

Introduction

Valuing and Timing Death

The problem of timing itself cannot be separated from value judgements about a person's social worth to others.

—Allan Kellehear, *A Social History of Dying* (2007, 237)

“How long does this usually take?” Marta asked, looking at Marcus, the geriatrician. “That is difficult to say,” Marcus hesitatingly answered. “It could be over in a day, but it could also take another two weeks.” On the table in our midst was a leaflet about palliative sedation that had just been handed to the family, while in the room next to us, Mrs. Van Doorn was dying.

After the meeting, Marta, her husband Roel, and I returned to Mrs. Van Doorn's room, where we all took a seat by her bedside. With her index finger, Marta caressed the back of her mother's hand. “She is calm now, that is a good thing,” she said, after we spent some time in silence. Mrs. Van Doorn was in bed, laying on her side with her eyes closed. She breathed deeply, though her breaths paused every now and then. Every time she stopped breathing for a moment, the three of us watched her tensely. “It startles me every time,” Marta said, sounding both relieved and worried, when her mother inhaled again. “Every time I think she has stopped breathing, and then she returns. Not that I don't want her to return—but still, this must not take too long.”

The next day, Marta, Roel, and I found ourselves again by the bedside of Mrs. Van Doorn. Time progressed slowly. Looking at her mother, Marta shook her head. “In this way, with her teeth pointing forward like that, she does not even look like my mother anymore.” “I don't think it's dignified, how she is laying here like that,” Roel added. “There is so little of her left.” In the course of the afternoon, they repeated several times that “I hope this does not take too long” and that “it's just not dignified

like this,” but also that “it is so difficult, it is your mother.” Once, when Marta returned to her mother’s room after going out to get a coffee, she exclaimed with concern, “Did it happen yet?”

These last moments Marta and Roel had with their mother reflect some of the ambiguities that I encountered in my ethnographic research on the end of life with dementia. The experience of loss was confusing, heartbreaking, and, sometimes, relieving. On the one hand, family members hoped their relative would die swiftly and without struggle, physical pain, or what they considered a loss of dignity. The family members themselves would then also be relieved from the unbearable suspense of waiting and witnessing that suffering. On the other hand, they dreaded the loss itself and wanted to remain close to their relative as long as possible. Family members were concerned with the timing of death while having little or no control over the process of dying itself.

These moments at the end of life highlight concerns that are central to this thesis, particularly the great importance of experiences and projections of time in death and dying with dementia. Managing the end of life—the project through which my interlocutors sought to navigate, negotiate, and exert control over death and dying—is infused with temporal orientations and experiences of enduring, waiting, prolonging, hastening, and anticipating. To a large extent, it is about “the right time” and “being in time.” Glaser and Strauss, in their classic volume *Time for Dying*, identified “dying as a temporal process” (1968, x). They argued that not only does dying take time—it has duration—but also the “trajectory” of dying itself is subjective and has a temporal shape. As I observed in the nursing home, the trajectory may be seen as “heading downward,” “stepwise,” “gradual,” or “fluctuating,” while death itself may be described as “timely,” “lingering,” or “unexpected.” In this way, the temporalities of dying are subject to evaluation and come to matter in how death itself is experienced. Particularly important therein is the temporal orientation of *anticipation*. The idea that it is possible to anticipate death—and that doing so will facilitate control over the end of life and “improve” decision-making and caregiving—was prominent among my interlocutors, but it also seems to be a dominant conviction underlying palliative care practices. In this sense, managing the end of

life is about producing and acting upon possible, alternative, or sometimes dreaded futures. Even being at the bedside of a dying person involves anticipating a final breath that is still to come. This study, therefore, foregrounds the role of anticipation in how people live toward the end of life; managing the end of life is future-oriented, from when death is still considered distant until the very last moment when it has drawn nearest.

However, managing the end of life and the pursuit of a good death are not just a matter of time: they are also about value. How life with dementia is valued matters to how death is experienced and managed. As the value of life itself, and of some lives more than others, is subject to debate (Agamben 1998; Kaufman 2005, 2006, 27; Rose 2007, 58; Svendsen 2015), I am concerned here with the moral value ascribed to life and death as articulated in my interlocutors' narratives and experiences. Often this was expressed in terms of worthiness and dignity. Marta and Roel, like many others I spoke with, were concerned with human dignity and suffering. Dementia, which too often still inspires strongly negative imaginaries, was regularly voiced as a fate worse than death, as when my interlocutors said that "this is not a life" or "this life is not dignified." Such sentiments pose a moral challenge to find ways to deal with forms of life that do not conform to normative, ableist views of the human subject due to frailty, loss of autonomy, or cognitive impairment (Buch 2018; Kovach 1997). The question of the extent to which a life with dementia is considered "worth living" is a moral question, and the value that my interlocutors ascribed to life and death with dementia is first and foremost a moral value. In my use of "moral value," I do not make claims regarding my interlocutors' moral standing—meaning the extent to which they are good and do good—but seek to unravel how they evaluate life, both their own and that of others, in moral terms (Mattingly 2014, 204).

