A hero and a criminal:

Dutch *huisartsen* and the making of good death through euthanasia talk in The Netherlands

Frances Norwood

*What does 'good death' mean to those on the front-lines of life and death in The Netherlands? Everyday in the Netherlands, general practitioners must negotiate the often difficult and very subjective terrain between life and death, leaving them feeling sometimes like heroes and at other times like criminals. In this paper, I will use data gathered during a 15-month ethnographic study with general practitioners (*huisartsen*) and their end-of-life patients to examine how the concept of 'good death' manifests in the experiences of general practitioners at the end of Dutch life. Focusing on the practice of euthanasia, I will use discourse theory from Foucault and a concept of the ideal from Lefebvre to explore the implications when general practitioners invoke concepts of good doctors, good patients, and good euthanasia requests.*

[general practice, euthanasia, end-of-life, discourse theory, good death, The Netherlands]

The concept of 'good death' is a theme that has run through many end-of-life studies. Social scientists, in particular, have spent a great deal of time exploring 'good death' in practice, juxtaposing it with 'bad death' and comparing end-of-life practices across cultures and times searching for commonalities (Bloch & Parry 1982; Seale 1998; Johnson et al. 2000; Pool 2000; Seale & Van der Geest 2004). In 2004, a number of social scientists explored in greater depth the meaning of good and bad death in a collection of articles (Seale & Van der Geest 2004). In this collection, Seale, Van der Geest and several others found evidence for commonalities in how good and bad death is perceived across cultures, geographical locations and times. Comparing data from eight different times (modern day, Biblical and Classical times) and locations (Japan, North America, Netherlands, Britain, Australia, Papua New Guinea, and Ghana), Seale and Van der Geest found that

> Some ideals about dying well seem nearly universal: a death occurring after a long and successful life, at home, without violence or pain, with the dying person being at peace with his environment and having at least some control over events. Conversely, ideas of

> bad death also have a remarkable overlap in very divergent cultures and societies (Seale & Van der Geest 2004: 885).

Where differences were most prominent was in views about dying within cultures, among persons from differing religious, political, or age-related perspectives.

In this article, I will focus on ideal conceptions of Dutch death and how these views may be impacting the practices, policies, and qualitative experiences at the end of life. Using data gathered during a 15-month ethnographic study with ten Dutch general practitioners (*huisartsen*)[1] and their end-of-life patients, I want to focus on the experience of *huisartsen* and the ideals that they invoke in end-of-life practices, especially those that are invoked in relation to euthanasia. What are the elements of a good death from the perspective of *huisartsen* and how do *huisartsen* participate in scripting good death in The Netherlands? What roles are *huisartsen* assuming at the end-of-life and how do *huisartsen* use ideal conceptions of good death to negotiate the more subjective gray areas that lie between policy and practice? As this is a qualitative study with a small, non-representative sample and cannot speak to concepts of good death across The Netherlands, the purpose of this article is to explore some of the nuances of the ideal and how these may be impacting some of the practices at the end of Dutch life.

Using Foucault's (1972; 1991) concept of discourse as a frame for the discussions that predominate in general practice at the end-of-life and Henri Lefebvre's (1991) concept of the ideal, I want to explore the implications of good death in policy, practice and experience. This article is intended to add another perspective to the literature on good and bad death and to the substantive literature on the role of *huisartsen* in euthanasia and end-of-life care.

Good death discourses and good death ideals

Foucault tells us, "… In every society the production of discourse is at once controlled, selected, organized 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). Euthanasia has been talked about openly and frequently in the Dutch public domain over the past twenty to thirty years to the extent that for many Dutch people, euthanasia has come to be associated with end of life. Legalized by court decision in 1984 and again in the Dutch Criminal Code in 2001, euthanasia practice and public discourse has normalized euthanasia to the extent that many Dutch people consider euthanasia as an option once they find out their prognosis is terminal. Foucault (1972; 1991) suggests that discourses produce 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 Foucault is less clear on is how involved those people are in conceiving of, creating, and changing discourses that affect their lives (cf. Paras 2006). An examination of the literature that deals more specifically with ideals and ideology may be helpful. Ideology can be generally defined as a collection of ideas (including ideals) that are shared by a grouping of people. In philosophy and the social sciences, ideology has most often been juxtaposed with knowledge, truth and/or reality (Weber 1930; Marx & Engels 1932; Foucault 1972; Foucault 1978; Geuss & Pippin 1981; Ricoeur 1986; Althusser 2001). In the social sciences, many have argued that ideology is a type of collective illusion that works to obscure a more true reality. Ideology acts as a guise to legitimize or disguise authority and power (Marx and Engels 1848; Weber 1930; Marx & Engels 1932; Weber 1968; Foucault 1973; Foucault 1978; Foucault 1979). Others have focused on the integrative aspects of ideology, how ideology defines a collective and binds people together (Geertz 1964; Ricoeur 1986). Some have examined the 'ideal,' often in relation to a 'real' (Goffman 1959; De Certeau 1984; Lefebvre 1991). De Certeau et al. talk about private space as a 'microcosm' of the ideal city in *The Practice of Everyday Life, Vol. 2* (De Certeau et al. 1998: 146-148). Max Weber introduced us to the concept of the 'ideal type,' an analytical construct that students of (real) human behavior can use to better understand behavior that is particular to a certain people and, at the same time, can be generalized across times and cultures (Gerth & Mills 1946: 60). Ideal types are not examples of real behavior, but are analytical tools that we can use to better understand reality.

