

Chapter One

**Moral Frames for Lives Worth Living:
Managing the End of Life with Dementia**

Abstract

Narratives that frame the end of life with dementia as undignified reveal moral claims on which lives are considered worth living. These claims are deeply rooted in the medicalization of death and its appeal to dignity. Drawing from ethnographic fieldwork in nursing homes for people with dementia in The Netherlands, I demonstrate how the end of life with dementia is managed through such moral frames. Specifically, I elaborate on the production of lives (not) worth living and explore how family members welcomed the death of a loved one with dementia. I argue that the welcoming of death is not an act of indifference but can be seen as a form of care.

Originally published as: Lemos Dekker, Natashe. 2018. "Moral frames for lives worth living: Managing the end of life with dementia." *Death Studies* 42 (5): 322-328.

Introduction

On the 29th of December 2015, an essay in one of the major newspapers in the Netherlands headed “Can I die properly if I am very demented?” (Blanken 2015).¹¹ The essay argued for euthanasia as a way to achieve a “proper” death, as opposed to a “disgraceful” end of life with dementia in which the author would “drooling forget who [he] was, or what or where.” As such, the essay seemed to be questioning the possibility of a good death with dementia, representing a broader discourse in Dutch society in which the end of life with dementia is conceived of as undignified and as suffering.

Worldwide, the numbers of people with dementia are presented as increasing rapidly (World Health Organization 2012). In the Netherlands, it is estimated that 270,000 people currently live with dementia and that this number will rise to half a million by 2040 (Alzheimer Nederland 2019; Deltaplan Dementie 2012). Although these numbers demonstrate that dementia is and will be affecting many people in society, the communication of such numbers also creates urgency and a sense of risk, that dementia can happen to any and all of us. It also reveals and installs a certain fear in society, a fear for a condition for which there is no cure available.

Although I will not be addressing the question of euthanasia in this chapter (see chapter two for a discussion on euthanasia), the essay exemplified how the end of life with dementia has become regarded, by some, as undignified. According to the essay, one would be better off dead than living with dementia. What does this communicate about this large, and growing group of the population, and about the values we ascribe to certain lives? As Kaufman has asserted, “inescapable today is the fact that demented life (as all forms of *life itself*) is the object of debate about value; it must be accorded a value” (2006, 27). Yet such activities of valuing which lives are worth living remain largely unexplored in social science (Biehl 2015, 248). Drawing on ethnographic fieldwork, in this chapter I explore the underlying frames of how family members in a

¹¹ Translated by the author from the original title: “Kan ik netjes sterven als ik heel erg dement ben?” (Blanken 2015).

Dutch nursing home would welcome the death of a loved one with dementia.

Butler (2006, 2010) has argued that the extent to which a life can be considered a liveable life is tightly connected to who can be considered as “normatively human” (2006, XV). In discussing a context of violence and armed conflict, in which certain geographically and historically located lives are deemed “ungrievable,” Butler shows it is social norms—or frames—that discern between lives that can or cannot be apprehended as fully human. A life that is fully apprehended and recognized as human is a life that can be grieved, for the practice of grieving sanctions the fact that a life has been lost. Or, to be more precise, different social practices of grieving retrospectively qualify certain lives as fully human and other lives as lives that were not worth living, in which case death becomes acceptable and legitimized. An engagement with Butler’s work allows us to interrogate the moral frames that are at work at the end of life of people with dementia. As I shall outline below, the construction of a life as not worth living is related to negative imaginaries of dementia, experiences of loss before biological death, and the construction of life as undignified through suffering. I argue that the seeming contradiction, in which people with dementia are grieved for even though the end of life with dementia is considered a life not worth living, can be understood in light of the acceptance of death as a form of care.

These lives are narrated as allowed to die, but not in the form of abandonment, indifference, and a lack of care such as discussed by Biehl, who writes of a “zone of abandonment” in southern Brazil where people are “left there to die” (2005, 1). Nevertheless, a similar creation of a category of individuals who are allowed to die is at stake, even if this materializes differently in the context of dementia in the Netherlands. In the Netherlands, people with dementia are, generally, and certainly when compared to Biehl’s ethnographic accounts, cared for well in nursing homes. The construction of lives as not worth living that I describe in this paper operates more at the level of narratives and experiences,

especially those of family members who are facing loss as dementia further develops,¹² than in acts of abandonment.