I explore in this thesis the entanglement of time and value at the end of life. Or, to be more precise, I argue that the value ascribed to death with dementia—the extent to which it can be considered a "good death"—is rooted in the intertwinement of the value ascribed to life with dementia and the timing of death. I am thus interested in how the

temporalities of death and dying are infused with moral evaluations, and how these moral evaluations are in turn characterized by temporal projections and orientations. I argue that the management of the end of life with dementia is both a temporal and moral project, one that is particularly future-oriented. It involves creating and working toward futures that may be idealized—as is the notion of a good death—or that may be dreaded and unwanted, but nevertheless vividly imagined and anticipated.

Contextualizing the Research

While I study primarily the everyday interactions and narratives through which the end of life is managed, nursing home regulations and legal frameworks for euthanasia mean that dealing with death also means dealing with institutions and protocols. The specific processes of dying that I discuss in this thesis happened mainly through institutional frameworks, namely in nursing home settings or in relation to euthanasia regulations.

In the Netherlands, most people with dementia move to a nursing home at some point, often when they are no longer capable of living by themselves or when family and professional home care can no longer provide the required care. The dominant discourse in Dutch society is that moving to a nursing home is undesirable, as it is often associated with a loss of autonomy and has even been dubbed as “death’s waiting room” (The 2010; see also Leibing, Guberman, and Wiles 2015). Despite such negative connotations, institutionalization at old age and of those with dementia is common practice in the Netherlands. The nursing home is thus for many people the last place of residence and the place where they eventually will die. Of those with dementia who died in 2016, 89.8 percent died in a nursing home setting (Volksgezondheidszorg.info 2019a). The last decade has also seen an increase in attention for palliative care for people with dementia and in nursing homes (Boddaert et al. 2017; van der Steen et al. 2013).

The other mode of dying that I address is through euthanasia. In 2002, euthanasia was legalized in the Netherlands, provided that it is

done by a medical professional who complies with specified criteria of due care, which must be confirmed by an independent medical specialist.¹ Most of my interlocutors who were in the process of requesting euthanasia were still living at home. Once the person with dementia moved to a nursing home this often implied that they had advanced to a point where they were also unable to confirm the request. This conundrum, in which cognitive decline both motivates the request and impairs its confirmation, is one of the central challenges for people with dementia gaining access to euthanasia. Nevertheless, 80 percent of the general population finds that euthanasia should be possible for people with dementia, if the request was made when the person requesting was still fully cognitively capable (CBS 2019). While I further discuss the question of euthanasia in chapter two, here it suffices to say that although euthanasia is legally possible for people with dementia, it is highly complicated in practice and subject to ongoing public debates.

More generally, dementia and dementia care have in the last decade gained much public attention. As societies are aging worldwide, the number of people with dementia is also expected to increase (WHO 2012). This is the case in the Netherlands, where the population of people with dementia was estimated to be between 254,000 and 270,000 in 2016 (Volksgezondheidszorg.info 2019b). The expectation is that this number will increase, although estimated numbers vary between 330,000 (RIVM 2019; Volksgezondheidszorg.info 2019c) and one-half million in 2040 (Alzheimer Nederland 2019). In 2012, the Dutch government launched the Deltaplan Dementie, a policy plan running until 2020 to find “solutions” focused on care, prevention, and cure, and which seeks to combine research, care practices, and monitoring systems in a single framework. Through such policies, as well as continuing debates on the quality and costs of care, Dutch society seems to be preparing itself for a future in which dementia is anticipated to become an increasing concern.

¹ These criteria of due care are outlined in the Termination of Life on Request and Assisted Suicide Act, also known as the Euthanasia Law.

While these numbers communicate a strong sense of urgency, there is also much uncertainty due to the difficulties of diagnosing dementia (Lock 2013). “Dementia” is commonly used (as I also use it in this thesis) as an umbrella term for a variety of conditions, Alzheimer’s disease being the most well known. Most dementia-related deaths in the Netherlands are statistically categorized as “unspecified dementia” (Volksgezondheidszorg.info 2019d). In 2016, dementia was even identified as the primary cause of death, comprising one in ten deaths (CBS 2017).² However, the end of life with dementia often involves comorbidity, challenging the possibility to ascribe a death to one condition or another; as Van der Steen and colleagues (2013, 2) write: people can “die *with* or *from* dementia” (see also Hennings, Froggatt, and Keady 2010). Ascribing a cause of death to a person with dementia is thus far from straightforward.

Aims and Questions

In this dissertation, I present an ethnography of people with dementia, their family members, and professional caregivers in their efforts to manage the end of life in pursuit of a good death. With this, I aim to provide insight into how people become oriented toward death and to underscore the importance of time and future-making in how the end of life with dementia is managed. The main research question that guided this research was as follows:

How are life, death, and the future with dementia imagined, valued, and anticipated in striving toward a good death, and what does this reveal about the entanglement of time and value at the end of life?