French philosopher, Henri Lefebvre, moves us in a different direction in his classic study of social, mental, and lived space. In *The Production of Space* (1991), Lefebvre argues that the ideal is not separate from reality. It is not a scientist's construct, nor is it something that can be regarded in opposition to reality. Like Foucault, he argues that ideology is concealing, and is often indistinguishable from knowledge. Ideal, he argues, is embodied within a framework of the real. Any study of space is the study of space as it is in material form and in daily reality (what Lefebvre calls spatial practice or perceived space). It is also the study of space as it is conceived or conceptualized in the realm of mental capacity, understanding what space could or should be (ideal or representations of space). Finally, any study of space is at the same time a study of the space where inhabitants and users of space live and experience space through all its ideations, symbols, and reality (representational space) (Lefebvre 1991: 1-39). Thus what is perceived, conceived and experienced is inextricably bound.

Foucault and Lefebvre both offer some helpful insights into what *huisartsen* might be experiencing as they speak, act, think, feel, and participate in Dutch end-of-life. In this article, I suggest that ideal conceptions of what good death is and means are a part of a larger end-of-life discourse (or discourses) that have emerged in The Netherlands, teaching and guiding Dutch citizens in their everyday roles and relationships. Ideals of good death, good doctors, good patients, and good euthanasia requests are embedded in discourse and are employed at times intentionally, at times unintentionally, and particularly when *huisartsen* are called on to make difficult and often subjective choices about life and death. In the following section, I introduce the reader to one *huisarts* as he explores what it means to be a physician engaging in euthanasia death (the termination of life by the physician at the explicit request of the patient) and, as it is most often experienced, in euthanasia talk (discussions among patients, families, and doctors that are centered around that patient's request for termination of life).

Een mooie dood (A beautiful death)

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 an interest with how people experience end-of-life. Dr. Rohmer was 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 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 *huisarts*). Married with two grown children, 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: What is your opinion about euthanasia?
>
> Dr. Rohmer: Hmm [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.[2] 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: *Ja*, 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?

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 his 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 directives 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 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, 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.[3]
>
> 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.[4] 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?
>
> 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 that day and every time I re-read his words, I am struck by his ability to uncover and expose what is surely one of the more intimate and intense 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 article. First, I am interested in how Dr. Rohmer formulates 'beautiful death' and how participation in euthanasia talk may be impacted by 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 cherish. 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.

Second, I am interested in how Dr. Rohmer has come to think about his role at the end of life. Who is the good doctor who helps people to die well? He describes himself as someone who is comfortable not providing medical treatment at the end, but he wants to be there when the person dies and to be there for his patients and their families through death and after. He is the one who alternates facilitating the discussions and bearing witness to the end of the lifestory. Finally, I want to focus on when Dr. Rohmer, and other doctors in my sample, invoke the ideal. How do ideal conceptions of good doctors, good patients, and good euthanasia cases impact the end of Dutch life? Although my sample size is small and thus non-representative, I want to explore what evidence qualitative data may offer about end-of-life discourses that circulate within the Netherlands.[5] Using Dr. Rohmer’s interview as an example of what was typical and not so typical of the physician experience, I will compare his experience with data gathered for case studies with ten *huisartsen,* fourteen patients with euthanasia requests, eleven patients with no euthanasia request and countless testimonials by and various encounters with patients, families, physicians and homecare employees during the course of the study. I will focus in the following sections on (1) elements that make up Dutch ‘beautiful death,’ particularly as they relate to euthanasia talk; (2) how *huisartsen* view their role in end of life and in euthanasia talk; and (3) when and how *huisartsen* may be invoking ideal conceptions of doctors, patients, and euthanasia cases in the pursuit of good death at the end of Dutch life.