This chapter draws upon eighteen months of ethnographic fieldwork in 2014 and 2015 in nursing homes for people with dementia in the Netherlands and 40 in-depth interviews with family members in their home setting. In addition, four focus groups were held, of which two with professional care workers, one including different disciplines within the nursing home, and one with family members of nursing home residents. Particularly, the accounts presented in this chapter are those of relatives who were witnessing the end of life of a loved one with dementia. I have spent many hours with family members at the bedside and spoke with them before, during, and after the process of dying. While building on a variety of examples from my fieldwork, the narrative of one family, namely, Sandra, her husband Willem, and her mother Ms. van Dijk,¹³ runs as a thread through this chapter to highlight the ambiguities that are at play in the experiences of family members as they welcome the death of their loved one with dementia.

The first section of this chapter addresses the negative imaginaries and stereotypes that often surround dementia as well as experiences of gradual loss, that, I contend, form the background for dehumanization at the end of life with dementia. I demonstrate that as the end of life is perceived as a *lijdensweg*, literally a pathway of suffering, it becomes strongly interwoven with understandings of dignity and what is normatively human. In the second section, I continue by discussing how family members seek control over the end of life. In the third section, I discuss how death is, as family members assert, welcomed as a relief to suffering and argue that this welcoming of death can be apprehended as a form of care.

¹² Here, I do not imply dementia should be approached solely on the basis of loss. I have met several family members who, while they experience loss, also have joyful moments with their loved one with dementia. I have addressed this ambiguity in a conference paper at the 115th annual meeting of the American Anthropologist Association in Minneapolis (November 17, 2016).

¹³ All the names of informants in this chapter are pseudonyms to maintain their privacy.

In so doing, this chapter contributes to understanding the often ambiguous production of lives as not worth living. I hope to do so with respect to the experiences of family members but nonetheless with a critical stance toward the tendency to represent people with dementia in ways that deprive them of human dignity and of life itself.

Framing the End of Life with Dementia

I had met Sandra and Willem on my first day in the nursing home. A couple in their early 60s, they visited the unit every Monday to see Sandra's mother, Ms. Van Dijk, who was 96 years old and had been living in the nursing home for just over a year. She was admitted to the nursing home for a temporary stay to recover from a fall at home, but eventually the family decided that it was best for her to stay in the nursing home. Now, a year later, the general practitioner had communicated that Ms. van Dijk was dying. Ms. van Dijk had an unfamiliar bump, the size of a tennis ball, between her shoulder and chest. Both the general practitioner and the nursing staff were uncertain of what it was or what had caused it. I asked Sandra if she wanted to know more about the bump, upon which she explained:

You know, to find out what it is, we would have to take her to the hospital, take x rays, etc. But she is already so frail, I don't want to put her through that. It would not be life-saving, but only to know what it is, perhaps to prevent it for others, in the future. But it would be of no use to my mother.

At this point, Sandra did not want to disturb her mother with medical examinations, fearing it would cause more suffering. She realized that these would not keep her mother from dying, in which a certain acceptance of her mother's approaching end of life became apparent. Ms. van Dijk had stopped eating and drinking and was asleep most of the time as a result of the morphine she had been given. The unwritten nursing home policy was not to send residents to the hospital, weighing the burden of undergoing treatment or surgery against the limited expected enhancement of quality of life. Willem remarked "early this year she was a normal woman, living independently, she did everything

herself. [Now] she is not sitting but hanging in bed and she is not able to wear her teeth. What life is this?" Sandra agreed, "when I see my mother lying there like that, I think, dear God, please let her close her eyes. Her life is done, she does not have anything left. Only her heart keeps ticking." "I find it sad," Willem continued, "to see how my mother in law sat there, and those other people as well. I wonder, what is the added value of a life like that? She has declined so fast. This is not dignified anymore, I believe it is no longer a humane life." Like many family members, Sandra and Willem related the state of their loved one with dementia to one of suffering and a loss of human dignity.