With this question, I engage with the fields of death studies, medical anthropology, and the anthropology of time. In death studies, I find

² These numbers have also been subject to critique. Dementia was the biggest category as an umbrella term for various diseases, including Alzheimer’s, while different forms of cancer were listed separately. Had the latter been grouped, then cancer would have been the primary cause of death (CBS 2017; Veldhuizen 2017).

inspiration to ask how people cope with the finitude of life and how death is socially managed. Two broader concerns in death studies—about what matters at the end of life and how death is valued—are reflected in my ethnographic explorations of the efforts and negotiations through which people seek to reach a good death. From medical anthropology I take the cue to look into the intimate human experiences of illness and suffering—including how to continue life in the face of disruption or loss—in relation to the medical, social, cultural, and political that mediate and frame experiences. The anthropology of time, and particularly the recent surge in interest in the future (see, e.g., Bryant and Knight 2019; Nielsen 2011, 2014; Ringel 2016, 2018), poses intriguing questions to ask in relation to illness and dying. This relationship to time I explore by questioning the temporal dimensions of living with and caring for dementia, and future orientations toward death.

In addition, I am inspired by queer and feminist approaches to exposing and questioning normativities and binary divides, and particularly those pertaining to the dualisms of life and death, living and nonliving, and grievable and ungrievable (e.g., Butler 2006; Radomska, Mehrabi, and Lykke 2019), to look at how dementia may challenge these norms. Finally, following Fassin’s take on studying value and morality, my aim is not to prescribe what a good death with dementia should be, but rather to take “moral tensions and debates as . . . objects of study” (2012, 3). Without seeking judgement, I take as a starting point what my interlocutors experienced or framed as “good” in their narratives and actions. I then embrace the complexities and contradictions they describe: the nuances of living and dying with dementia, of working toward the end of life, of experiencing loss and struggling to cope, of finding ways to maintain meaningful relations and to care, and of loss and love.

In the remainder of this introduction, I provide a theoretical discussion, first addressing the concept of the good death and its relation to dementia; second, the valuing of life and death with dementia; and, third, the temporalities of death and dying. I then turn to methodological and ethical concerns, and finally present an overview of the chapters in this thesis.

Aspirations of a Good Death

I began this research with an interest in what people with dementia, their family members, and professional caregivers found important at the end of life, how they aspired and worked toward a meaningful death, and the difficulties they faced. I turn to the concept of the *good death* to grasp the complexity of these experiences and aspirations. I take the good death to be an idealized frame that my interlocutors strove toward and sought to comply with. However, it also raises the question of for and by whom a death may be considered good (Seale and van der Geest 2004; Howarth 2007; van der Pijl 2016). In light of this, I ask how the good death is aspired to, facilitated, and negotiated. The notion of a good death has received considerable attention across various disciplines, including medicine, history, and anthropology (e.g., Ariès 1981; Green 2008; Howarth 2007; Seale and van der Geest 2004), following which I aim to present a critical account of how the good death is constructed as a moral and normative objective and the efforts that are put into its achievement.

Although my interlocutors did not explicitly use the term “good death” (cf. DelVecchio Good et al. 2004), they did attribute importance to what they referred to as “*waardig sterven*” (dignified dying). Often, after the person had passed away, family members and professional caregivers stated “*bet is goed zo*” (it’s good like this, or: it’s okay), expressing an acceptance of death despite the grief and sadness. In such expressions, the striving for a good death would be made explicit, as a process of attributing value and meaning to the end of life. Labeling a death as “good” provides it with meaning to the dying person and those surrounding them, allowing them to make sense of the disruption caused by death, and to construct a significant final chapter to one’s biography (Davis et al. 2007; Kellehear in Hart et al. 1998). Moreover, the good death, Kellehear writes, “reproduces the social order, sometimes even strengthening it” (2007, 104). It is an idealized notion of how dying should be, revealing a set of socially desirable aspects.

While there are different scripts for a good death, the pursuit of which is fluid and can manifest in a variety of ways, dominant in the context of my research were intertwined notions of control, suffering, and timing. In the Netherlands, as in many Western contexts, control

and self-determination have been identified as particularly important aspects at the end of life (Norwood 2007; Pool 2000; Rietjens et al. 2006). This is not necessarily a recent development, as becomes apparent in Aries's ([1981] 2008) historical account of attitudes toward death from the early medieval to the modern ages. Control, in terms of knowledge of and preparation for death, is a crucial and persistent factor in what Aries terms the "tame death." Nowadays, in a time when death has been medicalized and characterized by technological possibilities, control—in terms of maintaining autonomy at the end of life and making decisions on death and dying—remains highly valued (Borgstrom 2015; Howarth 2007; Kellehear 2007). This sense of control reflects in the efforts to relieve suffering through symptom management, which in the nursing home was a primary concern in the provision of end-of-life care. Also euthanasia is often requested with the aim to take control over the timing and manner of dying.

Moreover, temporal dimensions are of crucial importance in the pursuit of a good death (Glaser and Strauss 1968; Kaufman 2005; Kellehear 2007). The duration of dying matters: it should not happen suddenly and unexpectedly so as to give family members and caregivers an opportunity to say goodbye to the dying person, but neither should it be protracted, as suffering should be minimized. The good death also entails modes of anticipation: there is a lot of anticipatory work in filling in forms, establishing directives, and administering medication, reflecting the idea that an anticipated death is a controlled, and thus good, death. This further relates to the timing of death, as people actively attempt to manage its temporal organization by postponing or hastening it, or even by taking charge of it through euthanasia.