Making death beautiful: The elements of ideal Dutch death

When asked the first question about euthanasia, Dr. Rohmer replied that euthanasia was a “good death with lots of possibilities.” Thus his first response was to invoke an ideal of what he thought all euthanasia cases *should be.* Good death, he explains is when the circumstances are good; it is well thought out and well discussed (among patients, doctors and the family), he emphasized. Good death is peaceful and is conducted in a good environment (for most *huisartsen* this meant the home environment). Good death, Dr. Rohmer emphasized, is about communication and the memories that it leaves for the survivors. Dr. Rohmer’s conception of the good (the beautiful) death was quite similar to other doctors in my study. Eight of ten *huisartsen*, including Dr. Rohmer, were asked to describe the elements that make up an ‘ideal case’ of euthanasia.[6] One *huisarts* said there was no ‘ideal case for euthanasia.’ Five of ten said that an ideal case was well discussed; five of ten said that there should be good family involvement; and five of ten believed that it was best when the patient did not have much longer to live and when the disease, like most forms of cancer for instance, was predictable enough to determine that. Three of ten *huisartsen* also described ideal elements that did not fit into a category. These included one doctor who liked to have the nurse involved in discussions and did not want to be rushed by the patient or family (a sentiment that was echoed by *huisartsen* in other research activities). Another doctor preferred to be involved in euthanasia and not assisted suicide because of the tendency of self-administered drugs to leave patients alive for hours or days (a sentiment that was shared by *huisartsen* elsewhere). That same doctor also preferred the request to be a long-standing request for the purpose of ending physical suffering (a sentiment that was also echoed by *huisartsen* elsewhere). Still a third doctor preferred a euthanasia request for the purpose of relieving the kind of pain for which otherwise there is no relief.

Next, I had to know what *huisartsen* thought the difference was between euthanasia and other deaths. What is it about euthanasia that helps or hinders good death? I asked Dr. Rohmer and he said that the patient's ability to give directives at the end, helping to create the memories that he or she leaves behind is quite different in euthanasia deaths. The Dutch words he used were "*Dus 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.*" The word Dr. Rohmer used is '*regie,'* which invokes a theatre metaphor. In Dutch '*regie*' means direction; production, as in the production of a play (Hannay & Schrama 1996: 674). He said that when someone asks for euthanasia, they are also forced more than in other deaths to reflect on things. I then asked if euthanasia was a 'natural death' and he said it was not according to the law, but to him it was not unnatural, only a continuation of a medical condition and only a little 'extra push.' I still wanted to know more. Having witnessed how euthanasia requests keep physicians active at the end of life, giving them a series of activities when otherwise there is much less to do, I asked if euthanasia kept him active in the process, feeding his interest in maintaining continuity in his patients lives. Dr. Rohmer agreed that euthanasia requests kept him active in the process, but that did not necessarily mean taking action per se. For him, he wanted to be present often simply as a witness at the end of life and with euthanasia he found something "more exact, precise, more sharply defined" about his role. With euthanasia, he is the one to end life and that is quite different than in other deaths.

The doctor's role: What *huisartsen* do at the end of Dutch life

To understand more about what *huisartsen* think about end-of-life and how they employ ideals to shape their behavior, it is important to look more closely at what they *do* at the end of life and what role they have assumed, particularly as they engage in euthanasia talk and euthanasia death. A euthanasia request and the discussions that follow related to the patient's request for termination of life (what I am terming, 'euthanasia talk') give *huisartsen* an active role at the end of life. Euthanasia talk provides a framework and a structure for activities that occur at the end of life once euthanasia has been invoked. I have witnessed the shift that occurs when end-of-life discussions change to euthanasia discussions and it is literally as if a switch has been flipped. Once euthanasia is mentioned, the roles of patient, family and *huisarts* become more scripted (as Dr. Rohmer says, more defined) and a pattern of interaction emerges as several uniform stages of euthanasia talk begin (Norwood 2005: 14-39). Every *huisarts* with whom I worked, regardless of personality type or style, took charge of the discussion. Verbal requests were discussed with the *huisarts* and with family members, and then had to be repeated by the patient in order to keep the process moving towards a euthanasia death. Written declarations for euthanasia were made and signed by the patient and (in all declarations that I saw) were signed by family members as well. If everyone was in agreement, then the process was typically paused until the patient was ready to re-initiate a request. If the request was re-initiated, then more discussions ensued with the *huisarts* leading the flow and the content of discussions with the patient and their family. If in these discussions, the patient clearly wanted to continue and there were no major reasons not to continue towards a euthanasia death, an appointment for a second opinion was made and then a date for euthanasia death was scheduled.[7] In the Netherlands, patients may request euthanasia, but it is the physician's duty to decide whether a request meets the legal (and their personal) requirements for a proper euthanasia request.

