I spoke, euthanasia talk allowed Mr. Veenstra to avoid the same mistakes that he saw in the difficult deaths of loved ones who had already died. What happened to his father was not going to happen to his wife. And while Mrs. Veenstra certainly suffered near the end (incontinence, nausea and pain), her suffering was made bearable because together they already had a story with an acceptable ending, whether or not they chose for euthanasia at the end. Together they could maintain their family connection and exert some control over their last months and days together.

When Euthanasia Talk Does Not Bring Ideal Death

It is important not to think of euthanasia talk as something that always works to facilitate social bonds or ideal deaths. Engagement in euthanasia talk is a discursive practice that is constantly changing. It is in constant negotiation by those who invoke euthanasia discourse and among other competing discourses. This means that euthanasia talk does not always facilitate harmonious death within families. Family is central to

Dutch life, for example, but that does not mean that everyone has family or defines it in the same way. Han van der Horst finds a growing trend of isolation among the elderly (Horst 2001:228-231). As of 2003, while the Dutch have made considerable strides in shifting to more home-based support (e.g., through the support of *Thuiszorg*), the majority of Dutch people are still dying institutional deaths with approximately three-quarters of all people dying in either a hospital, acute care facility or a nursing home (CBS 2004). With more people living longer, with the shrinking of extended family networks into the smaller *gezin* (man-wife-children) and with more people dying in an institution than at home, elderly Dutch people do suffer isolation.

Some people are isolated from the Dutch healthcare system because they do not constitute the proper image of family. Others choose to isolate themselves from family or society, which impacts their ability to engage in euthanasia talk. Mr. and Mrs. Veenstra were the typical Dutch family, Matthijs and David, however, from the previous chapter were not. Compare their experiences and you will see some striking differences that I think can be attributed to differing definitions of “family.” As sociologist John Mollenkopf suggests, when foreign people or ideas cannot be related directly to trade in the Netherlands, they are not easily integrated (Mollenkopf 2000:198). Recall Matthijs and David – Matthijs, a gay Dutch man married to David, a gay man from the United States. While Matthijs and David were gay, not a common conception of “family” in the Netherlands, I believe that Matthijs’ marriage to a foreigner probably had the greatest impact on how they were perceived as a “family.” Traditional Dutch families either assimilate foreigners or they are not considered to be a “traditional family.” David’s American orientation to the Dutch system often left the couple in conflict over Matthijs’

care. They had largely isolated themselves from Matthijs' family and had also chosen to isolate themselves in part from the Dutch healthcare system (by refusing all medical treatment with the exception of Matthijs' standing request for euthanasia). In a society that revolves around consensus building, it is okay to be different and to express yourself. It is not okay, however, to fail to participate in the process of building consensus and it is not okay to fail to conform to Dutch ways of acceptable behavior and expression (Horst 2001:181, 249-250). Because in large part David did not conform to Dutch standards of what constitutes "family" in the Netherlands and because the Dutch healthcare system did not conform to David's standards of proper healthcare, he and Matthijs had experienced a series of conflicts with Matthijs' doctors and were likely to continue to experience some conflict as their euthanasia talks progressed.

When people are connected to family, euthanasia discussions still may not be without conflict. When family members object – and object strongly – euthanasia requests typically do not go through. I met one woman early on in my study. She was 82 years old with cancer of the esophagus. She had gotten so far as to schedule a date for euthanasia and then canceled it on the day she was to die. I asked her and her *huisartsen* why she cancelled and the consensus was that she had been pressured by her adult-age daughter to remain living. Her daughter was not yet ready to lose her mother. At the time, the woman said she wanted euthanasia because her suffering was "unbearable," her life was no longer meaningful, and she didn't want to be a burden to her daughter. Six months later, I asked her what she thought of her decision to remain living and she said during the night she regretted that she did not go through with euthanasia, but when her granddaughter visited she felt differently. She said she was okay with her decision.

This chapter has been about the presence of family at the end of life and in euthanasia discussions. Family is central to Dutch life and to discussions about Dutch death. Their presence (and their absence) makes a difference. When family do not participate or when family fall largely outside of Dutch norms, *huisartsen* are more reluctant to enter euthanasia discussions. When family members do participate, they have more power to sway the decisions of their loved one and the opinion of the *huisarts*, than is currently understood. Their absence in euthanasia law does not translate to an absence in euthanasia practice. Their ability to participate in *overleg* (consultation) of a euthanasia request allows Dutch *huisartsen* to spread the difficult and highly subjective task of determining “unbearable and lasting suffering” among several integral participants. This is not to say that *huisartsen* do not take responsibility for ultimately determining whether or not to go through with a euthanasia death, but it does mean that they take some comfort in the *process* that has emerged to manage end-of-life decision-making.

Euthanasia in the Context of Home and Family

Earlier in this chapter, I talk about a recent shift that has occurred in Dutch society from state responsibility for end-of-life care back to family responsibility for end-of-life care. I think a better way to characterize this tension that is playing out between family and state is to focus on the context of the home (versus the institution). Robert Pool (2000) found that in the Dutch hospital setting the role of the family in euthanasia discussions varied somewhat. He writes,

[s]ometimes the patient's relatives played a central role in the decision-making process, but on other occasions, the wishes of the relatives were ignored. These differences were related to the patient's medical condition, his or her personality and that of the doctor, the nature of the patient's immediate social environment, and the type of life-shortening action involved" (Pool 2000:205).

Given the advantage of comparison between institution and home,⁴² I would argue that the context in which people die and the meaning that that context has plays a larger role in euthanasia discussions than Pool suggests.

The venue in which these healthcare discussions and healthcare relationships occur is important. In a U.S. study of home care anthropologist Andrea Sankar finds that the context exerts a tremendous influence on what transpires between physicians and patients: it can strongly 'dictate' power relationships, what kinds of information are visible or invisible, and how physicians and patients know and experience each other (Sankar 1988:155).

Betty Hasselkus (1994) also looks at the role of context in her study of U.S. family-provider relationships as patients transfer from hospital to home. She finds that as patients move from hospital to home, the power dynamic shifts between providers and family. In the hospital, it is the health provider who is the "repository of expert knowledge," the one who knows the patient (the illness) best. In a successful transfer of the patient to home, however, family providers – now educated by the healthcare professional on the illness and educated on the how-to's of day-to-day care by their own hands-on experience – come to "know what's best."

It seems that in the Dutch situation, home has retained much of its power and place. Home is still integrally connected to family and families (*gezin*) have retained a considerable role at the end of Dutch life. It seems as if home is where public and private

⁴² Note that I conducted research in Dutch homes, in *verzorgingshuizen* (nursing homes) and in a *verpleeghuis* (acute care facility).

meet in the Netherlands. As I suggested in my last chapter, not only does public enter through the curtainless windows from the street, but it enters the home via *Thuiszorg* and the *huisarts*. The state is not going to let Dutch people die alone. Through public assistance, home care, and general practice the Dutch state has maintained Dutch citizens through life and now, with the option of euthanasia death and euthanasia talk, the Dutch state can maintain citizens up through and into death. The Dutch state has entered the home via euthanasia talk, but has done it in a way that fosters family involvement and family relationships. It has not taken over the tasks of the family, but has largely worked in cooperation with the family to support home death in Dutch ways.

6. A Friend of the Family: The *Huisarts* Perspective

Over the course of 15 months spent with ten *huisartsen* (and a number of other *huisartsen* not included in the main study), I found that many considered their role in euthanasia discussions and euthanasia deaths akin to a family friend doing a family favor. One *huisarts* described it as a “fellow companion (*lotgenoot*) in the human condition of disease and mortality together with my patient.” This, I came to understand, was not unusual given the unique nature of the relationship between Dutch *huisartsen* and their patients. *Huisartsen* (literally translated to mean “house doctor” or “specialist of the house”) have a long and historically particular practice that seems to have eluded some of the larger global influences in medicine and general practice. Somehow the Dutch have maintained an old-style, home-based practice in the midst of modern problems, such as aging baby boomers and rising healthcare costs.⁴³

One of the first things I noticed is that *huisartsen* work is distinctly different than general practice in the U.S. *Huisartsen* tend to work alone in offices situated within neighborhoods, homes converted into office space, and they continue to this day a long tradition of conducting home visits, or house calls. In 1999, 77 percent of Dutch *huisartsen* worked either in solo practices or with only one other *huisarts* (Hingstman 1999:12). Rarely will you find a *huisarts* in an office building or other commercial setting, most are situated in neighborhoods and in homes that have been converted into office space. Eight of 10 *huisartsen* in my sample practiced in home-to-office converted

⁴³ This has not been easy to maintain, however. In the year I lived in Holland one of the most prevalent complaints by *huisartsen* was the increased volume of patients and workload. This, among other things, led to a call by the National *Huisarts* Association (*Landelijke Huisartsen Vereniging*) for a strike of *huisartsen* in February 2001. While this strike did not go through, concerns by *huisartsen* remained eventually leading to a strike in May 25-27, 2005 (Ministerie van Volksgezondheid 2005).

settings. On the average, *huisartsen* see approximately 28 patients a day, including approximately seven house calls.⁴⁴ House calls are generally conducted before lunch and at the end of the day and include visits to homes and nursing homes (*verzorgingshuizen*), also the domain of the *huisarts*.

Another important distinction between Dutch and U.S. general practice is the power differential, the *relationship* among patients, families and *huisartsen*. In some ways, the power differential in terms of physician authority is more equalized between patients and *huisartsen* than between their U.S. counterparts. Dutch custom is to downplay difference in status (Horst 2001:23), thus doctors are encouraged to facilitate health, not proscribe it. Cultural historian Han van der Horst labels the practice an “engineer’s mentality.” He writes, “[m]any people and organizations see their tasks as largely a matter of stimulating or facilitating, promoting processes, guiding the activities of others” (Horst 2001:126). This is largely what *huisartsen* do as well. Their practice is based on dialogue with the patient and family members, providing information and building consensus. In a typical office visit, the visit begins in the *sprekkamer* (or consultation room) seated across from or catty-corner to the *huisarts*. Most of the visit is spent discussing the problem, including any “psychosocial issues” that the *huisarts* deems relevant, such as stress on the job or problems in the marriage. Examination of the body always occurs second and sometimes not at all in a separate room called the *onderzoekskamer* (or examination room). In a typical morning of office visits, the *huisarts* uses the examination room in less than half (5 of 11) visits.

⁴⁴ This and the following estimates are derived from observations of four different *huisartsen* over the course of one week in my study. Because of the small sample size, these figures are not necessarily representative of the population. For more information on the entire study sample, see the Appendix.