While in my research the intertwinement of control, suffering, and timing took center stage in notions of the good death, several other related aspects should be mentioned. At old age, death was often more or less expected and accepted as part of the life-course (cf. Howarth 2007). Relatives often mentioned that the person with dementia had had a long and good life, and that the final chapter had arrived—although many would also argue that a good death would be one that occurs before the development of dementia, in that dementia was considered an

undignified condition. It was further considered important that the person should not die alone, but be accompanied by relatives or caregivers, and that they should die at a preferred place. Often this preferred place was the home, or if this was not possible, then at least in a familiar surrounding (Visser 2019).

Overall, the good death forms an objective that underpins people's narratives, decisions, and actions. In this sense, the good death is a normative death. The various aspects that comprise it both reveal the morality of and values attributed to the end of life, and provide directives for how the end of life should be managed. Such aspects are primarily desirable and may not be feasible in practice. In this regard I agree with Hart and colleagues that the good death "exposes an ideology that constructs a socially approved form of dying and death with powerfully prescribed and normalized behaviours and choices" (1998, 72). This idealized death may be difficult to achieve and there is no guarantee that fulfilling all aspects will lead to a good death. But it is important to note that people with dementia, family members, and professional caregivers negotiate the situation they face with the means at their disposal, trying to facilitate the dying process as well as possible.

A Good Death with Dementia

The normative frames of the good death present challenges particular in the context of dementia. Many of the aspects mentioned above, and with them the ideal of the good death in general, are based on the assumption of a rational subject (Read and MacBride-Stewart 2018). The emphasis on control as a crucial aspect of the good death, for example, becomes problematic as dementia encompasses a loss of cognitive capacities. As the disease progresses the person with dementia becomes increasingly unable to oversee decision-making processes. Control then often shifts to family members who take on the task of decision making and feel responsible to maintain the person's dignity. Further, while the preferred location of dying is generally at home, people with dementia in the Netherlands commonly move into institutional care as the disease progresses and eventually die there. Also assessing whether the person

with dementia is free of pain, a crucial aspect of the good death, is coupled with great uncertainties as the person may be unable to express or confirm this. Even if physical pain was absent, my interlocutors often associated life with dementia with a broader, existential suffering in which human dignity was at stake. Given these concerns, it would seem that a good death with dementia would be difficult, or perhaps even impossible, to achieve (Read and MacBride-Stewart 2018). Underlying this, is that the value attributed to death is closely tied to the value attributed to life with dementia.

While the good death is surrounded by grand notions of control, suffering, and timing, facilitating a good death is also embedded in small gestures and personal acts of care (Buch 2015; Kaufman and Morgan 2005). Family members were often concerned with guiding the dying process in such a way that suffering could be minimized, and creating a serene atmosphere using things that mattered to the dying person such as music, prayers, or touch. They made efforts to be present as much as possible so that the person would not die alone. Also professional caregivers in the nursing home often said that “you can only do it once,” emphasizing the importance of providing good end-of-life care as “the last thing you can do for the dying person.”

In the nursing home, the values commonly associated with a good death were embedded in the institutionalized and medicalized paradigm of palliative care (e.g., McNamara 2004). Although palliative care is attentive to psychosocial and spiritual needs, its primary focus is on symptom management to relieve pain and discomfort.³ This focus on comfort was materialized in various kinds of guidelines and care tools that were primarily intended to structure caregiving, and to anticipate and control the end of life through regular monitoring (Lemos Dekker,

³ The WHO defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2019).

Gysels, and van der Steen 2018).⁴ In this way, palliative care may be seen as an institutional model in service of broader aspirations for a good death.

Furthermore, death was often welcomed and accepted as an end to suffering at the end of a life that was already considered undignified. This became apparent in the narratives of family members that centered on the idea that life with dementia had become a *lijdensweg*, a “pathway of suffering” that was considered pointless or without virtue. Death would relieve the person from this suffering. Also euthanasia—derived from the Greek “*eu*” and “*thanatos*” meaning “good death”—was an active attempt to prevent a person from entering an undignified state of life. Being in old age, and having lived a long and full life, further allowed for the acceptance of death. Here, the end of life with dementia, perceived as suffering, created the possibility for a different type of good death: an alleviating death. Where the ideal of the good death has been conceptualized to center around the circumstances of death, here death per se becomes good.

Valuing the End of Life with Dementia

A central premise of this thesis is that the value ascribed to death, the extent to which it may be welcomed or considered good, is related to the value ascribed to life. I explore how this relation plays out in the context of dementia, demonstrating that negative imaginaries and public discourses of dementia, and the various ways that the disease challenges normative categories of life and death all play a role in the moral evaluation of the end of life.