What *huisartsen* do at the end of Dutch life is not dissimilar to what they do for any of their patients. What I first noticed conducting observation with *huisartsen* was that their daily practice was quite different from what I had observed in my personal experience of general practice in the United States. Dutch *huisartsen* tend to work alone in offices situated within neighborhoods, homes converted into office space typically, and they continue to this day a long tradition of conducting home visits, or house calls. In 1999 (the first year of my study), 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. Eight of the ten *huisartsen* in my sample practiced in home-to-office converted settings. On the average, *huisartsen* in my study saw approximately 28 patients a day, including approximately seven house calls (Norwood 2005: 164-168).[8] 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* between patients, families and *huisartsen*. In some ways, the power differential in terms of physician authority is more equalized between Dutch patients and *huisartsen* than between their U.S. counterparts. Dutch custom is to downplay difference in status (Van der 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, "… many people and organizations see their tasks as largely a matter of stimulating or facilitating, promoting processes, guiding the activities of others" (Van der Horst 2001: 126). This is largely what *huisartsen* do as well. Their practice is based in dialogue with the patient and family members, providing information and building consensus. In a typical office visit, the visit begins in the *spreekkamer* (or consultation room) seated across from or cattycorner to the *huisarts*. Most of the visit is spent discussing the problem, including any 'psychosocial issues' that the *huisarts* or patient 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* (examination room). In a typical morning of office visits, the study *huisartsen* used the examination room in less than half (5 of 11) visits and the average length of a visit was approximately 12½ minutes, time typically spent in discussion (Norwood 2005: 164-168).

Compare that to the scene of a typical visit to a U.S. family doctor. U.S. family doctors typically work in office buildings, where the distance between doctor and patient tends to be well delineated. The U.S. family doctor is dressed in a white lab coat with the stethoscope worn like a necklace to clearly communicate, in case there was any question, who is the doctor and what is most important, the examination. The doctor breezes into the examination room (there is not much time) and the patient has already been instructed by the nurse to remove any intrusive street clothing and to don the costume of the patient, a large paper gown that is simply not designed for discretion. There is no time for discussion of home life or other psychosocial factors that may impact health and if that does occur it is a short, polite conversation that can be awkward when it occurs while a doctor is conducting any physical or internal examinations. Meeting in what the Dutch would call the *spreekkamer* to discuss health issues is not the norm, although there has been a trend with some doctors to start the first meeting with a patient in what the Dutch would call the *spreekkamer,* seated opposite a desk, clothes intact, to discuss generally why the patient has come. Also, the American *spreekkamer* is sometimes used after an examination when there are 'results' to communicate, particularly if they impact seriously on health. U.S. family doctors do not have time, however, to *discuss* and no reason generally to include family or build consensus around everyday medical decisions. Factor in that most U.S. general practitioners do not conduct home visits and you have two systems that are subtly, yes, but markedly different.[9]

What Dutch *huisartsen* do at the end-of-life is similar to what they do with any of their patients. Theirs is a practice that is based predominantly in discussion. Thus, it is understandable why Dr. Rohmer (and many other *huisartsen* in my sample) say that good death is about good communication and leaving good memories for family and other loved ones who will be left behind. In fact, the *huisarts* focus on communication is even less surprising when you consider the broader social practice that is so prominent in Dutch social life. The Dutch have a long-standing practice they call, *overleggen*, a term that means "to consider, consult, or confer" (Hannay & Schrama 1996: 609). *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 is sought 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 (Van der Horst 2001: 170).

But *overleggen* is not just about a process for making decisions; I argue it is a manner in which Dutch relationships are defined. The emphasis in much of Dutch communication is on affirming a rather flat hierarchical social structure. Everyone should participate in *overleg*; and everyone should be able to communicate their perspective, but in ways that are conducive to consensus building, not counter to it. *Overleg* is a cultural form, another form of discourse that teaches participants how to communicate and relate to one another. 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 (Van der Horst 2001: 257-8).

To maintain *gezelligheid,* a term that is invoked regularly in the Netherlands, people must participate in discussions, have their voice heard and be part of the process that guides the flow of Dutch life and Dutch decision-making.