At the same time, there is a respect for authority that maintains some of the power differential in the *huisarts*-patient-family relationship. The Dutch have a long-standing respect for authority and, specifically, for Dutch doctors. Looking back to World War II, or “the War” as it is referred to, the Dutch were left with many grim memories. When they were first occupied by Germany, only the top governing bodies were replaced; otherwise, most Dutch civil servants kept their posts.⁴⁵ By tapping into the administrative structure of the Dutch people and their trust in authority, Nazi Germany was able to take control much more effectively than if they had opposed Dutch control more overtly. The impact was devastating. The Dutch helped transport more Jews to concentration camps, per capita, than any other occupied country. A trust in governing bodies and systems, coupled with little resistance from the Dutch people themselves, resulted in a 79 percent camp death rate, compared to 40 and 38 percent in neighboring France and Belgium, respectively (Horst 2001:155-166).

Resistance during the War is a prized cultural commodity in the Netherlands today (Mak 2000:264-269). One group that continues to maintain a reputation for resistance against former German occupation is Dutch doctors. Early under occupation, Dutch physicians were instructed to collaborate with the gruesome experiments that were being conducted in Germany with living subjects commandeered from Nazi death camps. Dutch doctors staged a walkout, refusing to participate in the experiments, and in doing so gained a trust of the Dutch population that has lingered.

This chapter is about the distinctive role of *huisartsen*, what they do at the end-of-life and what they think about their role in euthanasia. The chapter begins with an

⁴⁵ According to historian Geert Mak, “[t]he Germans never posted more than 60 officers in Amsterdam, even at the height of the persecution of the Jews. The rest was done by the Dutch” (Mak 2000:265).

interview of one *huisarts*, a man who has spent some time contemplating what it means to perform euthanasia. Using his story, I will examine how *huisartsen* have come to interpret their role in euthanasia talk.

“A Little Extra Push”

Dr. Maarten Rohmer was one of my favorite doctors. We spent a lot of time together and I came to feel that even though we were quite different in personality, we shared a love (and fascination) with how people experience end-of-life. Dr. Rohmer was always soft spoken and older than many of the other huisartsen in my study, with a practice spanning almost three decades. Tall and good-looking with brown hair flecked gray at the temples, Dr. Rohmer was always impressive in size, but quiet in demeanor. Dressed in the typical uniform of the Dutch huisarts/citizen, Dr. Rohmer usually wore jeans and a rumpled jacket with shoulders caved in from casual wear (no white lab coat for a Dutch general practitioner). He was a thoughtful man, whose interest in euthanasia led him to explore the meaning euthanasia had for him both personally and professionally. The following is an excerpt of an interview where we explored what it meant to him to talk about and perform euthanasia for his patients and his patient's families:

Frances: Why did you become a huisarts?

Dr. Rohmer: My father was a huisarts, so he was an example for me from birth. I entered my studies, and, well, I don't like hospitals, from the inside they are dull and the atmosphere, I don't like. I saw so many fights against specialists and assistants and all those networks and they were angry, on the ground angry, and I don't like that as well.

And I like continuity. I thought when I started to learn about being a huisarts, I thought that would be the most interesting thing, the continuity. You know people in normal, ordinary settings. I think that is one of the most important factors and as a specialist it is seldom that you know the whole story. I help with delivery and now the children that I delivered are having babies. That's the good part.

Frances: Is your expectation of the importance of continuity turning out to be true?

Dr. Rohmer: Yes, and the longer I do it, the longer it is important, so I must continue.

Frances: How long have you been a huisarts?

Dr. Rohmer: Since 1976. I graduated in 1974 and I started the practice in 1976.

Frances: Were you raised in a religious environment?

Dr. Rohmer: Yes, in a liberal Protestant family. I went until I was 21 for church service but not every weekend.

Frances: Are you religious now?

Dr. Rohmer: No, and we didn't baptize our children either.

Frances: Do you believe in God?

Dr. Rohmer: No.

Frances: So that changed for you?

Dr. Rohmer: When I went to church before, I didn't know what it was. It doesn't interest me anymore. For another person, if He is there, that's good.

Frances: What is your opinion about euthanasia?

Dr. Rohmer: Hm [thinking], a good death with lots of possibilities. When all the circumstances are good, when it is well thought out initially and well discussed, not only between the patient and the doctor, but also with the family involved, then it is a good death, a really beautiful death.⁴⁶ It is beautiful to say your goodbyes together in a good form, in your own environment, then it is something you can look back on because it went well, that is a beautiful last day, a beautiful last day. If this always happens then it is a good death, but this doesn't always happen.

Frances: Thus good communication is important?

Dr. Rohmer: Yeah, for me euthanasia is really about communication, not only with folks who are dying but also with those who are intimately involved with the dying person and that is happening more and more. When I first did it that was not the most important aspect but that has grown to be more important. When I am busy with it I think more and more about the bystanders, about the people who remain behind and what it means for them. And if it is well discussed then it means also a peaceful death, a better death than at some deathbeds where things are not well discussed. That is important with euthanasia.

Frances: So is it what is left behind that is important?

Dr. Rohmer: Yes.

Frances: Because that is what is going to last a long time?

⁴⁶ Dr. Rohmer's exact words in Dutch were, "dan is het een goede dood, echt een hele mooie dood." *Goed* translates fairly easily to mean "good," but *mooi* is a little more complex. The Van Dale definition of *mooi* includes: 0.1 good-looking as in handsome, pretty, beautiful 0.2 lovely as in beautiful 0.3 smart 0.4 beautiful 0.5 good as in excellent 0.6 good as in fine, nice, handsome 0.7 good as in nice 0.8 pretty as in fine (Hannay and Schrama 1996:514). *Mooi* is used more in speech than *goed* and can apply to a much wider range of topics.

Dr. Rohmer: Ja, and people who have asked for euthanasia have assisted in this, they have been active and that is also important. A person can be busy with their future and that is much more clear-cut with euthanasia than with most deathbeds. Sometimes it happens naturally, of course, that people don't ask for euthanasia and that they are nonetheless well prepared with their family for the future, but with euthanasia that is more sharply defined.

Frances: So you say that euthanasia is different from other deaths because in euthanasia more often you are talking about the future for the survivors?

Dr. Rohmer: Ja, and that has possibly changed for me because I find that so important and that's where I begin but eventually the patient must deal with death within their own family because it doesn't end when you die, it goes on. Giving directives⁴⁷ in death is so central that it brings the entire future into relief. Therein lies a clear difference than with other deaths.

Frances: What exactly is the big difference between euthanasia and other deaths?

Dr. Rohmer: That someone who asks for euthanasia is forced much more than others to reflect.

Frances: Is euthanasia a natural death?

Dr. Rohmer: Not according to the law, but I find it quite natural. If euthanasia is a continuation of a medical condition then for me it is a natural death. It doesn't make

⁴⁷ The exact word Dr. Rohmer used was "regie," which invokes a theatre metaphor. In Dutch "regie" means direction; production, as in the production of a play (van Dale 1988:674). His words in Dutch were, "[d]us de regie is zo centraal dat daardoor de hele toekomst ook in beeld komt, omdat hij zelf ermee bezig is en dat is een heel duidelijk verschil met het andere sterven."

so much difference, only a little extra push. The difference is not great enough to be unnatural.

Frances: You have been doing euthanasia a long time.

Dr. Rohmer: I have thought about it a lot. Why do I do it? A psychologist once helped me with that and he said, if someone is dying then the medical care is done, then it is more stepping back and maybe that is your strength. I am not such a doer. I am more someone who processes things, steps back and watches. I like to step back and perhaps guide them, but I am not someone who must wham-bam someone is sick and I must give them medicine and cure them immediately. No, I watch what happens. I am more a waiting person, that's what I am good at, I think. And if someone can't be treated anymore, then I still have a whole lot to offer: attention, warmth, but no medical intervention, no heroic measures. No treatment is sometimes better and I'm not scared to do that. I think that that is my personality – that I am not scared not to treat. That is what I'm good at. I notice with people who choose euthanasia or not that afterwards, after accompanying a deathbed, I am often thanked with presents.

Frances: If you're not afraid when the treatment has to end, there is nothing left to do in terms of the physical body, is euthanasia keeping you active as a doctor in the process?

Dr. Rohmer: I agree, more than without euthanasia. With euthanasia you can be active at any given moment and that keeps you pretty busy, while when there is no euthanasia, it's more hands off. I am more hands off. When I know it's coming to an end, I don't need to go as often. Now, I go see patients frequently when it's near the end, but I don't need to. With euthanasia you have to do something. With that comes

adrenaline, not only on the last day, but often before that. Each time I feel that talk is going in the direction of euthanasia, then I become more awake, alert, active. It's really something different.

Frances: I wonder if that helps with that feeling of wanting continuity?

Dr. Rohmer: Yes, but that's not different with a natural deathbed. With a natural deathbed you still have the feeling that you finish things, but with euthanasia that is more exact, precise, more sharply defined. With euthanasia you are there at that moment that someone dies and with a natural deathbed you are called when it's over. Thus that makes it really personal, I finish it, the lifestory.⁴⁸

Frances: But that is not the central thing?

Dr. Rohmer: No, but it's good to experience the deathbed, regardless of whether it's euthanasia or a natural death.⁴⁹ It's important for me that I be there, maybe not at that exact moment but an hour or so later or a day later, and then again a week later.

Frances: Is it a feeling of being needed?

Dr. Rohmer: Yes it's mutual, they need me and I need them. It really is mutual and that grows with almost everyone. There are only a few people where I think that feeling didn't occur. In my practice there are a number of people I don't really get along with, some I don't really like, or don't have a connection with, but when it comes to the end, that relationship improves almost always.

Frances: And it doesn't matter if it's euthanasia or another form of dying?

⁴⁸ Dr. Rohmer code switched between Dutch and English. His exact words were: "*dus dat maakt het heel persoonlijk, ik maak het af*, the lifestory."

⁴⁹ Even though Dr. Rohmer defines euthanasia earlier as a "natural" death. Several times in our interview he makes the distinction between euthanasia and natural death (*natuurlijke dood*).

Dr. Rohmer: No, that doesn't matter. It's about dying and euthanasia is a form of dying. It is one of the possibilities. The deathbed changes people, at least for people who need other people.

Dr. Rohmer's reflections touched me deeply and every time I re-read his words, I am struck by his ability to uncover and expose what is surely one of the most intimate relationships that occurs in life – helping someone else to die. His story brings up many important themes that I saw reflected in the stories of other *huisartsen* with whom I worked, three of which I will focus on in this chapter. First, I am interested in how Dr. Rohmer has come to think about his role at the end of life. He describes himself as someone who is comfortable not providing medical treatment at the end. Yet he wants to be there when the person dies and to be there for his patients and their families up through death and after it. I want to explore his role alternately as a guide, a witness, and a facilitator in the process of planning for death.