Constitutive to this construction of the end of life with dementia as undignified are negative imaginaries and stereotypes that are attached to dementia. The negative image of the end of life with dementia that family members addressed can be understood in light of what Gilleard and Higgs (2010) have termed the fourth age, an undesirable social imaginary that reflects the marginalization of old age. Encapsulated in this imaginary, and especially in an institutional setting, is a homogenization of elderly people and people with dementia as a category to which one does not want to belong, and wherein choice, autonomy, and agency are lost. Negative stereotypes surround dementia, stigmatizing people with dementia as "living dead," "zombies," "undead" (Behuniak 2011) or "empty shells" (Snyder 2001). These stigmas are fed by the perception of people with dementia, who may be seen as being in between life and death and often unable to comply to socially desirable behavior. Implicit in such representations is a certain worthlessness of life, of not qualifying to a dignified end of life. This can be traced back to the prominence of values such as autonomy, independence, and control in Western, and in this case particularly Dutch society (Pool 2004).

These negative imaginaries, and the dehumanization they imply, are closely related to the degenerative character of dementia. Prominent in the experiences that family members shared with me were what Taylor (2008) has termed "firsts"; the moments at which it becomes clear for the first time that the person with dementia is unable to do something she was capable of doing earlier in life. These indicate a gradual regression that takes place over a protracted period of time (Kaufman

2006), and that should not be understood as linear, but rather as a fluctuating process. During one of their last weekly visits before Ms. van Dijk passed away, Sandra and Willem reflected on the year in the nursing home: “we saw it coming. You cannot imagine it, but every week her condition had worsened. And then you think, it cannot become worse than this, but still every week it became worse.” Sandra further explained that every time she visited her mother, it felt as if she was saying farewell, being confronted with losses and expecting her mother not to live much longer. In going through this process, family members often expressed the feeling that they had already lost or partly lost the person with dementia before biological death. Sandra remarked, “there were always people who said, at least you still have your mother, to which I responded, well my mother is not there anymore.”

In the literature on dementia such experiences of gradual loss are often related to debates concerning personhood that revolve around the question of to what extent dementia consists of a “loss of the person” (Sweeting and Gilhooly 1997). Countering this idea, Kitwood (1997) has argued for a conceptualization of personhood that includes relationality and that can account for the present capacities of the person with dementia. Higgs and Gilleard (2016), however, have argued that personhood remains an unsuitable concept in informing care practices for people with dementia. Hence, rather than discussing the experiences of gradual loss and the sense of having “already lost” the person with dementia, through these debates on personhood, I am interested in what such experiences reveal about the moral and normative construction of lives worth living and their relation to (good) death. For to what extent can a life that is considered to be “already lost” ever be worth living?

Family members often came to view the trajectory of dementia, and particularly the end of life, as a *lijdensweg*, echoing the dehumanization that takes place in representations of dementia and their own experiences of gradual loss. When Sandra remarked “if living becomes suffering, that is no life anymore” she was thus not only referring to the physical pain her mother was enduring. Instead, suffering in this context encompassed her whole being—a being deemed undignified, bringing about an existential suffering in which humanity was at stake. Similarly, Elena,

whose mother also lived in a nursing home, reflected on the prospect of further degeneration: “walking is already very difficult for her, and if she at a certain point does not recognize us anymore, and becomes expressionless, I would find that so dehumanizing.” As the person with dementia is considered “already lost” or “not there anymore,” it appears that the end of life with dementia does not comply to what is normatively human—strengthening the idea that this life, the end of life with dementia in suffering, is not a life worth living.