There is a social element to euthanasia talk that encompasses two very important elements of the Dutch ideal that is evidenced in the *huisarts* role at the end of life. There is an element of social control, as touched on by Dr. Rohmer when he invokes the term '*regie,*' and there is an element of social bonding and social affirmation that occurs during the course of euthanasia discussions. Euthanasia talk orchestrated via one arm of society (the doctor) standardizes the process for dying, making an often uncertain and unpredictable time in life, more certain and more directed. In the process, roles and relationships are affirmed, society demonstrates care toward the dying person and the family, and euthanasia talk provides an avenue for participants to process meanings of life and death, suffering and family. U.S. healthcare is often criticized for leaving end-of-life patients in a no-man's-land once treatments are no longer needed (Kaufman 2005). In the Netherlands, dying individuals are not left alone to die. Compared to those who die in the U.S., those engaged in euthanasia talk in the Netherlands more typically leave consciousness as active, socially connected participants. Their role in life may be diminished, but the structure of euthanasia talk holds them central.

Recall when Dr. Rohmer talked about his strengths as a *huisarts.* He said he had the ability to 'step back' and 'watch what happens.' 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. In a previous study of chaplains who minister to patients and families in a U.S. hospital, I found a similar practice that is in large part neglected in hospital medicine in the U.S., but does find presence in the work that chaplains do on the borders of hospital medicine (Norwood 2006). I borrow the term, 'witnessing,' from medical anthropologist Beverly Davenport who finds it an indigenous term used by medical students in a homeless clinic to describe a practice that would typically not find place in mainstream medical education. It is a practice they described as "focus[ing] on the entirety of a person's life situation, not merely on their ailment" and 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* at the end of life. *Huisartsen,* and other Dutch physicians, find it important to witness the end of Dutch life, providing direction (and control) and being present at the end to help families by participating in the memory that includes an ideal of a caring, connected society.

I believe that the focus on *overleggen* coupled with an aesthetic that favors both an active practice of control and a more passive practice of witnessing culminate in a general end-of-life discourse that affirms Dutch sociality even at the end of life. There seems to be an underlying ideal regarding good death in the Netherlands that emphasizes the collective. *Huisartsen* often reflected on how relationships with their patients and the surviving family members deepened during the course of euthanasia discussions and euthanasia deaths. Dr. Rohmer touches on this at the end of his interview. We were talking about how the deathbed 'changes' things. He says,

> 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.

Every doctor with whom I worked either mentioned that relationships tended to deepen in the course of euthanasia talk or they showed me how that happened.

In the beginning of my research, I was struck by the extent of the role that *huisartsen* assumed within the family unit, particularly 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 and (more likely) as illegal. This is not so in the Netherlands. At first, I thought that maybe this was a factor of living in a small town (where half of my sample was located), where everybody knows everybody else and *huisartsen* are often friends and social acquaintances with many of their patients outside of their practice. Comparison between my small town and Amsterdam study samples demonstrates 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. Small town and city *huisartsen* alike view their role in euthanasia discussions as a facilitator of family relationships.

Good death is not just about good discussions at the end of life, inclusion of family in euthanasia talk, or the image of family assembled around a deathbed, it is an emphasis on connection and sociality, on the bonds that keep Dutch people, even people who are dying, connected to Dutch society. Euthanasia death need not come to pass in order to achieve an ideal death scenario and while the many of the end-of-life practices based in palliative care and general practice include the elements of fostering and maintaining relationships, it seems that in euthanasia talk, the roles are more clearly defined and a structure is in place that more clearly focuses on fostering bonds among participants. Physicians urge patients and their families to talk about the request (what it means and why) and in doing so, a linguistic space has been created for processing relationships, identity, and meaning at the end of life.

Invoking the ideal: Good doctors, good patients, and good euthanasia requests

I have argued that a fairly uniform ideal for death exists in The Netherlands and that these ideals are part of a larger discourse that tends to structure end-of-life practices towards an experience that promotes consensus-building, sociality and a greater feeling of control over unpredictability. In this section, I examine when ideal concepts are invoked (with intention) by *huisartsen* in the course of euthanasia talk.

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 better. 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. When do Dutch *huisartsen* invoke concepts of good doctors, good patients, and good euthanasia requests? They do it frequently and particularly in response to the more subjective areas of euthanasia practice. Dutch end-of-life discourse is not fluid nor is it as cohesive as the above analyses may suggest. Among other things, it limits what is sayable and who has access (Foucault 1991: 59-60). At the same time, it also exists in competition with other discourses, creating a fragmented practice that is not always conducive to maintaining social bonds or facilitating ideal death (Durkheim 1912; Durkheim 1951; Foucault 1972). 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 ideals are most often invoked when *huisartsen* must negotiate these more subjective and liminal areas.