I build on anthropological inquiries into the negotiation of the value of lives at the margins (e.g., Kaufman and Morgan 2005; Rose 2007), and in particular Kaufman’s insight that life with dementia “is the object of debate about value; it must be accorded a value” (2006, 27). I am thus

⁴ Two examples of such tools are the Liverpool Care Pathway, which is a tool for monitoring and structuring end-of-life care, and the Surprise Question, which seeks to make explicit expectations of the extent to which a person is nearing the end of life.

concerned with expressions of the moral evaluation of life and death with dementia.⁵ I have been inspired in this approach by Mattingly's (2014) ethnographic focus on how people pursue a good life in the face of suffering. In her work with African American families with children with severe disabilities and chronic illnesses, she demonstrates how her interlocutors (re)evaluated their own lives and moral objectives, in what she calls a "moral project" that found expression in mundane activities of everyday life as well as in narratives of transformation. In a similar way, I address in this dissertation how people with dementia, their family members, and professional caregivers ascribed moral value to life, the future, and death with dementia.⁶ I show that my interlocutors throughout the trajectory of the disease were concerned with moral value, as they struggled with questions of how to maintain human dignity and of whether, and until when, life was considered "worth living." Following Stevenson (2014), whose Inuit interlocutors challenge the Canadian state-held idea that life is inherently valuable, I aim to take seriously what is at stake when my interlocutors disputed the value of life in relation to the prospect of death. In so doing, I seek to underline that this moral evaluation matters to how the end of life is experienced, anticipated, and managed.⁷

I am also inspired by feminist and queer approaches to exposing and problematizing normative frames through which lives are valued. This

⁵ Several authors (e.g., Heuts and Mol 2013; Pols 2014; 2015; Pols, Pasveer, and Willems 2018) demonstrate that valuing does not necessarily have to be a matter of judgement, but can be observed in practices. In this "empirical ethics" approach (Pols 2015), value is thus seen as inherent to specific practices, rather than existing outside of the relations between humans, things, and technologies. While I consider these insights to be highly relevant, I have in this dissertation primarily been interested in how value is expressed in my interlocutors' narratives and in societal discourses, followed by how my interlocutors experienced and negotiated this in their everyday practices and encounters.

⁶ My concern is thus not with economic value or with how moral value is translated into economic value and vice versa. Even though these types of value may be considered incommensurable (Lambek 2008), the context of dementia does raise important questions of how lives that cannot conform to the norm of economic contribution may be evaluated differently in moral terms, and of how lives whose moral value is at peril are incorporated differently in economic state policy.

⁷ In a similar way, Zhang (2012), building on Butler's (2006) notion of grievability, underscores that how a death is mourned is essential to how that life is valued.

approach shows that certain lives are valued according to the norms that qualify them as human, while other lives may be marginalized for being unable to comply to those norms (Radomska, Mehrabi, and Lykke 2019). I draw on Butler's (2010) work, wherein she critically assesses the normativity through which lives are apprehended and recognized. On the life that is excluded from the norm, Butler writes: "though it is apprehended as 'living,' it is not always recognized as *a life*" (2010, 8, emphasis added). This distinction between apprehension and recognition matters here, as acknowledging that someone is alive is not the same as acknowledging the fullness or worthiness of that life. No one would make the claim that people with dementia are not alive: clearly, people with dementia are apprehended as living. However, my interlocutors also repeatedly expressed that "*dit is geen leven*," which can be literally translated as "this is not a life." Life with dementia was often described as undignified and as if the person was "already gone." This entails a moral claim that raises the question of value: what is the value of life and death with dementia? I ask this question rhetorically and with caution, not aiming to establish what life with dementia is or should be worth, but to expose the normativities through which life is apprehended and valued. Underlining that "to look at value inevitably brings hierarchy to light" (Robbins and Sommerschuh 2016, 8), my interrogation of moral value here is to show how lives are unequally constructed as "worth living" against normative ideas of a "desirable" or "good" life and death.

Although my interlocutors sought to maintain meaningful relations and live a good life with dementia, and several scholars have studied the possibility of a good life with dementia (Driessen 2018, 2019; Taylor 2017), negative imaginaries of dementia, due to its associated loss of cognitive abilities, were still dominant both in media discourses and in the narratives of my interlocutors. This is related to what Gilleard and Higgs (2010, 2011) have termed the "fourth age," a social imaginary of frailty, abjection, and othering at old age. Commonly associated with a loss of control and self-determination, dementia is often portrayed as a disease in which the person is set to lose their grip on life and their human dignity. The very image of the human and the self as a cognitive, rational being is at stake. As such, dementia has been theorized as

entailing a loss of personhood—although this has been countered by including relationality and other capacities of the person with dementia in the conceptualization of personhood itself (Buch 2018; Kitwood 1997)—and has been addressed in terms of “social death” (Sweeting and Gilhooly 1997; see also Králová 2015; Mulkay 1993; Sudnow 1967) or “bare life” (Leibing 2006; see also Agamben 1998). All these denominations refer to a perceived absence and disconnectedness of the person, placing dementia at the margins of what constitutes a dignified and meaningful life.

Disentangling this imaginary further, it seems that dementia does not fit in dominant cultural notions of what constitutes life and death. People with dementia are often positioned in what Kaufman calls a “zone of indistinction” (2005, 62) or a “gray zone” (2005, 1; 2006, 40) of life-in-death and death-in-life. Such a blurring of boundaries between life and death is reflected in pejorative descriptions of people with dementia as “already gone,” which risks becoming infused with demeaning stereotypes, such as “the living dead,” “zombies,” or “empty shells.” As Behuniak (2011) has cautioned, this can have marginalizing and dehumanizing effects. Accordingly, dementia seems to call into question what it means to be alive and to be human, whereby “the human is not a neutral term [but] loaded with power differentials” (Braidotti 2019). Dementia comes to challenge the normal order of things, and it is precisely this ambiguity that makes dementia so disruptive and demanding.