Death as Manageable

This form of suffering was deemed unnecessary. One daughter said, “there are people who say that a certain amount of suffering is part of the process. But for me, I do not see the use of it, or if it contributes anything to your life.” Sandra was also quite explicit about this, arguing that, “I think unnecessary pain is not acceptable, because it serves no purpose. Here, in that warm bed you do not have to suffer from pain. There are resources to ease it. You do not want your loved one to be in pain.” Upon asking why she considered pain at the end of life unacceptable, Sandra elaborated, “we are not living in a developing country, or in the bush. We are in a world where, although not much is allowed, we do not have to, as civilized people, we do not have to be in pain.” This view was shared by many family members, who referred to The Netherlands as a society that should be capable of minimizing pain, if not excluding it altogether, through state-of-the-art medical technologies and a liberal view on life and death. Certainly at the end of life, there is, ideally, no place for suffering, which was considered to bring “nothing in return.” In a medicalized Western context, in combination with highly valued notions of control, pain has become framed as unnecessary.

This medicalization of death, conceived of as the process through which death becomes framed as a medical concern, grounds a view on death as controllable through medical knowledge (Green 2008; Howarth 2007). The medicalization of death is usually discussed as the effort to stave off dying, using the possibilities of medical treatment with the

ultimate goal of prolonging life (e.g., Green 2008; Howarth 2007; Kaufman 2005, 2006). To the contrary, my observations in the nursing home point to the tendency of family members to welcome death. Still, this can be seen as operating in the same logic as that of staving off death, whereby death is medicalized and approached as something that can be managed. Surely, to consider the option of welcoming death, one must first conceive of the end of life as under control, at least to some extent. Specifically, family members sought to control the end of life with dementia through its timing, although in practice they had little influence on the duration of dying. They would search for windows of opportunity, defined by Kitzinger and Kitzinger as “the time-limited period when withdrawing or withholding medical interventions can achieve the desired outcome of allowing a patient to die” (2013, 1095). In Sandra’s case, the bump on her mother’s shoulder had presented such an opportunity. She remarked, “we should see what happened as a way out. That we are now allowed to give her morphine, is a small step and in a legal way. In another example, Ms. Meyer had been diagnosed with Alzheimer’s disease five years ago and moved to a nursing home because family members feared for her safety if she continued to live by herself. In one conversation, Ms. Meyer’s daughter told me she and her sister were considering whether or not Ms. Meyer should receive her yearly flu vaccine, using the rhetoric of, “she should die of something.” The underlying thought was that if Ms. Meyer would not receive the flu vaccine, she would perhaps develop pneumonia and die without too much suffering and further degradation. However, their brother argued that dying of the flu might also encompass pain and discomfort. Uncertain of what the consequences would be they decided to postpone the decision, so that Ms. Meyer would still receive her flu vaccine this year. At that time, Ms. Meyer still noticeably enjoyed small things in life such as the chirping of birds, feeding the animals, or sitting in the sun, and even stated she still saw life as valuable. Ms. Meyer’s children seemed more preoccupied with the end of life than Ms. Meyer herself. In looking for a window of opportunity, the daughters aimed at preventing further degeneration and a future suffering, a suffering that was not there yet but they expected to witness as the disease progressed. Ms. Meyer’s

daughter said: “people dying with dementia are often confined to bed, like fetuses. They do not respond to anything and do not recognize anyone anymore,” revealing that her attitude of welcoming death was linked to the negative stereotypes surrounding dementia that I addressed above.

Family members wished to influence the process of dying up to a limit of what is morally and legally acceptable. For example, in the nursing home, morphine was often seen by family members, care workers and general practitioners, as the beginning of the end. Creating a window of opportunity for death is then about setting a process in motion that still can be labeled as a “natural” death. This is not a fixed category, but as Pool (2004) has demonstrated negotiable; even if the dying person is heavily sedated, it may still be seen as a natural death in Dutch society.