According to Dutch euthanasia policy, physicians 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” [and] “that the patient’s suffering was lasting and unbearable” (The Act 2001). 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 good doctor, good patients and good euthanasia requests. 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 framework of euthanasia talk. 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 and falling back on the shared process of decision-making (*overleg*) 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 as a reason for euthanasia 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 or suicidal thoughts (not acceptable reasons 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 a good reason to die a euthanasia death and newer immigrants and those not versed in Dutch ways of engaging in these discussions, are more often turned away from euthanasia discussions.

The hero and the criminal

Dutch physicians have come in the course of euthanasia policy and practice to be situated somewhere between the Dutch family and the Dutch state. One *huisarts* described the precariousness of this position as falling somewhere between a ‘hero’ and a ‘criminal.’ After a euthanasia death, the *huisarts* must call the local coroner who comes to 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 in 2001, the coroner forwards the paperwork to a Regional Assessment Committee (*toetsingscommissie*) where it is mandated by law to take 6 weeks before a determination is made that the *huisarts* has acted with due care as per Dutch regulation. Since the establishment of the Regional Assessment Committees in 1998, the notification time has been significantly decreased (from an average of 103 days prior to the establishment of the committees to an average of 28 days in 2001) (Van der Wal et al. 1996: 152-170; Van der Wal et al. 2003: 152-177; Klijn 2006). Regardless, until notification occurs, *huisartsen* tell me that it feels like a criminal waiting for a verdict. 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 and the patient, they are often the hero, the member of society who is willing to stay with them through to the end of life, 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.

Foucault teaches us that discourses exist that structure both intentional and unintended ideas, feelings and actions that impact end-of-life. Lefebrve argues that within these discourses ideals co-exist with reality as it is socially conceived, mentally perceived, and spatially experienced. I have argued that ideals of Dutch good death, good doctors, good patients and good euthanasia requests exist within a larger discourse that shapes how Dutch people have come to think, feel and act at the end of life and I have attempted to show the reader a little bit of what that discourse looks like. This is a qualitative study so its value is in the subtleties and nuances that a few Dutch people and their experience offer. While qualitative data can allude to larger, shared processes (like discourse), it is important to view these findings not as an explanation of the (total) Dutch experience with euthanasia but as clues to some of the shared and more nuanced practices that occur around end of life.

Given the daunting task of managing end-of-life and (when deemed appropriate, ending life through euthanasia death), *huisartsen* in the Netherlands have learned to use what they know to do the best they can to provide their patients and their families with a good death. That means using available discourses that have emerged around palliative care, general practice and euthanasia (just to name a few). What *huisartsen* and other Dutch physicians know is what they have learned in their profession, in their experience as physicians, and as members of Dutch society. The ideals that they invoke and the ideals they participate in without, perhaps, fully being aware of what it is or where it comes from, these are the pathways that they walk – a sometimes delicate line between the hero and the criminal at the end of Dutch life.

Notes

Frances Norwood has a PhD in medical anthropology from the University of California-San Francisco and Berkeley and is Director of Research at the Inclusion Research Institute in Washington, DC. She is currently working on turning her dissertation into a book. Her dissertation is titled, *Euthanasia Talk: Euthanasia Discourse, General Practice and End-of-Life Care in the Netherlands*. E-mail: francesnorwood@aol.com

I would like to thank my Dutch Advisory Committee, Gerrit van der Wal, Anne-Mei The, Dick Willems, and Sjaak van der Geest for their invaluable suggestions during the course of my research. I would like to thank the Department of Social Medicine at the Free University in Amsterdam for their professional support and the University of California-San Francisco, University of California-Berkeley, and the American Association for Netherlandic Studies (Nuffic) for providing financial support. Thank you to the reviewers and editors of *Medische Antropologie* for their comments. Any mistakes are my own.

1 I use the term '*huisarts*' (pl. *huisartsen*) throughout this text for a reason. The term can be literally translated to mean 'specialist of the home' and as I looked deeper into the role of the Dutch *huisarts*, I found an orientation to medicine and practice that is different than family practice in the United States and is strongly connected to Dutch family and home. So to denote the culturally and historically-specific practice of the Dutch general practitioner, I use the indigenous term, '*huisarts*.'