Second, I am interested in how Dr. Rohmer formulates “beautiful death” and how participation in euthanasia discussions facilitates his conception of ideal death. Beautiful death is well thought out and well discussed. Families and patients play active roles, saying goodbye in their own environment and leaving peaceful memories for families to remember. Dr. Rohmer says his role in co-creating beautiful death comes to be more “sharply defined” when euthanasia is invoked. This is something I would like to explore. Finally, I was struck by Dr. Rohmer's desire to deepen relationships with patients and families through participation in their death, especially in the case of euthanasia talk. Using these three themes as a basis for analysis of the *huisarts* perspective, I want to

focus in the following sections on (1) how *huisartsen* view their role in end of life and in particular as participants in euthanasia discussions; (2) how *huisartsen* are defining ideal death and creating it using euthanasia talk, and finally (3) how *huisartsen* may be facilitating social bonds and interpreting euthanasia discourse as citizens and messengers of the Dutch state. The participation of *huisartsen* in euthanasia talk is not always conducive to maintaining social bonds, however, so I will spend some time exploring when this does not occur. Finally, I want to revisit the distinctiveness of Dutch *huisartsen* and how they have come to participate in Dutch end-of-life.

***Huisarts* as Guide, Witness and Facilitator.** I saw the *huisarts* role in euthanasia talk and euthanasia deaths as something that alternated between an active guide, a witness, and a facilitator. As Dr. Rohmer described, when euthanasia is invoked it is a call to action and *huisartsen* are the guides to that process. A euthanasia request and subsequent euthanasia talks gives *huisartsen* something to do; providing a framework and a structure for activities beyond palliative care. I have witnessed the shift that occurs when end-of-life discussions change to euthanasia discussions many times. It is literally as if a switch has been flipped, because once euthanasia is invoked, the roles of patient, family and *huisarts* become more scripted and a pattern of interaction emerges as the stages of a euthanasia discourse begin. When euthanasia has been invoked the phrase “*niks meer aan te doen*” (nothing more to do) no longer applies, instead there is a flurry of activity (mostly conversations) that occur with the *huisarts* taking the lead. Verbal requests must be discussed with the *huisarts* and with family members, and must be repeated. Written declarations for euthanasia must be made and signed by the patient and (in all declarations I saw) by family members as well. If everyone is in agreement then

the process is paused until the patient is ready to re-initiate a request (until the time is right for them to continue). If the request is re-initiated, then more discussions occur among the *huisarts*, the family and the person choosing for euthanasia. An appointment for a second opinion will be scheduled and then if the patient decides to continue, a date for euthanasia will be set and ultimately a euthanasia death may occur. Euthanasia talk clearly gives *huisartsen* a specific and active role to play at the end-of-life, over and above the on-going palliative care that is given.

There is also a “witness” aspect to what *huisartsen* do. Recall when Dr. Rohmer talked about his strengths as a *huisarts*. He said he had the ability to “step back” and “watch what happens.” What he described, however, was more than just watching, it was a witnessing that he described. He wanted to be there at the deathbed (in euthanasia or in “natural” death). That was important to him and I think tapped into his need for continuity. Medical anthropologist Beverly Davenport conducted a study of medical students in a homeless clinic and found that medical students used the term “witness” to describe how they “focus on the entirety of a person’s life situation, not merely on their ailment” as a way to “acknowledge the whole lives” of their patients (Davenport 2000:311, 316). There is a similar “witnessing” that goes on with *huisartsen* in euthanasia talks and euthanasia deaths. *Huisartsen* want to be there for the entire life cycle, it is why many *huisartsen* in my study chose their profession. Dr. Rohmer became a *huisarts* because his father was one and because he was attracted to “knowing the whole story,” from birth to death.

There is also a role that *huisartsen* take on that lies somewhere between the active guide and more passive witnessing. *Huisartsen* also act as facilitators of euthanasia

discussions. Euthanasia talk follow rules for Dutch *overleggen* (consultation), which means that there is a facilitator, everyone must have equal participation, and in the end a decision will be reached that includes input from all participants. *Huisartsen* are facilitators to euthanasia talk. In a study of Dutch *huisartsen* and their end-of-life patients, Dutch researcher van der Muijsenbergh found that *huisartsen* often took responsibility to foster dialogue between patients and families, particularly concerning any angst over dying (Muijsenbergh 2001:107-118). It is not surprising that Dr. Rohmer saw euthanasia as a practice that was “really about communication,” because in practice “euthanasia” was largely experienced as talk. Every *huisarts* in my study told their patients to talk their request over with their family and every *huisarts* required the patient to speak repeatedly about why they wanted euthanasia. In the end, many people did not die euthanasia deaths, but a lot of people talked about it.

Dr. Rohmer describes what he does in euthanasia deaths, as a “little extra push.” I thought about what he said in the context of the other *huisartsen* I came to know, and I think that Dr. Rohmer probably speaks for many of the others. Dutch people do have a unique relationship with nature and most *huisartsen* do not see what they do as something that infringes upon any natural order. They are co-creators with nature and managing death, even to the extent of intentionally taking a life, is in the Netherlands not in conflict with how Dutch people view nature and their relationship to it.⁵⁰ *Huisartsen* (and their physician colleagues) feel *responsible* for Dutch life and Dutch death, and while most

⁵⁰ For more on the Dutch relationship with nature, see Chapter 3.

huisartsen in my study preferred not to perform euthanasia, they were also not willing to abandon their patients at the end-of-life.⁵¹

Making Death Beautiful. What made the prospect of a euthanasia death acceptable to all *huisartsen* with whom I worked was their shared belief that they were helping make death beautiful. I asked all *huisartsen*, with whom I worked, to describe to me their version of a “good case of euthanasia.” Their answers were strikingly similar. As Dr. Rohmer suggested, “beautiful death” was a “good death” that gave patients and families options to choose from. It is peaceful, well thought out, and well discussed among patient, family and *huisartsen*. Also, there is a good memory of the persons’ death left behind for the survivors, a memory of “goodbyes” said at home in the context of family. Ideal Dutch deaths give patients space to reflect on one’s life and relationships. Dr. Rohmer was talking about how it is different when euthanasia is invoked. He said that when talking about euthanasia, the “patient must deal with death within their own family because it [relationships, memories of a loved one] doesn’t end when you die, it goes on.” Ideal Dutch deaths also have an element of planning and control. Dr. Rohmer touched on this when he said that the direction or production (*regie*) that euthanasia talks provide is what makes euthanasia different. There is something about being able to plan and envision ideal death that makes engagement in euthanasia talk valuable.

⁵¹ *Huisartsen* are not obligated to perform euthanasia for their patients. Each *huisarts* can choose whether or not he or she wishes to perform that service. Not surprisingly, there is a range of attitudes by *huisartsen* about their willingness to perform euthanasia. All 10 in my study were willing to perform euthanasia, but most (6 of 10) self-reported being “willing with reservations” to perform euthanasia. One reported being “reluctant,” two reported being “willing,” and one *huisarts* did not respond to the question. I also interviewed two *huisartsen* who were not willing to perform euthanasia. For more on the study sample, see the Appendix.

In my last chapter, I talked about how families use euthanasia talk to script ideal deaths. Just as euthanasia talk provides families with a script for how death should occur, so too does it provide *huisartsen* with the script they need to manage end-of-life. Robert Pool (2000) examines the role of hospital physicians in his study of euthanasia in a Dutch hospital. In his conclusion, Pool suggests that euthanasia offers Dutch people an alternative to what is perceived as “bad death” in the Netherlands. He writes,

In the Dutch context, death as a result of a long, wasting disease over which the sufferer has no control shares many of the characteristics of bad death in non-Western cultures, and euthanasia, increasingly, is coming to be seen as offering an alternative good death (Pool 2000:211-212)

Control, he argues, is the defining characteristic of the Dutch “good” death. The difference between good Dutch death and bad Dutch death is subtle. Suicide, for example, while it gives the person control to attempt death, is not a sure thing and a botched (assisted) suicide is usually not worth the risk (Pool 2000:212).

I had *huisartsen* in my study describe to me the difference between euthanasia and assisted suicide, and many described assisted suicide (having a physician provide you with the means to kill yourself) as less predictable, less orderly and more drawn out than a euthanasia death. Assisted suicides typically occur with *huisartsen* present, but because patients often are ingesting the lethal drugs, vomiting may result making it difficult for the patient to ingest enough of the necessary drugs to ensure a quick (and orderly) death. Assisted suicides sometimes go into a coma for hours or days before dying and, for this reason, assisted suicide is not considered ideal by Dutch standards. Assisted suicide, while just as “legal” in the Netherlands, is rarely practiced.⁵²

⁵² In 2001, between 0.1 and 0.2 percent of all deaths were the result of assisted suicide, compared to 2.2-2.6 percent of deaths by euthanasia (Wal, et al. 2003:46).

What Pool suggests (and I support) is that ideal Dutch deaths are orchestrated by *huisartsen* and planned by patients, families and their doctors. The Dutch have a particular aesthetic about death that favors planning and regulation (rules and structures). Mystery, unexpected occurrences, or allowing “nature” to take its course are not held in particular esteem in the Netherlands. It suggests to me that the long-standing relationship that Dutch people have holding the waters back in the Netherlands that have allowed the Dutch to reclaim as much as one-third of their existing country from below the sea has impacted how the Dutch have come to view death in its ideal form.⁵³ Dutch people control the water; why not also control death? Couple the Dutch relationship with nature with rapid secularization that has occurred in the Netherlands (CBS 2004) and you find that perhaps God and Nature have been replaced in the Netherlands with a faith in society to *make* life good. And in practice that means it is the doctor (the *huisarts*) who acts as the agent of society to make death (through talk of euthanasia) better.

Maintaining Dutch Families. Euthanasia death need not come to pass in order to achieve an ideal death scenario and the focus of much of the practice of euthanasia in the Netherlands is on the talk, not on the moment of death itself. Dr. Rohmer says that euthanasia is “really about communication” and that a beautiful death is one that is “well discussed.” For the *huisarts*, the focus is on bringing the family together in open dialogue before death occurs. Once a euthanasia request is initiated, all *huisartsen* with whom I worked, told their patients to spend time talking about the reason for their request with family members. At least half of the *huisartsen* with whom I worked either initiated

⁵³ For more on the water thesis, see Chapter 3.

some kind of family meeting or even initiated phone calls to estranged family members in hopes of facilitating a reunion before death.

I remember in the beginning of my research being struck by the extent of the role that *huisartsen* assumed in bringing families together once euthanasia was initiated. In the U.S., I would think that a general practitioner initiating a phone call to an estranged family member would be viewed (at the very least) as intrusive. This is not so in the Netherlands. At first, I thought that maybe this was a factor of living in a small town, where everybody knows everybody else and *huisartsen* are friends and social acquaintances with many of their patients outside of their practice. Recall that half of the *huisarts* participants lived and worked in a small cluster of towns outside of Amsterdam and half lived and worked within the city of Amsterdam. Comparison between these two groups showed that while city *huisartsen* have more transitory patient populations, more non-Dutch patients, and may have known their patients on average a shorter time, their orientation to their patients is similar to their small town counterparts.⁵⁴ Small town and city *huisartsen* alike view their role in euthanasia discussions as a facilitator of family relationships.