While I seek not to reproduce these negative images of dementia, I often encountered them in this research as foundational to the narratives and experiences of my interlocutors. These imaginaries, I emphasize, impact life with dementia and how death and dying with dementia is managed and ascribed with meaning. Hence, I am interested here in how people engage in the end of life of a person who is conceived of as existing in between life and death. How do people live toward death when their life is framed as undignified?

Temporalities of Death and Dying

The negative image of dementia discussed above, often appears as a *future* imaginary. The process of decline involved, although uncertain to some extent and characterized by experiences of loss in the present, involves dynamics of expectation and anticipation. As dementia gradually unfolds over time, the future becomes infused with projected stereotypes. The negative imaginaries, in other words, present a foreclosed future that comes to weigh on the present and, as some scholars argue, deprives people with dementia of their personhood (Gjødsbøl and Svendsen 2019). As Kafer (2013) has suggested in the context of disability, it is as if there is no room in the future for people who do not conform to the able-minded and able-bodied norm. The future is either imagined as very negative—as becomes apparent, for example, in the apocalyptic scenarios that people with dementia and family members shared with me—or as better without dementia—as is reinforced by current policy that prioritizes disease prevention and cure rather than the possibilities of a positive future with dementia (Leibing and Schicklanz, forthcoming). Whereas Kafer uses her critique to explore alternative futures that could allow for lives that do not conform to ableist norms, I am in this thesis primarily interested in how people live and work with the negative future imaginaries of dementia. How do people with dementia and their family members live with this prospect of a mournful, unwanted future? How do they confirm or challenge this? How does it come to haunt the present? And what are the moral implications of these temporal orientations?

The management of death, I argue, is about future making. In this research, death mostly figures as future, but a future that is diffuse and lived in the present through experiences of gradual loss, and anticipated as a constant marker of finitude. I draw on recent anthropological interest in the future as culturally produced and embedded and articulated in the present (Appadurai 2013; Bryant and Knight 2019; Ringel 2016; Salazar et al. 2017). I understand the future as entangled with past experiences and as embedded and articulated in the present (Munn 1992; Bryant and Knight 2019), and pay particular attention to anticipation. Anticipation is a mode of being in time that is oriented

toward the future. While people anticipate important and impactful events, such as, in this case, the end of life, it also infuses the more mundane layers of everyday life. Beyond imagining or merely expecting a future, it involves actions in the present. Through anticipation, imagined futures can legitimize actions in the now that are intended to influence and shape that future. In this way, anticipation brings the future into the present (Adams et al. 2009; Bryant and Knight 2019; Clarke 2015). As this dissertation shows, the pursuit of a good death seemed to constantly require my interlocutors to live in a state of anticipation.⁸

I suggest that anticipating the end of life involved “time-reckoning,” defined by Munn as “the use of selected cultural categories, or contingent events . . . to ‘tell time’—to ask ‘when’ something happened, will or should happen—and to ‘measure’ duration—to ask ‘how long’ something takes, or to ‘time’ it” (1992, 102). I observed that my interlocutors constantly sought to understand how dementia was progressing in order to anticipate future decline and the proximity to the end of life, even though, in practice, the course of dementia progresses gradually, is difficult to predict, and is characterized by uncertainties. Both family members and professional caregivers, and in early stages people with dementia themselves, attuned to the process of decline in an effort to grasp its projected course. Palliative care in particular is premised on expectations of the nearness of death. This can be seen in the many palliative care tools that have been developed to “mark” the dying phase and monitor decline, although in practice there was a lack of clarity about whether palliative care started at the moment of admission into a nursing home, or if it was synonymous with terminal care. Advance care planning, wherein preferences and wishes are established regarding future treatment and care, builds on a similar logic of anticipation (Denning, Jones, and Sampson 2012). The importance of formulating one’s wishes, and thereby acting upon the future, was often emphasized

⁸ Related to this is also the notion of anticipatory grief, which refers to grief experienced in relation to anticipated losses and before death (see Boss 1999; Doka 2010; Fulton 2003; Fulton and Gottesman 1980; Lindemann 1944; Rando 1986).

due to the expected loss of cognitive abilities. The underlying assumption is that being able to “tell time” and to predict when dying will take place can enable control and preparation and thus improve caregiving. Articulations of duration and timing, in this sense, are not neutral (Munn 1992, 104); this becomes apparent in statements describing dying as taking “too long” or happening “too early” or “too late.” In this sense I consider time-reckoning not simply as estimating and calculating time, but also as an effort of my interlocutors to make sense of, and attribute value to, the time they experienced.