While family members could make choices regarding treatment or its withholding, the trajectory that followed remained uncertain. Sandra and Willem were waiting for Sandra’s brother, who lived in France, to arrive to see their mother. They were planning to come directly from the airport to the nursing home, considering that “each minute counts.” “I truly hope she can hold on a little longer so tomorrow I can arrive with my brother. It would be so good if we would stand by her bed tomorrow and so we would be present, and she would go like, pff” Sandra closed her eyes calmly while throwing her head to the side, performing a peaceful last breath and instantaneous death. She continued, “at least I hope it will happen one of these days, and not take another entire week.” Several family members shared similar views on the duration of dying, voicing that it should not take too long. For example, when I asked Marianne, during a conversation at her sister’s bedside, how it was for her to see her sister in her current condition, she responded that she found it “inhumane that this [dying] must take so long.” Often, the duration of dying was considered a cause of suffering both for the dying person, as for the family members who would be present at the bedside. Sandra admitted, “since she is in pain they now can give her medication. For my mother this has come as a relief, and to be honest, also for us.”

Not surprising, then, is the frustration and despair family members felt when they witnessed their loved one with dementia suffer from either

physical pain or what in their eyes was seen as an undignified state of being. In a context where the end of life is presumed to be manageable, the lack of control over the process of dying, whether in terms of its timing or the relief of suffering, left family members often with a sense of impotence. “There is nothing you can do,” Sandra said, “we have to leave it to nature to run its course. That is disempowering. And then I think, for what? She is not going to get better. In a way it would be better if she would go today instead of tomorrow.” In addition, hoping that death would no longer be postponed can be related to the *nitzichtloosheid* that many informants referred to: a combination between a lack of prospect and hopelessness. Elena addressed this *nitzichtloosheid* she anticipated in the trajectory of dementia, stating that “I think it would be good if my mother would pass away now. All that is left is further decay and loss. Things can only become more hopeless, from now on.”

Welcoming Death as a Form of Care

Among my research participants, death was welcomed as an end to suffering. The end of life with dementia as a *lijdensweg*, perceiving the person with dementia as “already lost” or in a dehumanized condition, was regarded a fate worse than death. In addition, being in old age and thus regarded as being closer to death, made death more expectable and in some cases more acceptable. “She [Ms. van Dijk] has reached a nice age and had a beautiful life,” Willem said, “it’s okay.” In many cases, this was further strengthened by the idea that the person with dementia herself would not have wanted this life. For example, one son told me, “my mother has said to us she is done with it. I don’t mean this in a cruel way, but we also think my mother has deserved to quietly fall into sleep.” Knowing their loved one with dementia would not have wanted this situation reinforces the apprehension of life with dementia as a *lijdensweg*, and strengthens family members in the conviction that death is not only welcomed by them but would also have been by their loved one.

The welcoming of death of a loved one with dementia that I have been describing in this paper should not be seen as an act of indifference or cruelty. Rather, I argue that welcoming death can be apprehended as

a form of care. This argument resonates with Scheper-Hughes' work in northeastern Brazil on child death and the structural violence of poverty wherein some babies and young children were considered "better off dead" (1993, 365). Scheper-Hughes argues that while the practices through which mothers would allow some of their children to die may seem inhumane, they are better understood as "reasonable responses to unreasonable constraints and contingencies" (1993, 400). In studying the moral framing of these lives as better off dead, Stevenson has pointed out, Scheper-Hughes "effectively decouples care and the unceasing effort to keep someone alive" (2014, 177 n6). However, where Scheper-Hughes reads the mothers' responses to infant deaths as indifference (1993, 354), I see this differently at the end of life with dementia in the Netherlands: death had not become something family members had grown accustomed to but was seen as a relief to suffering.

I further build on Stevenson's (2014) work on the tuberculosis and suicide epidemics among Canadian Inuit populations, wherein she demonstrates that an overall effort to keep someone alive, regardless of what kind of life that is, should not necessarily be approached as good care. She describes a form of what she calls "bureaucratic care" (2014, 3), wherein it does not matter who you are but that you stay alive, not as an individual but as a population and for the sake of statistics. This manifests, she argues, a certain "indifference from the part of the state" (2014, 73). As such Stevenson's work is helpful in thinking through a further decoupling of care and keeping someone alive at all costs. This creates an opening for a discussion of the extent to which allowing someone to die may be a form of care. Stevenson's conceptualization of care as "the way someone comes to matter and the corresponding ethics of attending to the other who matters" (2014, 3) is productive in understanding how death may be welcomed precisely because the person with dementia still matters.