According to Dr. Rohmer, part of what makes a Dutch death beautiful, and what has become increasingly a focus for him, is management of the memories that remain for those who are left behind when someone dies. He says, “When I am busy with [euthanasia] I think more and more about the bystanders, about the people who remain behind and what it means for them.” This he says was not the most important aspect when he first started with euthanasia, but, he says, “that has grown to be more

⁵⁴ For more on the characteristics of the *huisarts* participants in the study, see the Appendix.

important.” *Huisartsen* are managing family relationships by managing the memories that family members will carry of their loved ones last days.

When Huisartsen Do Not Facilitate Good Death

The popular criticism outside of the Netherlands of Dutch euthanasia practice is that they are on a “slippery slope;” that legalizing the one practice will lead to more illegal deaths, particularly in vulnerable populations. All practices have limitations and there will always be gray (or liminal) areas where those limitations get worked out. In my study, I found that there are several ways in which ideal death and social bonds are not facilitated by *huisartsen* engaged in euthanasia talk.

First, according to Dutch euthanasia policy, *huisartsen* are given the daunting task of determining “lasting and unbearable suffering.” The consequence of mandating such an impossible task is that sometimes they do it well and other times they do not. Current policy dictates, among other stipulations, that physicians must “hold the conviction that the request by the patient was voluntary and well-considered... that the patient's suffering was lasting and unbearable... and that the patient holds the conviction that there was no other reasonable solution for the situation he was in” (The Act 2001b). How is a *huisarts* going to meet these requirements, to determine what is “voluntary,” “well-considered,” “lasting,” and “unbearable”? These are highly subjective concepts. Take the term “unbearable,” *ondraaglijk* in Dutch. In euthanasia talk, *ondraaglijk* is typically invoked by the *huisarts* in response to initial requests for euthanasia. “Is your suffering *ondraaglijk*?” the *huisarts* asks. “Why? Why is it *ondraaglijk*?” The answer is not an easy one to articulate. Typically, it just is.

The *huisarts* response to these murky waters is often to invoke the ideal, to fall back on their concept of the ideal euthanasia patient and their ideal of what it means to assume the role of *huisarts* in Dutch society. Ideal *huisartsen* are concerned with the *whole* patient and input from the family. They are almost a family friend of sorts, responding to ideal patients who have the right disease and know how to ask for euthanasia, how to suffer in proper Dutch ways, and who demonstrate the necessary connection to family and society. In euthanasia talk, the burden of determining "*ondraaglijk*" is actually shared by patients, families and *huisartsen* structured within the discourse of euthanasia. Patients can wish no longer to live, but cannot wish to die. Depression and social isolation red flag the process, while predictable and definable diseases and disease trajectories make the process of considering someone's request for euthanasia less risky for the *huisarts*. Cancer, for example, is an ideal disease for "*ondraaglijk*" suffering, with predictable stages of decline and tangible symptoms of pain and discomfort. Illness due to old age and diseases of the heart, on the other hand, make the determination of *ondraaglijk* suffering much more difficult for the *huisarts*.

Falling back on constructions of the ideal (ideal disease, ideal patient, or ideal euthanasia discussion) and falling back on the shared process of decision-making (*overleg*) that is typical in the Netherlands, allows *huisartsen* some comfort in the gray areas of subjective determination in euthanasia cases. Gray areas persist, however, and it is inevitable that some people who "should" live by Dutch standards die and vice versa. Euthanasia law, for example, does not exclude emotional suffering and much of the public debates in recent years within the Netherlands have centered on where the limits of the euthanasia law should be in terms what constitutes sufficient emotional suffering for

euthanasia (NVVE 2000). When is it depression (not an acceptable reason for euthanasia) and when is it “lasting and unbearable” emotional suffering (an acceptable reason for euthanasia)? At the same time, certain people come to be excluded from engaging in euthanasia talk that might benefit from it. In my study, I found that aging and being elderly is not necessarily a reason to die and newer immigrants, not versed in Dutch ways of engaging in this discourse, are often turned away from euthanasia discussions.

Another way in which ideal Dutch death is not achieved is when *huisartsen* intentionally end life without following proper euthanasia procedures. One *huisartsen* with whom I spoke told me about a patient of his who was in his 80s who was seemingly healthy and active had a heart attack that left him in the hospital. Once there, it was determined that he also had inoperable, end-stage cancer. According to his *huisarts*, he had only a few days or a week left to live. They brought him home to die and the family asked the *huisarts* to “*hem te laten inslapen*” (to “let him sleep” or “let him go to sleep”). They said it was what he would have wanted. The *huisarts*, who knew the man and his family well, told me that he had spoken to the man before he fell ill at which time the man had “made his wishes clear.” The *huisarts* agreed to increase the dosage of morphine and the man died two days after coming home from the hospital. It was not technically euthanasia (it was reported as a death due to natural causes and did not follow the proper procedures for a voluntary euthanasia death), yet his life was intentionally ended.

This is a case of “intentional death” that speaks to the proponents of the slippery slope argument and is an example of when *huisartsen* do not facilitate ideal Dutch deaths

according to commonly accepted concepts of “ideal” death. In 2001, van der Wal and van der Maas conducted the third of a series of longitudinal studies on the prevalence and incidence of euthanasia, assisted suicide and other medical behavior that ends life. They found that approximately 0.7 percent of all deaths in 2001 could be attributed to medical behavior that ends life without an explicit request by the patient (Wal, et al. 2003:67).⁵⁵ Giving patients higher doses of morphine *without* the explicit intention of ending someone’s life is an example of this kind of medical behavior that ends life. It is likely that cases like the one described above may be folded into this category of behavior. I would argue that this, and other cases like it, happens but probably less so in a country that favors public disclosure of this kind of activity. The Dutch do not favor acts done in isolation. They say the law works because it brings out into the open – in the forum of public debate and public regulation – a practice that has always existed.

A Friend of the Dutch Family and an Agent of the State

Dr. Rohmer, and other *huisartsen* with whom I worked, described what he does as a family friend doing a family favor. In the course of euthanasia discussions, he said, the bond that he had with his patient and the patient’s family typically grew stronger, and it was not unusual for him and members of the surviving family to consider each other “friends” after the intensity of euthanasia talks. This is because many *huisartsen* consider what they do at the end of Dutch life akin to a family friend doing a decent family favor.

There is more to it than that, however, because the *huisartsen* is situated between several competing concerns – the concerns of the profession versus the concerns of the

⁵⁵ The exact wording in Dutch is, “*levensbeëindigend handelen zonder uitdrukkelijk verzoek van de patient*” (Wal, et al. 2003:67)

family, concerns of his or her personal beliefs versus the concerns of the state. The *huisarts*' role as family friend is not sufficient to describe what they do, because *huisartsen* really are not family and must act in accordance with their own personal beliefs, professional ethics, and state policies. *Huisartsen* are agents of the state, guided themselves by a discourse that has emerged giving them a hand in managing Dutch death.

Euthanasia is a burden that *huisartsen* and other doctors in the Netherlands carry, but they do not carry it alone. The Dutch are a consensus-building society and no burden is carried by one member alone, it is shared. The Dutch have been criticized for rarely punishing doctors who do not follow proper procedure and get caught doing it (Griffiths, et al. 1998:43-85). If doctors are not being punished for indiscretions in euthanasia practice, they ultimately are not the ones being held accountable. Dutch law was reached by countless years of informal practice and by more than 30 years of public debate and consensus building. Dutch *society* created the policy and the state (through its policy) manages the burden of life and death, yet who is accountable is not clear.

Dutch *huisartsen* are situated somewhere between the Dutch family and the Dutch state. One *huisarts* described the position as being something between a criminal and a hero. On the day of a euthanasia death, the *huisarts* must report to the local coroner who must come and view the body (determining that death has occurred) and review the documentation provided by the *huisarts* in the case of an "unnatural" death, which is the language used for a euthanasia death (Griffiths, et al. 1998:39-40). In the case of an unnatural death, the coroner must forward the paperwork to a regional assessment committee (*toetsingscommissie*) where it may take months before a determination is

made that the *huisarts* has acted with due care as per Dutch regulation.⁵⁶ Until that time, *huisartsen* tell me that it feels like being a criminal. I have been in the office when a *huisarts* takes the phone call from a *toetsing* committee member, relieving them from the possibility of prosecution. Waiting for this call can be nerve wracking and no *huisarts* enjoys this process. To the family, they are often the “hero,” the member of society who is willing to stay with them through to the end of life, facilitating family relationships, letting them know that society will not abandon them, eliciting talk and planning for ideal death, witnessing the end of the lifecycle, and occasionally stepping in to end life prematurely.

⁵⁶ In 2001, it could take up to several months before the *toetsingscommissie* determined whether a *huisarts* had followed proper procedures. Today, it typically takes up to three weeks.

7. Conclusion

In the introduction to my dissertation, I explained that 25 percent of people who die in the Netherlands request euthanasia, but only a few (1 in 10) die that way (Wal, et al. 2003:46). These statistics sparked a study of what it means to talk about euthanasia. My findings suggest that the Dutch have developed a practice, which I call “euthanasia talk,” that manages life at the end of Dutch life. Euthanasia talk is the product of a discourse that has emerged in the course of Dutch culture and Western history to shape how Dutch people have come to think, feel and act at the end of life. Discourse produces knowledge in forms that we come to think of as normative (as assumed) and, in doing so, discourse obscures its own very nature – that it is a cultural form constructed by and among people.

Ironically, the presence of a euthanasia discourse in the Netherlands has not resulted in a population that predominantly dies by euthanasia. It has resulted in a population that largely *talks* about euthanasia. Most of what a dying person needs (socially and emotionally) is available in euthanasia talk, making euthanasia death often unnecessary. Engaging in euthanasia talk keeps people feeling connected to their family and their society. Dying persons stay active in their family relationships in spite of losses due to illness. Families are encouraged by *huisartsen* to maintain their central role in the lives of their dying family member as active participants in the process of discussing and planning for euthanasia. And *huisartsen* keep patients and families connected, letting patients and families know that they will not be left to die alone, outside of their society.

Based on a shared concept of what it means to die “beautiful” Dutch deaths, euthanasia talk exists as a script for ideal ways of dying. Ideal Dutch death is well

planned, well discussed, not extremely painful or full of undue suffering, and occurs at home surrounded by family. Euthanasia death does not need to occur to make death beautiful in the Netherlands. The Dutch are less focused on avoiding suffering, than they are on the desire to plan and control what might occur in death. It seems to be the process of planning among key participants (dying individual, family and the *huisarts*) that allows Dutch people to feel better about death.

This is not say that Dutch people are not dying euthanasia deaths, that a slippery slope does not exist in the Netherlands, or that all Dutch citizens are dying beautiful deaths connected to family and society. Like any practice, there are those who have difficulty accessing it and there are those who experience it differently. Foucault's concept of "discourse" is not meant to be seamless; it is something always in the making, always in competition with other dominant discourses.