Further, I should underline that the project of pursuing a good death often also involves “time-tricking,” which refers to how people attempt to modify and influence the temporal dimensions of life (Moroşanu and Ringel 2016; Ringel 2016). Moroşanu and Ringel introduce this concept to explore the potential and limits of temporal agency, arguing that “human beings are not just subject to time. They exercise agency in relation to time” (2016, 18). My interlocutors did not only seek to apprehend the temporal dimensions of the end of life with dementia, as noted above, but they also sought ways to influence and intervene. This involved for example attempts to hasten death, in order to bring an end to suffering, or to slow down the process of dying to allow for time to say goodbye. It could reflect in postponed decisions about treatment or moving to a nursing home, as well as in detailed plans for future caregiving. It also became apparent in debates and negotiations about the timing of euthanasia. And often it implied prolonging current states of being, delaying or hastening expected futures, projecting alternatives, and a great deal of preparation. I consider such instances of time-tricking as attempts to exert control over the process of dying by influencing its temporal aspects. While time-tricking does not have to be future-oriented (although Ringel [2016] does consider the future to be the most common object of temporal agency), I am primarily interested in this thesis in how people seek to manage death and dying with dementia as a projected future. This explains as well my approach to anticipation as a mode of being in time through which my interlocutors acted upon the future in the present, as they lived toward the end of life.

In bringing together perspectives on time and value, I further find resonance in anthropological works that have explored, in more or less explicit ways, the entanglements of temporal orientations and moral evaluations of life and death. These include works on how the moral becomes embedded in everyday life (Han 2012; Fassin 2012), on the moral becoming of the self through the cultivation of a good life (Mattingly 2014), on how the present may be understood in light of morally charged and aspired futures (Robbins 2004), and on how the value of life and death change when the future is imagined as bringing an increase in suffering (Stevenson 2014). While these studies tend to focus on the project of the “good life,” the “good patient,” or the “good self,” I turn to the temporal dynamics of the good death. My interlocutors’ efforts to stave off or hasten death, for example, are infused with the value they ascribed to the end of life with dementia, as well as with judgements of its timing, duration, and anticipation. In this way, time is valued: the morality of the end of life with dementia is to a large extent embedded in the temporal orientations of people with dementia, their family members, and professional caregivers.

In the pursuit of a good death, timing thus plays a central role. I observed that my interlocutors attached great importance to the moment of death and to the duration of dying. They evaluated timing and duration in relation to ideas of the “good,” effectively ascribing the experience of time with moral value. The value of timing further became apparent in experiences of waiting by the bedside of the dying person, as described in the beginning of this introduction, and wherein death was near but had not yet arrived, and wherein time became suspended in the impossibility to act or move on. This was often a tense moment for family members, or what Baraitser calls an “intensive experience of time” (2017, 137). Waiting could also constitute a form of care (Glaser and Strauss 1968; Han 2012, 20), wherein the dying person would not be left alone, a mode of *being with* the dying person that gave substance to the passage of time. However, in instances when dying was considered to take “too long,” its duration was viewed as a prolongation of suffering; when death came unexpectedly, it could be experienced as overwhelming and simultaneously appreciated if it meant the person would not have to

suffer at the end of life. Such temporal orientations pertaining to the moment of death, I stress in this thesis, underline that the value of life and the timing of its ending are strictly intertwined in the pursuit of a good death. Hence, I explore the pursuit of a good death as a temporal as much as a moral project.

Methodology

The research presented in this thesis is based on eighteen months of ethnographic fieldwork in 2014 and 2015 in two nursing homes in the Netherlands, and interviews in the family home setting with people with dementia and their family members.

The two nursing homes, one located in one of the larger cities of the Netherlands and the other in a small town in the south,⁹ both consisted of closed wards and *kleinschalig wonen* (small-scale living) units, arranged to resemble households. Through participant observation in these units, I gained insight into everyday life with dementia, the social response to perceived and projected cognitive and bodily decline, and how the end of life was discussed, negotiated, and experienced. In the nursing home I listened, observed, and participated in activities. I was present at medical consultations and accompanied professional caregivers, psychologists, and chaplains in their work with residents, but also took part in everyday activities, such as singing afternoons, and helped out by bringing residents to, for example, the in-house hairdresser.

I usually opened conversations and interviews by asking “What do you find important?” or “Can you tell me your story?” This allowed my interlocutors to start with the subjects they valued, struggled with, or were eager to share, as well as choose where they wanted their story to start. Family members often talked about how their relative with dementia was before moving to the nursing home and how she had declined. As I did not know the person before, I did not share this frame

⁹ Although cultural diversity does play a role in the management of the end of life, this has not been the focus of my analysis. For studies addressing this diversity, see Fortuin, Schilderman, and Venbrux (2017) and Gunaratnam (2008).

of reference. After some months, once I had spent an extended period of time in the nursing home, I was able to see for myself how residents' conditions changed, through which I also gained a more in-depth understanding of the experiences and narratives of family members. It is one thing to speak about change, it is another to witness it. Important were also the moments when I was able to sit with family members by the dying person's bedside, where stories about their lives were shared, where I saw how family members interacted with the dying person, and how they, together with professional caregivers, tried to provide comfort. Furthermore, taking part in everyday life in the nursing homes meant spending many hours with residents and drinking lots of coffee. Usually, during the afternoon I would take a moment to further elaborate and develop the field notes I had written in the morning. I would do this in the in-house café on the ward, so I could reflect on observations and conversations while remaining in—and part of—the field. Doing “anthropology at home,” the nursing home opened up a world I was previously not familiar with.