2 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 & Schrama 1996: 514). *Mooi* is used more in speech than *goed* and can be applied to a much wider range of topics. *Mooie dood* often has a special connotation, however: it may refer to the fact that the person died suddenly without suffering. Such a 'beautiful death' is *not* a 'good death' in the sense that the deceased did not have the opportunity to prepare for his departure. Relatives and friends were not prepared either and regret that they could not say farewell. But they comfort themselves with the knowledge that the deceased did not have any pain; he had a *mooie dood* (Sjaak van der Geest, personal communication).

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

4 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*).

5 I conducted participant observation and interviews with 9 *huisartsen* and 1 *huisarts/ verpleegarts,* half of whom worked in the city of Amsterdam and half of whom worked in a cluster of small towns within a 25-mile radius of Amsterdam. Through the 10 *huisartsen*, I met approximately 650 of their patients through observation activities in the office and on house calls. Twenty-five of these patients were identified as participants for case studies. These 25 were identified as terminal, dying or with a standing request for euthanasia and were tracked more intensively than other patients, with multiple visits and interviews (with doctors, patients, family, home care, friends) depending on how long the patient remained living. Participant observation or interviews were also conducted with other *huisartsen,* including *huisartsen* who were not willing to perform euthanasia; with *Thuiszorg* (the state-subsidized home care organization); with other patients and families considering euthanasia; within nursing homes and acute care facilities (*verzorgingshuizen* and *verpleeghuizen*); with Hospice, and with various organizations and individuals on both sides of the euthanasia debate. While I heard countless testimonials about euthanasia cases from physicians, patients, families and others throughout the course of the study, case study participants were only those who I had the opportunity to meet and to track over the course of time. For more on study participants and study design, see (Norwood 2005: 164-178).

6 All study *huisartsen* were asked to participate in a series of interviews, which included an introductory interview that was audio-taped and then later transcribed and translated. Eight of 10 were asked the question (either in Dutch or English), "In your opinion what makes up an ideal case for euthanasia?" If respondents had difficulty responding, the following prompts were included: time frame from request to decision, type of illness/suffering, type of patient/patient attitude; type of family or support network of patient; family attitude; length of time knowing the patient/family. Responses were recorded and then coded according to similarities. For instance, under the grouping labeled 'well discussed,' *huisartsen* described long *overleggen* (consultation), good talk with patients/families, and able to visit with patients and families regularly.

7 The three top main reasons for euthanasia talk not to continue on to euthanasia death in my sample were the patient deciding not to continue, family objecting to the request, and an illness that either goes into remission or takes the life of the patient before euthanasia can be scheduled. There are also a wide range of issues that *huisartsen* use as clues to stall the process. These include signs of major depression, patient hesitation, familial conflict, a pushy patient, and lack of family involvement.

8 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 (Norwood 2005: 124-138).

9 There have been changes to the Dutch health care system since my study. In January 2006, healthcare reform was passed in the Netherlands which should have an impact on the nature of the *huisarts*-patient-family relationship and how primary medicine is practiced. During my study, the Dutch insurance system consisted of public and private sector funding streams that gave coverage to almost 100 percent of the population. Anyone below a certain salary (€31,750 gross per year in 2003) was covered by *Ziekenfonds*, the government subsidized, but privately managed insurance system which covered approximately two-thirds of the population. The Dutch system also includes the AWBZ (*Algemene Wet Bijzondere Ziektekosten*, or the General Law for Extraordinary Medical Costs), which is available to anyone to cover the cost of nursing home care, some home care and medical equipment. On January 1, 2006, the Dutch passed healthcare reform, changing to a single, compulsory system of national health care insurance for all. It is a new system of 'managed competition,' which keeps general practitioners as the gatekeepers, but allows consumers freedom now to change their insurer and insurance plan. According to *huisartsen* with whom I worked and popular media accounts from 1999 to 2001, general practice had increasingly been burdened by more work without equivalent increases to pay. The new payment system for general practitioners includes annual capitation payments per patient and a fee per consult (both available under the former system), plus reimbursement for costs related to type of service rendered, staff employed, and quality and efficiency indicators. For more on the Dutch health care system and the 2006 reforms, see (Klijn 2006; Vries 2004: 52-54; Grol 2006; Weel 2004).

References

Act
2001 Termination of life on request and assisted suicide (Review Procedures) Act. *Article 293, 294, 40*.

Althusser, L.
2001 *Lenin and philosophy and other essays*. New York: Monthly Review Press.

Bloch, M. & J. Parry (eds)
1982 *Death and the regeneration of life*. Cambridge: Cambridge University Press.

Davenport, B.A.
2000 Witnessing and the medical gaze: how medical students learn to see at a clinic for the homeless. *Medical Anthropology Quarterly* 14 (3): 310-27.