Dutch people are not offering themselves up for euthanasia, because agency does exist even in a Foucauldian framework. The rules for engaging in euthanasia talk have resulted in several stages of talk, each of which begins because a patient initiates it⁵⁷ and ends when a *huisarts* pauses until the next stage is initiated. Patients can stop euthanasia death from occurring. Once euthanasia talk begins, it is not like a train you cannot get off. Its progress relies on patients determined to get to a euthanasia death; patients who must continuously re-initiate euthanasia talks in order to keep it going. If someone does not want euthanasia, they have several options. They can fail to ask for it again; they can hesitate when asked why they want euthanasia; or they can say outright that they are not interested. Families can stop euthanasia death from occurring. They can oppose it

strongly enough that their loved one relents. *Huisartsen* can stop euthanasia death from occurring. *Huisartsen* do not say “no” to patient requests for euthanasia, it is not in keeping with Dutch cultural ways of *overleg* (consultation). They do, however, use the stages to pause the process and frequently stall it or redirect the conversation to something else, if they are uncomfortable with whether the request is meeting the requirements of the policy or their personal and professional limitations of what makes an acceptable request for euthanasia.

Euthanasia talk is a product of a Dutch discourse that is constantly changing, being made and re-made in the realm of public debate and euthanasia practice. It is certainly not the only discourse on end-of-life that exists in the Netherlands, but it is a dominant one that impacts at least one-quarter of the people who die every year there. It is my hope that with this dissertation I have been able to elucidate euthanasia as a discourse and as a practice, so that outsiders to the Netherlands may have a better understanding of what euthanasia is and what it is not.

⁵⁷ This is with the exception of the first request for euthanasia, which may sometimes be initiated by a physician who is laying out the options for a patient once the treatment phase of someone’s illness is over. For more on the stages of euthanasia talk, see Chapter 2.

Epilogue: Coming Home

The phone rang for me in June and ten days later I was on an island off of Florida in the hospital with my mother. Like Mr. Veenstra, I, too, am a cuddler so the first thing I did was crawl in bed with her, hugging her small and unsteady frame. She seemed so shaky and frail, and I think I felt like my hugs could keep her grounded, give her life even when we both knew her life would soon be over. She was not a fan of Western doctors, so it took a long time to discover the cancer. By the time they did it was too, too late. They opened her up and found it in her intestine, her liver and her lymph nodes. They took some of it and left her with a ragged scar held together by staples spanning most of her belly.

My mom, matriarch of our family at 4 foot 11 and only 63 years old, came home to die two days later. Since I was the one in the family without a "real" job and without a family of my own, I was the one to care for her. My dad still had to work during the day. They didn't have health insurance, so money was an issue. I called Hospice and the nurse came over to set us up with the drugs we would need. After experiencing Thuiszorg, it was shocking how little help is available to Americans who want to die at home and how prevalent the issue of money is in healthcare decisions to those who don't have an extensive system of welfare to back them up. Thank goodness for what Hospice could do and luckily for now, dad had his job and mom could still move around on her own.

As it turned out we had five weeks together before she died. We brought her home and I remember the first week was rough. She barely ate and was often in pain. The nausea was worse. We had several different medications for nausea and pain and

the days were marked every four hours with these pills, every two hours with those pills. Some nights I slept on a mat at the foot of her bed, other nights she preferred to be alone. She needed her space and she wanted us to have our rest. On the weekends, family came to visit. My sisters and my brother all took turns visiting. Our mother was dying and we were all devastated.

During the week, I had mom mostly to myself. My dad and I gathered around her bed in the morning, then he went off to work for the day. Usually I stayed with her awhile after he left and we talked and enjoyed the view from her bed of the back yard with all the beautiful flowers and plants. She was artist and, like everything else she touched, the yard had a uniquely artistic touch, with sections arranged around interesting, homemade wind chimes, statues and other pieces of art. We talked about a lot of things. She decided she wanted to be in my study, so we taped some of our conversations about how it felt to die, how morphine feels, and what had become in her last weeks most important to her.

When we weren't taping, we talked about anything. We talked about family, how the others were taking it, and we reminisced about things we both loved. Other times I just let her be. We were similar in that we liked to socialize, but we needed our private time, too. Sometimes I went for a short run on the beach, then came home to sit in the next room reading. She mostly stayed in her bed and called for me when she needed something.

Not knowing when she would die was difficult. Time seemed to linger between the immediate – dealing with the nausea and the pain, wanting her to eat, keeping up with the medication schedule – and an uncertain future – what would I do when she died, I

mean that moment, that day, what would I do? And what about after? I couldn't get that far. Since we didn't know how long it would be, I took a job waiting tables on the weekends, something to get me out of the house two nights a week.

After the first week, I think some of the fear she had settled down and we got into a routine that worked. During the week, she went through her old papers and letters, throwing out things that were no longer necessary or too private to leave behind. We also wrote her Last Will and Testament and started planning the party that we would throw for her after she died. Mom wanted something not too serious and she thought it would be good to have us bring a lot of her artwork so that friends could take something home with them.

Two things really changed for my mom once she knew she was going to die. I asked her once what she got scared about and she said when she got scared it was not fear for herself, but fear for how her family might feel when she leaves. She didn't want us feeling unresolved about anything, so her five weeks was largely spent trying to give to each of us what she thought we needed most. The other thing that changed for her was her ability to stay in the moment. As a long-time practitioner and teacher of Buddhism, she had always attempted to live in the moment. Now she really was. She explained,

Now I'm seeing things as having an ending. Every morning I wake up, it's another morning that I didn't know if I'd have or not. It's a beautiful morning and the beauty is more alive and real than the beauty I was seeing before because it's not overlaid with concepts of what I ought to do or what it ought to be or what I want it to be or what other people might want it to be. It doesn't have any of that. It just is. So you start seeing it without these little parameters. And when

you hear people talk it's so strange because they seem to be talking about a lot of things that don't matter, because you can't really do anything about them. In the other world I used to live in I would go along with it, but now I don't have to put up with that. I don't want to waste my time with stuff that is junk, that isn't going to get resolved, that isn't going to make people happy. Just let the world happen, watch it a little bit and it will tell you what it wants and what it needs from you. It doesn't need a whole lot, maybe just a little acceptance, maybe, or appreciation and participation.

She really was living more in the moment and so were we. When the future is so uncertain, it is hard not to live in the present. And what really mattered was what was happening right then. The end was difficult to predict so on the night she died, the rest of the family was either on their way or getting ready to come. I watched her die and when the final moments came, I went and got my father. We prayed for her until she stopped breathing, then my father did a special Buddhist prayer at the foot of her bed. We cleaned her up and covered her and went in the next room to share some tea and to start making phone calls. My feeling was surprisingly one of elation. She had accomplished what she set out to do. She wanted to die in a way that was congruent with her beliefs and the kind of life she had lived. While her death was painful and messy and it was terrible to lose her, there had also been a lot of beauty and connection. For that I am very grateful.

Two weeks later, I was back in the Netherlands, completing the last of my interviews. I was tired and sad and ready to finish things. I'd had enough of death for probably a lifetime, but it was time to finish it. I sat down with the family of Mrs. van der

Horst (remember Mrs. van der Horst – from the prologue – who like my mother also died at a young age, stricken with inoperable cancer, but taken by euthanasia). I asked them why euthanasia. I reminded them that in most countries, people can't get euthanasia, so why was it important for them? This is what they told me:

Joop (husband/widower): When you love someone, you don't want them to suffer and my wife also didn't want that. She didn't want to be always sick or always tired. She wanted to live a normal life. But it didn't happen like that.

Frije (daughter): And how much pain can someone have? How long must a person suffer? That is why euthanasia is so important.

Maarten (son): There are so many different ways to die and this is a really beautiful way to go naturally. Just like Frije said, maybe she would have lived another month and then [died].

Joop: How so?

Maarten: This is a much more beautiful way to die than to die of pain. That is when euthanasia is more beautiful and more peaceful and more humane.

Joop: I agree.

Maarten: That's what I find beautiful about euthanasia – that so much pain can be taken away from someone.

Frances: And was it what you expected – what happened?

Frije: For me, it went way too fast.

Joop: There was an appointment and the appointment lasted three hours.

Frije: No, I don't mean that, I mean after the prick [the injection] it went real fast. I thought she would calmly close her eyes and peacefully drift into sleep, but it was [so fast]. I found that...

Joop [interrupting]: Ja, I hadn't thought about that before and I also had that picture and I will keep that with me. I also found it to be quick, but good quick.

Frije: I just thought that she would calmly close her eyes and then fall to sleep. That's what I found to be too fast.

Joop: But it is still the most beautiful death there is, seems to me. Once again, I said it before, I would have preferred it two weeks earlier. Those were two really difficult weeks.

Maarten: Ja, those were almost inhumane weeks, actually.

I think about the similarities and differences between dying Dutch and dying some place else. In the U.S., too often, I saw people dying on their own with only their family to help. What Hospice is able to do is not equivalent to what *Thuiszorg* in the Netherlands does to help people stay at home to die, because they do not have the resources or the backing of the state. I think of my grandmother who lived with us for years in an upstairs bedroom far removed from where our family spent most of our time (on the first floor of our house). I think of other families I met during my time with U.S. Hospice who made do, usually with so little. Like in the Netherlands, for those in the U.S. who do not have a lot of money, elderly parents often lived in a bed crowded into the living or dining room on the first floor, almost always parked in front of a television that was always on. My mother was lucky. She had a bedroom that was just off of the

kitchen and living room (so she could be close to the main family spaces in the house) and, by choice, she (like many Dutch people) spent her last weeks enjoying her back yard from the vantage point of the picture window in her room.

Death is hard. It just is. Which is why rituals and practices have always existed to help ease the passage for those who are dying and those left behind. If my mother's death taught me anything, it is to live in the moment as much as you can and to let the ones you love know it, because people do die. Euthanasia was not an option for us because we live in the United States where it is not legal. Euthanasia was also not an option, because my mother's belief in Buddhism gave meaning to the suffering at the end of her life. That was the script – a product of an American-Buddhist discourse on death – that eased her passage and to a large extent, my experience, of her death.

For those who look to the Dutch experience at the end-of-life as a model for other countries, it is critical to consider Dutch euthanasia in the context of the discourses that inform end-of-life practices. Dutch euthanasia is not something that can be easily exported, but the Dutch experience with euthanasia is something that can help us look more critically at the norms and practices that make up our own end-of-life experiences.

Appendix. On the Study Samples

Research activities were focused on a group of 10 *huisartsen*, five in Amsterdam and five in a town nearby and 25 of their end-of-life patients (patients who were terminal or dying, with or without a euthanasia request). The following tables provide detailed information on my study sample of *huisartsen* and their patients.

***Huisartsen* (Dutch General Practitioners) (n=10)**

I was introduced to potential *huisartsen* for the study via snowball sampling techniques where researchers and doctors I knew introduced me to *huisartsen* they knew. I attempted to select *huisartsen* for the study so that sample characteristics (such as gender, age, type of practice) would mirror population characteristics. (See Table A.1).