For most families, the welcoming of death then did not unfold as a form of abandonment but was often paired with the aspiration of providing attentive and affectionate care. Family members would, as Sandra formulated it, "lovingly accompany her to the end." She continued:

I cannot be with her twenty-four hours a day. But I find it important to know that she has not spent hours alone without seeing anyone. Even if it is only to say, 'hello Ms. van Dijk', just someone who can stroke her hair and who is there. We do not know if she will perceive it, but still. As a relative I find that comforting, knowing that when I am not there, every now and then someone checks up on her. So she knows she still matters.

However, these acts were intertwined with narratives of welcoming death and of seeing the end of life with dementia as undignified. One family made sure one of them was always present in what turned out to be the final week of their (grand)mother's life, even though they made it clear that they were "hoping it will be over soon." Their mother was lying in bed, her denture was pointing forward, not quite fitting in her mouth, upon which her daughter who was sitting next to her said she thought it was a horrible sight and that she did not look like her mother anymore. In the kitchen, her brother told me in a frustrated tone that he considered the situation his mother was in "inhumane."

Hence, caring for the dying person did not only take the form of providing comfort and attention. Rather, allowing and welcoming death itself were experienced by family members, and sometimes nursing home staff as well, as a form of care, a relief to suffering. As one professional care worker said, "to reach a good death? I find that very difficult because you cannot know what goes on in their minds. So I hope and pray for little soft heart attacks in their sleep. I think every human deserves that." And, as one family member remarked, "perhaps it sounds harsh, but it is also compassionate not to let someone suffer." Sandra also explained, "out of love we say, this is better. It is out of love that we say, mom, you don't have to live another month, you can now peacefully go to sleep. And you do that out of love, this letting go." Welcoming death, then, did not imply the absence of sorrow or grief. Sandra continued, "yes, it is a relief, but can you imagine, when I go home I will be crying."

Conclusion

In this chapter, I have discussed how the end of life with dementia in Dutch nursing homes is experienced by family members as a *lijdensweg*, wherein a perceived loss of dignity and suffering reinforce each other. Suffering becomes seen as undignified, and the loss of dignity as a form of suffering. Against a backdrop of broader societal trends in which death is rendered manageable through medical frameworks and the end of life with dementia is discursively framed as undignified, family members welcome death as a relief to suffering. Here, I have addressed “welcoming” as an attitude toward death that is intimately bound up with the construction of the end of life with dementia as a life not worth living, and that may, in some cases, culminate in attempts to manage the end of life.

Here, I would like to emphasize again that welcoming death should not be seen as a form of neglect. While people with dementia continue to be cared for at the end of life, family members often hope the process of dying will not be prolonged and for death to arrive soon. I argue that the welcoming of death can be seen as a form of care, as death would bring an end to the suffering of the person dying with dementia. Welcoming death as a form of care confirms that the person with dementia still matters, even though their lives are framed as lives not worth living.

People with dementia, Lock argues “are liable to be stripped of the usual complement of moral entitlement, even when clearly alive physically” (2002, 119). Although the preference of death over life with dementia could be read as such, the care provided at the end of life and the welcoming of death as a form of care demonstrates that a perceived loss of dignity does not necessarily culminate in complete worthlessness. In the context of the end of life with dementia, a life often considered unworthy of living, death becomes acceptable but not “ungrievable.”

Although I understood the experiences of family members, I believe we should be careful in framing certain lives as undignified. In conforming to normative constructions of lives worth living, and thus those that are not worth living, death understandably becomes a way out of a life that was not, in Butler’s words, “a life” in the first place.

However, exposing and challenging the frames that prescribe which lives are worth living, and which lives are not, might open up possibilities to apprehend life through non-normative frames. This is not to be pro-life or a call to keep people alive at all costs. It is necessary to create space in public and academic debates to acknowledge the ambiguities that are at play in deciding on life and death.