De Certeau, M.
1984 *The practice of everyday life*. Berkeley: University of California Press.

De Certeau, M. et al.
1998 *The practice of everyday life. Volume 2, Living and cooking*. Minneapolis: University of Minnesota Press.

Durkheim, E.
1912 *The elementary forms of religious life.* New York: Free Press.
1951 *Suicide, a study of sociology.* Glencoe, IL: Free Press.

Foucault, M.
1972 *The archaeology of knowledge*. New York: Pantheon Books.
1973 *The birth of the clinic: An archaeology of medical perception.* New York: Vintage Books.
1978 *The history of sexuality, volume 1.* New York: Pantheon Books.
1979 *Discipline and punish: The birth of the prison.* New York: Vintage Books.
1991 *The Foucault effect: Studies in governmentality. With two lectures by and an interview with Michel Foucault*. G. Burchell, P. Miller, and C. Gordon (eds). Chicago: University of Chicago Press.

Geertz, C.
1964 Ideology as a cultural system. In: D. Apter (ed.), *Ideology and discontent.* Glencoe: The Free Press, pp. 47-56.

Gerth, H.H. & C.W. Mills (eds)
1946 *From Max Weber: Essays in sociology.* New York: Oxford University Press.

Geuss, R. & R.B. Pippin (eds)
1980 *The idea of a critical theory: Habermas and the Frankfurt school.* Cambridge: Cambridge University Press.

Goffman, E.
1959 *The presentation of self in everyday life.* Garden City, NY: Doubleday.

Griffiths, J. et al.
1998 *Euthanasia and law in the Netherlands.* Amsterdam: Amsterdam University Press.

Hannay, M. & M.H.M. Schrama
1996 *Van Dale handwoordenboek, Nederlands-Engels.* Utrecht/Antwerpen: Van Dale Lexicografie.

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

Johnson, N. et al.
2001 Towards a ‘good’ death: end-of-life narratives constructed in an intensive care unit. *Culture, Medicine &Psychiatry* 24: 275-95.

Kaufman, S.
2005 *...And a time to die: How American hospitals shape the end of life.* New York: Scribner.

Klijn, A.

2006 Personal communication with A. Klijn, Chief Program Advisor, Netherlands Council for the Judiciary.

Lefebvre, H.

1974 *The production of space.* Malden, MA: Blackwell [1991].

Marx, K. & F. Engels

1848 Manifesto of the Communist party. *The Marx-Engels reader*. R.C. Tucker (ed.). New York: W.W. Norton & Company, pp. 469-500 [1972].

1932 The German ideology: part I. *The Marx-Engels reader.* R.C. Tucker (ed.). New York: W.W. Norton & Company: 146-200 [1972].

Norwood, F.

2005 *Euthanasia talk: euthanasia discourse, general practice and end-of-life care in the Netherlands.* University of California-San Francisco and Berkeley, Medical Anthropology program, dissertation. http://www.proquest.com/products_umi/dissertations/

2006 The ambivalent chaplain: negotiating structural and ideological difference on the margins of modern-day hospital medicine. *Medical Anthropology* 25: 1-29.

NVVE

2000 *Overzicht euthanasiewetgeving.* Amsterdam: Nederlandse Vereniging voor Vrijwillige Euthanasie.

Paras, E.

2006 *Foucault 2.0: Beyond power and knowledge.* New York: Other Press.

Pool, R.

2000 *Negotiating a good death: Euthanasia in the Netherlands.* New York: The Hawarth Press.

Ricoeur, P.

1986 *The lectures on ideology and utopia*. G.H. Taylor (ed). New York: Columbia University Press.

Seale, C.

1998 *Constructing death: The sociology of dying and bereavement*. Cambridge: Cambridge University Press.

Seale, C. & S. van der Geest

2004 Good and bad death: Introduction. *Social Science & Medicine* 58: 883-85.

Van der Horst, H.

2001 *The low sky: understanding the Dutch*. Schiedam: Scriptum Publishers.

Van der Wal, G. et al.

1996 *Euthanasie en andere medische beslissingen rond het levenseinde: De praktijk en de meldingsprocedure*. Den Haag: Sdu Uitgevers.

2003 *Medische besluitvorming aan het einde van het leven: De praktijk en de toetsingsprocedure van euthanasie*. Utrecht: de Tijdstroom.

Weber, M.

1905 *The Protestant ethic and the spirit of capitalism*. New York: Scribner [1930].

1914 *Economy and society: an outline of interpretive sociology*. New York: Bedminster Press [1968].