TABLE A.1 *Huisartsen* Characteristics, Study Sample versus Population

Category	Subcategory	Sample Number (Percentage)	Population Percentage*
Sex	Male	8 (80%)	80%
	Female	2 (20%)	20%
Age	<40 years of age	1 (10%)	17%
	>40 years of age	9 (90%)	83%
Type of practice	Solo	3 (30%)	45%
	Duo	5 (50%)	32%
	Group (3 or more)	0 (0%)	14%
	Health Center	1 (10%)	9%
Time worked	Full-time	5 (50%)	70%
	Part-time	5 (50%)	30%

*Source: Hingstman, L. 1999. Cijfers uit de registratie van huisartsen. Utrecht: NIVEL.

Through participant observation in the office and on house calls with these ten *huisartsen*, I was able to meet patients who were terminal or dying, either with or without a request for euthanasia. Of a total of approximately 650 patients whom I met through observation with the *huisartsen*, 25 agreed to participate in the study. Of these 25, all

were either terminal or dying, or had made a request for euthanasia. Once patients were included in the study, their case was closely tracked. Research activities with patients included house calls with the doctor and home visits on my own; formal, taped interviews and informal discussions with the patient, the doctor, family members, and/or home care employees from *Thuiszorg*.⁵⁸

The main field site was Amsterdam; chosen for its central role in implementing the latest healthcare schemes in the Netherlands and for its proximity to a team of euthanasia researchers and other research resources.⁵⁹ To get some feel for the differences between the “town” and the “city,” research was also conducted in a small township situated within 25 miles of Amsterdam – a township that I will refer to as *Amsterdorp*.⁶⁰

I wanted to make sure that I could collect enough data at the sites that I chosen, so the decision was made not to conduct research elsewhere in the Netherlands. Given the multi-sited nature of the research, I was immediately at a disadvantage in terms of building rapport. Unlike in a hospital or nursing home setting, the *huisartsen* could not see me everyday. Spending time with one doctor meant that I could not spend time with

⁵⁸ *Thuiszorg* is literally translated to mean “at home care.” *Thuiszorg* is the state-subsidized home care organization available free or on a sliding scale to all Dutch citizens. They provide home health services up to four visits daily, including overnight service. Services include serving meals, personal care, administering medications, nursing care, house cleaning, and respite.

⁵⁹ I gained entrée to the field via a group of researchers in the Department of Social Medicine at the Free University in Amsterdam. Through the generosity of Dr. Gerrit van der Wal, chair of the Department of Social Medicine, I was offered both professional and office support. I also had an advisory committee which met once a month, providing me with on-going introductions, research and ethical advice, and general professional support. The committee consisted of Dr. Anne-Mei The, chair of the committee, medical anthropologist, and author of *Vanavond Om 8 Uur*, one of the two existing ethnographies on euthanasia in the Netherlands; Dr. Gerrit van der Wal, *huisarts* and lead author of the first, government-sponsored 1991 and 1996 nation-wide studies on euthanasia; Dr. Dick Willems, *huisarts* and bioethicist in the Department of Social Medicine at the Free University; and Dr. Sjaak van der Geest, medical anthropologist at the University of Amsterdam.

⁶⁰ Amsterdam is large enough that participants in the study cannot be identified by identification of this location. “Amsterdorp” is small enough that a pseudonym is necessary to ensure anonymity.

nine others. I attempted to alleviate this problem by including *huisartsen* from the same group practice in my study. Group practice, however, is rare in Holland – 77 percent of *huisartsen* work in either a solo or two-person practice (Hingstman 1999:12). In addition, *huisartsen* tend to work independently of one another, so a day spent with Doctor A in a group practice would include minimal interaction with Doctor B in the same practice, and since *huisartsen* are doctors least likely to have their activities scrutinized (compared to hospital doctors who may be more likely to work in a team), participant observation with them was sometimes challenging. To combat these issues, I limited the number of *huisartsen* to ten and the geographic radius to 25 miles of Amsterdam.

TABLE A.2 *Huisartsen*: General Figures (n=10)*

Average length of office visit	12 ½ minutes
Average number of patients seen daily	Home visits: 7
	Home/Office visits total: 28
Average number of patients (per practice)	1828
Percent of patients on <i>Ziekenfonds</i>**	62%
Total number of euthanasia deaths performed (2000-2001)	5
Cost of office visit (FY 2001)	fl 40,00 (= \$17.10)
Cost of home visit (FY 2001)	fl 50,00 (= \$21.38)

*Because of the small sample sizes, I do not assume that these figures are representative of population figures.

***Ziekenfonds* is the national health insurance program available to all Dutch citizens on a sliding scale fee and free of charge to those who cannot afford it.

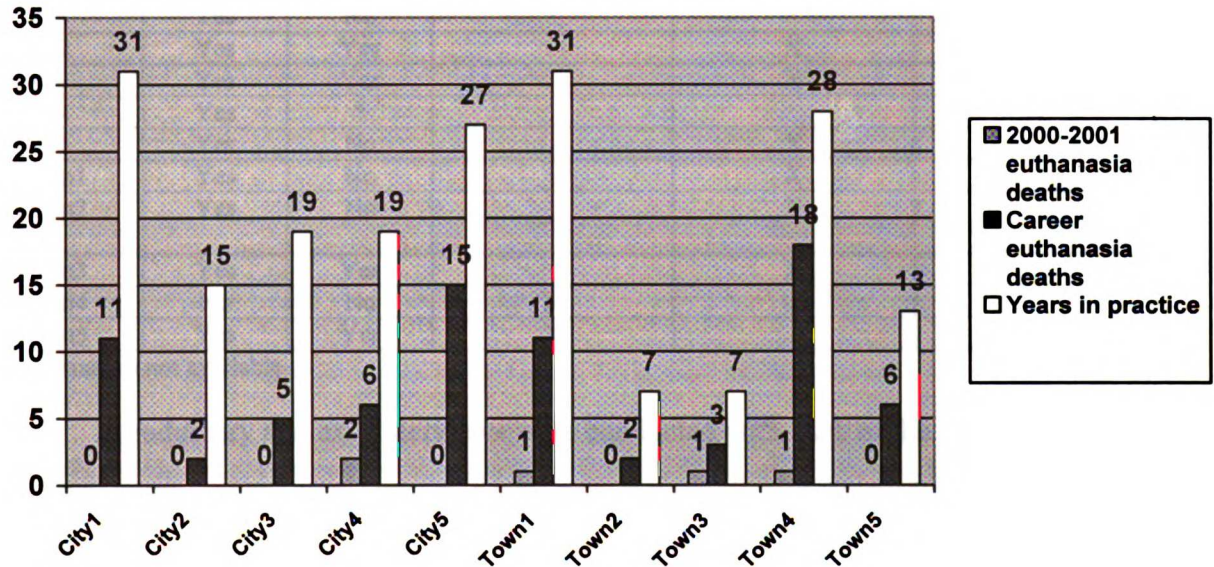
The *huisarts* daily practice is generally divided into two parts: morning and afternoon. Morning generally consists of back-to-back office visits, averaging approximately 12 ½ minutes each. The bulk of the office visits are usually done in the morning, broken up by a coffee/tea break at 10:15, and completed occasionally by one or a handful of house calls, or home visits. *Huisartsen* in the city, generally bike to their house calls, because their patient radius is typically manageable by bicycle. Their “town” counterparts all drove by car. Afternoons are typically slower (less patients) and office visits generally last longer (more complex problems are intentionally scheduled in the afternoon). Afternoons might include an hour of phone consultations (when patients can call in to talk to the *huisarts* personally) and typically include the bulk of home visits. On average, a *huisarts* will see approximately 28 patients per day, 7 of which will be home visits.

Each *huisarts* works a varied schedule. The average number of patients total was approximately 1,828 with as many as 62 percent using *Ziekenfonds*, the national Dutch healthcare insurance program that provides health insurance on a sliding scale fee or at no cost to Dutch citizens who cannot afford it. The cost of seeing the *huisarts* is regulated by the Dutch *Huisarts* Association (LHV), which in 2001 charged the equivalent of approximately \$17.10 for an office visit and \$21.38 for a house call. I asked several *huisartsen* how much it cost/how much it saved in cost to receive euthanasia. One *huisarts* explained that with euthanasia, the *huisarts* typically does more home visits leading up to the euthanasia death than in a non-euthanasia death. On the day of the scheduled death, one *huisarts* said he might charge double the normal cost (to compensate for the amount of time it takes), but many chose to waive the fee entirely on

the last day. Drugs for the euthanasia death are given free-of-charge by the pharmacy.

(See Table A.2).

FIGURE A.1 Number of Euthanasia Deaths* Performed by Study *Huisartsen* Compared to Years in Practice (n=10)



*Includes both euthanasia and assisted suicide deaths performed.

Prior to initiating my study, I knew from a month long pilot study and discussions with experts that on average I could at the most anticipate 10 cases of euthanasia from 10 *huisartsen* over the course of a year. Because I also selected *huisartsen* who had not performed euthanasia frequently over the course of their career, I had concern that I would get enough cases of euthanasia to complete my study. Over the course of my study year (2000-2001), ten *huisartsen* performed a total of five euthanasia deaths. Careers ranged from veterans with 28 to 31 years of general practice experience to relatively new *huisartsen* at 7 years. Career euthanasia deaths ranged from 2 to 3 for the 7 new *huisartsen* and 11 to 18 for veteran *huisartsen*. Euthanasia deaths that occurred

prior to my involvement with the *huisarts* were not included in the patient study sample. (See Figure A.1).

TABLE A.3 *Huisarts* Interview Data (n=10)

<i>Huisarts</i>	Raised Religious	Belief in God Now	Willingness to Perform Euthanasia (self rating)		
			Willing	Willing with Reservation	Reluctant
City1	Yes	No	*	*	*
City2	Yes	Yes		X	
City3	Yes	Yes		X	
City4	Yes	*			X
City5	Yes	No		X	
Town1	Yes	No		X	
Town2	Yes	No		X	
Town3	Yes	Yes		X	
Town4	No	No	X		
Town5	Yes	Yes	X		

*Information not available

Introductory and exit interviews were conducted with each of the ten *huisartsen* in the study (and in addition to multiple interviews with *huisartsen* in regards to the patient case studies conducted throughout the study year). Introduction interviews included a number of questions about the *huisarts*' personal and professional background. Among the various topics discussed, interviews revealed that 9 out of 10 *huisartsen* were raised in a religious environment, yet only 4 out of 9 reported a current belief in God (information was not available for one *huisarts*). This seems to mirror secularization trends in the population. From 1960 to 1970, the Netherlands experienced some of the sharpest declines in church attendance compared to the rest of Europe. In 2003, 42 percent of all Dutch citizens identified themselves as having no religious affiliation, followed by 30 percent who identified as Roman Catholic and 13 percent who identified as Dutch Reform (CBS 2004).

Huisartsen were also asked to self-report on their "willing to perform euthanasia." The majority (6 out of 9) reported that they were willing to perform euthanasia, but only

with reservations. No obvious connection could be drawn between the *huisartsen* self-reported willingness to perform euthanasia and their track record of career euthanasia deaths. (See Table A.3).

End-of-Life Patients and their Families (n=25)

While I met with over 650 patients in the course of my study year, only 25 met the requirements for the study – were identified as terminal, dying, or had a request for euthanasia – and agreed to participate in the research. Of the 25, 14 had requests for euthanasia and 11 had no request for euthanasia. Of those with euthanasia requests, 3 died euthanasia deaths, 5 died without euthanasia, one received medical attention that hastened the end of life, and 5 were still alive at the end of the study.

TABLE A.4 Patient Demographics (n=25)

No.	Gender	Age	Marital Status	Home Location	Country of Origin
1	Female	72	Married	Amsterdam	Netherlands
2	Female	59	Single	Amsterdam	Netherlands
3	Female	82	Widow	Amsterdam	Netherlands
4	Male	80s	Married	Amsterdam	Netherlands
5	Male	74	Married	Amsterdam	Netherlands
6	Female	58	Married	Amsterdam	Germany
7	Female	78	Widow	Amsterdam	Netherlands
8	Female	57	Married	Amsterdam	Netherlands
9	Male	54	Married	Amsterdam	Netherlands
10	Male	52	Married	Amsterdam	Netherlands
11	Female	75	Widow	Amsterdam	Netherlands
12	Male	57	Married	Amsterdam	Netherlands
13	Female	55	Married	Amsterdam	Netherlands
14	Male	89	Widower	Amsterdam	Austria
15	Female	90	Widow	Amsterdam	Netherlands
16	Female	91	Widow	Amsterdam	Netherlands
17	Male	77	Single	Amsterdam	Netherlands
18	Female	91	Single	Amsterdam	Netherlands
19	Female	77	Widow	Amsterdam	Netherlands
20	Male	52	Married	Amsterdam	Netherlands
21	Male	87	Married	Amsterdam	Netherlands
22	Female	79	Unknown	Amsterdam	Netherlands
23	Male	78	Unknown	Amsterdam	Netherlands
24	Female	75	Unknown	Amsterdam	Netherlands
25	Male	81	Married	Amsterdam	Netherlands

General Characteristics. The distribution of gender across the sample was fairly even. Fourteen of 25 patients were female. Of those who chose to die in nursing homes, nearly all were female (8 of 9 persons) and the majority was older, with a mean age of 85. Of persons with euthanasia requests, eight of 14 patients were female.

The majority of patients were either married or widowed and nearly all were Dutch natives. Twelve were married, 7 were widowed, 3 were single and for 3 persons in the study, their marital status was not known. Twenty-three of 25 participants were born in the Netherlands, one was born in Austria and another in Germany. Six patients were currently living in Amsterdam and 19 were living in a small cluster of towns outside of Amsterdam (aka, Amsterdorp). (See Table A.4).

End-of-Life Characteristics. Fourteen of 25 persons included in this study had euthanasia requests with their doctor. Of those included in the study, not everyone was necessarily dying. Seventeen of 25 patients had a terminal prognosis; two patients were in remission (one from cancer, the other from complications related to HIV/AIDS) and six were not diagnosed as terminal cases. Cases that were not terminal tended to be considered end-of-life patients by their *huisarts*, but tended to have less specific illness and illness trajectories (one had a stroke, three had diseases of the blood, and one had been diagnosed with dementia and other non-specific complications).

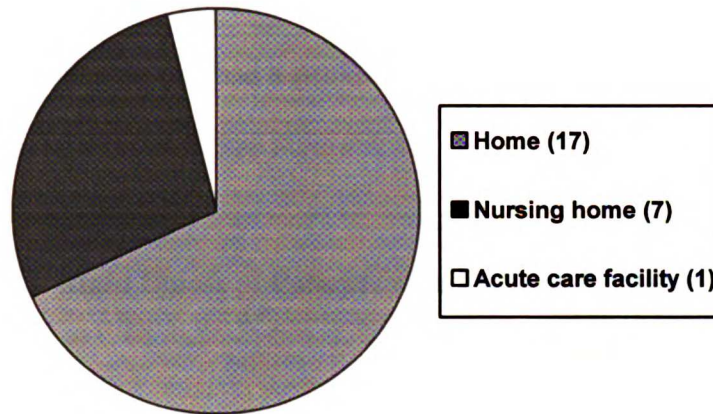
Most of the study participants were those who had chosen to die at home, typically with the help of *Thuiszorg*, the national homecare agency, and family. Seventeen of 25 patients chose to die at home; seven were in nursing homes (*verzorgingscentra*), and one in an acute care facility (*verpleeghuis*). (See Table A.5).

TABLE A.5 Patient End-of-Life Information (n=25)

Case No.	Euthanasia Request	Main Illness	Prognosis	End-of-Life Location	Home Care Used	Primary Caregiver(s)
1	Yes	Cancer	Terminal	Home	No	Husband
2	Yes	Cancer	Terminal	Home	Yes	Sister/Father
3	Yes	Cancer/ Aneurysm	Terminal	Home	Yes	Daughter
4	Yes	Cancer	Terminal	Acute Care	N/A	Wife/Children
5	Yes	Cancer	Terminal	Home	Yes	Wife
6	Yes	Cancer	In remission	Home	N/A	Husband
7	Yes	Stroke	Not terminal	Nursing Home	N/A	Son
8	Yes	Cancer	Terminal	Home	Yes	Husband/ Childr
9	Yes	Cancer	Terminal	Home	Yes	Wife
10	Yes	HIV/AIDS	In remission	Home	No	Husband
11	Yes	Diabetes/ Kidney failure	Not terminal	Nursing Home	N/A	Daughter
12	Yes	Cancer	Terminal	Home	No	Wife
13	Yes	Cancer	Terminal	Home	No	Husband
14	Yes	Diabetes	Not terminal	Nursing Home	N/A	Children
15	No	Non-specific	Not terminal	Nursing Home	N/A	Daughter
16	No	Anemia	Not terminal	Nursing Home	N/A	Sister
17	No	Dementia, non-specific	Not terminal	Home	Yes	Live-in Friend/Sister
18	No	Cancer	Terminal	Nursing Home	N/A	None
19	No	Cancer	Terminal	Home	Yes	None
20	No	Cancer	Terminal	Home	Yes	Wife/Brother
21	No	Emphysema	Terminal	Home	Yes	Wife/Daughter-i law
22	No	Cancer	Terminal	Nursing Home	N/A	Unknown
23	No	Cancer	Terminal	Home	Unknown	Daughter-in-law
24	No	Cancer	Terminal	Home	Unknown	Son
25	No	Cancer	Terminal	Home	No	Wife

Of those who choose to die at home (n=17), nine used *Thuiszorg* or family to aid them in their care. Of those who needed home health assistance, only one of 17 had no other assistance other than *Thuiszorg* to help them stay at home. In other words, only one person in this study was able to stay home with no family involvement in their home care. (See Figure A.2).

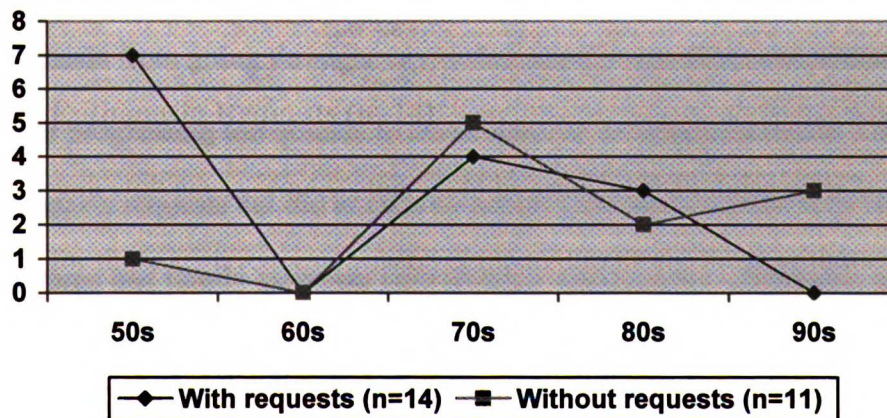
FIGURE A.2 Number of Patients Planning to Die at Home versus in an Institution (n=25)



Patients with Euthanasia Requests (n=14)

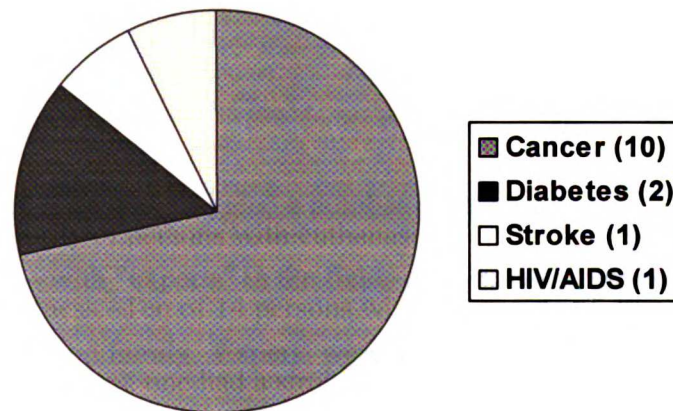
Those with euthanasia requests tended to be younger than those without requests. The mean age for those with requests was 68 compared to 80 for those without euthanasia requests. Of those with euthanasia requests, seven of 14 persons were in their 50s, with the youngest at age 52. No one with a euthanasia request was over the age of 89. (See Figure A.3).

FIGURE A.3 Age Range of Persons with Euthanasia Requests versus Patients without Euthanasia Requests (n=14)



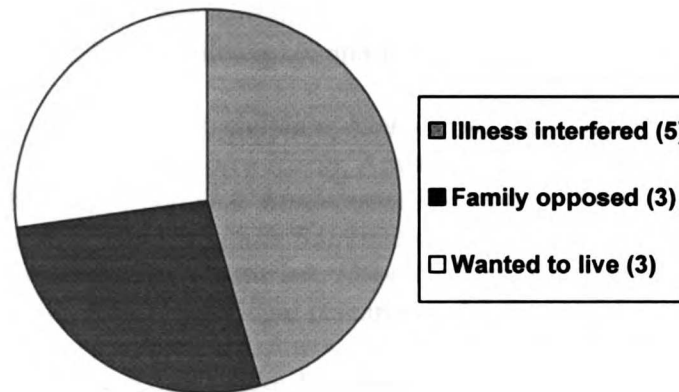
The large majority of persons with euthanasia requests were diagnosed with cancer as their main illness. Ten of 14 persons with euthanasia requests had cancer. Two were diagnosed with diabetes, one had a stroke and one had been diagnosed with complications due to HIV/AIDS. (See Figure A.4).

FIGURE A.4 Main Illness of Patients with Euthanasia Requests (n=14)



Of those who talked about euthanasia but did not die a euthanasia death, there were three reasons why they did not complete their plans for euthanasia: (1) they want to live the life they had left; (2) family opposition was enough to influence their choice to stop the euthanasia from going through; or (3) their illness was either not severe enough, in remission or progressing too quickly to allow time for a euthanasia death. Of 11 who initiated euthanasia requests but did not die by euthanasia, three decided they wanted to go on living; three had family members who strongly opposed the euthanasia; and five had illnesses that interfered with the process. (See Figure A.5).

FIGURE A.5 Reasons for Canceling a Euthanasia Request (n=11)



Other Research Activities

Other research activities included a number of interviews – and countless informal discussions – with “experts” in the fields of euthanasia, general and end-of-life practice, Dutch culture and family. Experts were identified and recruited to the study using reputational case selection and triangulation of recommendations of experts in the field (Miles and Huberman 1994:28). Experts included persons and groups on both sides of the euthanasia debate from across the country. Other research activities included, for example:

- Participant observation and interviews with *Thuiszorg* employees
- Participant observation in an acute care facility (*verpleeghuis*) and palliative care unit (*verpleeghuis*)
- Interviews with *huisartsen* not willing to perform euthanasia
- Interviews or consultations with:
 - Willem Beertse, *Uitvaartcentrum Zuid*, Amsterdam
 - Diny de Bresser, Group Director, *Amsterdam Thuiszorg*, Amsterdam
 - Dirk van Dijk, *Amsterdam Thuiszorg*, Amsterdam
 - Anneke Frank, Rio (on home care coordination), Amstelveen
 - Sjaak van der Geest, PhD, anthropologist, *Department of Anthropology, Universiteit van Amsterdam*, Amsterdam
 - A.J. Gelderblom, PhD, *Department of Literature, Universiteit Utrecht*, Utrecht

- John Griffiths, PhD, sociologist of law, *Groningen Universiteit*, Groningen
- Tony Hak, PhD, medical sociologist, *Department of Social Medicine, Vrije Universiteit*, Amsterdam
- Larry Heintz, PhD, philosopher and medical ethics, *University of Hawaii*, Hawaii
- Caroline van der Horst, chaplain, *Sint Jacob*, Amsterdam
- Marijke ter Horst, *Hospice Kuria*, Amsterdam
- Dr. Jochemsen, *Prof. G.A. Lindeboom Instituut*
- C. Kalis, *R.K. Begraafplaats Buitenveldert*, Amsterdam
- James Kennedy, PhD, historian, *Hope College*, Holland, Michigan
- Albert Klijn, PhD, socio-legal researcher, *Ministry of Justice (WODC)*, Den Haag
- Roel de Leeuw, *Nederlandse Vereniging voor Vrijwillige Euthanasie*, Amsterdam
- Ellen Looman, humanistic chaplain, *de Venser*, Amsterdam
- David Mehr, MD, *University of Missouri*, Columbia, Missouri
- Bregje Onwuteaka-Philipsen, MA, PhD, *Department of Social Medicine, Vrije Universiteit*, Amsterdam
- Henk Poolen, *Terra Nova Uitvaartvereniging*, Utrecht
- Marijaane van der Schalk, MD, palliative care specialist and verpleegarts, *Sint Jacob*, Amsterdam
- Piet Schoonheim, MD, huisarts trainer, *Vrije Universiteit* (huisarts in Schoonheim (1982) court case, acquitted), Amsterdam
- *Stichting SOKA*, Cure & Care conference, September 29, 2001
- Anne-Mei The, PhD, medical anthropologist, *Department of Social Medicine, Vrije Universiteit*, Amsterdam
- Dr. J van der Ven, PhD, *Katholieke Universiteit*, Nijmegen
- Gerrit van der Wal, MD, PhD, chair, *Department of Social Medicine, Vrije Universiteit*, Amsterdam
- Dick Willems, MD, PhD, bioethicist, *Department of Social Medicine, Vrije Univesiteit*, Amsterdam

Results of the study were presented regularly to members of my Dutch Advisory Committee⁶¹ and analytic field memos were submitted for feedback to my Dissertation Committee in the United States periodically over the study months. In addition,

⁶¹ My Advisory Committee consisted of Dr. Anne-Mei The, chair of the committee and medical anthropologist in the Department of Social Medicine at the Free University (VU); Dr. Gerrit van der Wal, *huisarts* and chair of the Department of Social Medicine at the VU; Dr. Dick Willems, *huisarts* and bioethicist in the Department of Social Medicine at the VU; and Dr. Sjaak van der Geest, medical anthropologist at the University of Amsterdam (UVA).

preliminary results were presented (and feedback obtained) with Dutch researchers at *Vrije Universiteit* (VU) and the *Universiteit van Amsterdam* (UVA) prior to leaving the field and with American researchers at the American Anthropological Association on return (Norwood 2001a; Norwood 2001b; Norwood 2001c).

Ethics and Informed Consent

Prior to entering the field my proposal was submitted for a full committee review at the University of California-San Francisco, Committee on Human Research. As an additional measure, I also submitted the same proposal for review by the ethics committee at the *Vrije Universiteit*. During the course of my research, written consent was obtained from anyone with whom I conducted a formal interview. Verbal consent was obtained from everyone else I encountered in all consultation settings. In observation with *huisartsen* in their offices, patients were informed of my presence often by a letter posted in the waiting room and by the *huisarts* prior to any consultation. On home visits, I was introduced to patients at the door, which included a short introduction to my study. Patients who were interested received copies (in Dutch) of my informed consent form and the UCSF Experimental Subjects Bill of Rights.

I gauged that my efforts at informed consent were successful by the number of people who felt comfortable either refusing or avoiding participation in the study. I had several patients during office visits that asked to see the *huisarts* privately. I had several patients outside of the office that withdrew or avoided participation in the study. I also had a number of *huisartsen* who either refused or avoided participation.

A Study in Dutch

The Dutch language was used for the majority of interviews and in the majority of participant observation scenarios. Many Dutch people are also conversant in English, so English was at times used (initiated either by myself or the participant) when that facilitated communication. Because I wanted to hear what Dutch people thought about life and death *in their own words*, it was important to me to become proficient in Dutch. Two years prior to leaving for the field, I took Dutch language courses at the University of California Berkeley. I also took three intensive Dutch language courses in the Netherlands prior to fieldwork in the summers of 1999 (*Nuffic Nederlandse Taal Unie*) and 2000 (*Utrecht Universiteit*). While living in the Netherlands, I continued weekly lessons to fine-tune my proficiency. By the time my study began, I considered myself between conversant and fluent in the Dutch language.

To make up for my not being a native speaker of Dutch, I built into the study design several safeguards. During participant observation with *huisartsen* I made it a habit to check my interpretation of office visits and house calls with the *huisarts* between visits. If I still did not understand the explanation or a term in Dutch, and depending on the proficiency of the *huisarts*, I asked for an explanation in English. All formal interviews were taped and transcribed by a native Dutch speaker. Finally, I attempted to corroborate my interpretation with the interpretation of other participants by triangulating data whenever possible. For important events, I would record my interpretation of the event (typically while it was occurring or immediately thereafter), then I would interview participants of the event for their take on what happened. As a final validity measure, I asked participants to review a draft of their sections prior to publication.

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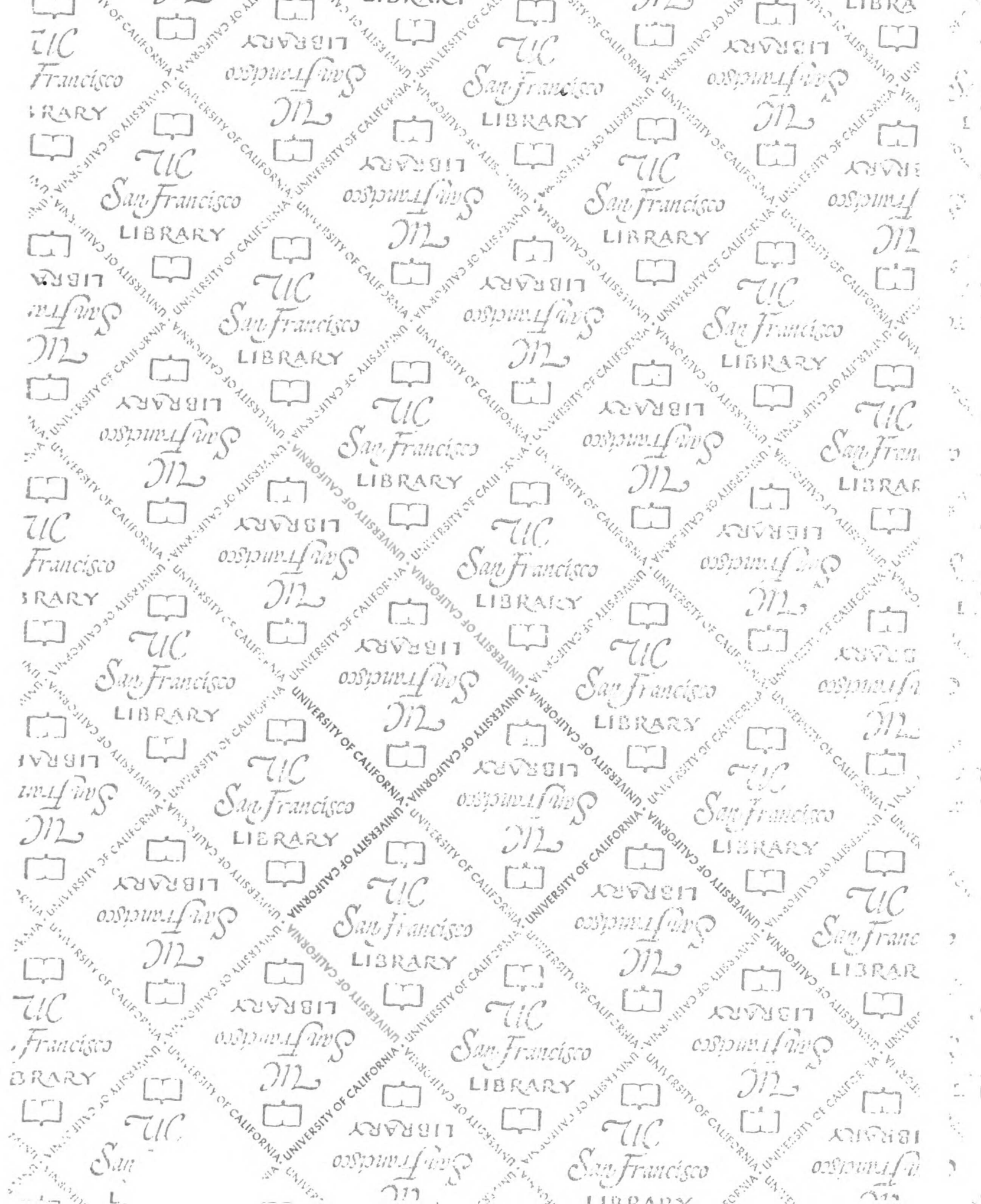
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