I conducted informal conversations and semi-structured interviews with professional caregivers, family members, and, insofar as this was possible, with people with dementia (see also the “ethics” section below). Care workers tended to be hesitant to grant more formal interviews due to the limited time they had available and in some cases were not comfortable with having their words recorded. In informal conversations, however, and knowing that what they said would be anonymized, they spoke more freely about their experiences of caregiving, everyday life in the nursing home, and death. I also conducted semi-structured interviews with managers and geriatricians. Managers shed light on institutional concerns, clarified organizational arrangements, and reflected on the unending projects to improve life, care, and death in the nursing home. Geriatricians, in turn, reflected on the possibilities and choices available at the end of life, including ethical concerns regarding life-prolonging treatment.

Toward the end of my fieldwork, I held a series of three focus groups in one of the nursing homes to discuss some of the ideas and insights that had emerged from the field. One group consisted of care workers,

one was made up of family members of nursing home residents, and the third was a multidisciplinary group that included the nursing home geriatrician, psychologist, physiotherapist, ergotherapist, and chaplain, as well as the janitor, ward manager, and the daily activities supervisor. While many of these last participants beforehand indicated that they were not usually involved in the end of life of residents, their participation in the conversation made it possible for the whole group to reflect on how each *could* contribute. Several participants afterwards indicated that they came to see possible ways to play a greater role at the end of life.

I also held forty in-depth interviews with family members in the nursing home, their family homes, or a place of their preference, such as a cafe. These were often longer conversations (two hours was not uncommon) and I noticed that family members were often more at ease when they were at home, and would thus elaborate on sensitive topics such as experiences of loss or their outlook on the end of life. To recruit participants for these interviews I posted a call for participants on the website of the Dutch Alzheimer's Society (Alzheimer Nederland) and also placed a call to interview people with a euthanasia request on the website of the Dutch Association for Voluntary End-of-Life (NVVE). The semi-structured interviews and focus group conversations were audio recorded. The focus group conversations and twenty of the interviews were transcribed, selected according to the content of the interview. The remaining recordings I listened to and summarized.

Ethics: Careful Considerations and Voices out of Order

I have found it important to make this a study not only *about* but also, where possible, *with* people with dementia, with the aim to engage them as serious interlocutors in the research. Thereby it has been important to build relationships, both with the person with dementia and the people surrounding them (McKillop and Wilkinson 2004). Just as building rapport is a crucial aspect of ethnographic research in other contexts, so it was in this research. I actively involved people with dementia in the ethnographic work according to their capacities, by spending time with them, following their focus of attention, and participating in their

everyday rhythms. I have interviewed interlocutors with dementia who were capable to maintain conversations, which required being aware of the need to ask clear questions, to ask only one question at a time, and to be particularly patient. When my interlocutors were unable to express themselves in coherent narratives or even sentences, it required listening between the lines, following their moods, expressions, and gestures as much as their words (e.g., Pols 2005). The hours or days before the moment of dying involved sitting by the bedside with family members, and noticing breath, movements, facial expressions, and sounds.

Being attentive and building relationships gained further importance due to the sensitive nature of the moment of dying. In the first months of fieldwork, colleagues at the university would often inquire if I had already witnessed a death. This repeated question seemed to reduce death to a moment in time. On the contrary, I have taken a more encompassing approach, not only looking at death as an event—the moment of dying—but also at everyday life, the process of decline, and how death manifested therein. I think it is important to know about someone’s life in order to be able to understand the moment of death. This moment is not only emotional as interlocutors undergo a loss, but it is in most cases also shared only with professional caregivers and close relatives. Being present at, or rather, being granted access to, the moment of dying as a researcher, I have thus found it especially important to get to know the nursing home residents and their family members by taking part in everyday life in the nursing homes, so that I was not a stranger who only entered their lives at the moment the person with dementia was dying. It was important not only for me to know them well, but also for them to know me (cf. Abu-Lughod 1993). Considering that, as Fassin puts it, “moral anthropology encompasses the delicate topic of the moral implication of the social scientist: it is reflexive as much as descriptive” (2012, 4), I turn in chapter four in more detail to these ethical and methodological concerns of doing research with this vulnerable population and on the sensitive topic that is the end of life.

Consent was sought at multiple levels and in various ways throughout the research. I have approached consent not as an exercise in ticking boxes, but as a process that involves the person with dementia, family

members, professional caregivers, and the nursing home management (Dewing 2002; McKillop and Wilkinson 2004). Access to the nursing homes was granted by their boards of directors and client councils. To inform family members about the purpose of the research and my presence in the nursing homes, a letter was sent out to families of all residents along with an informative flyer. The letter made clear that family members could indicate at any time if they did not want themselves or their relative to be involved in the project. Introducing myself to residents, family members, or professional caregivers, I always made transparent that I was a researcher and brought this to their attention again when I felt it was necessary to clarify my presence and my role in the nursing home. Consent was further acquired verbally and was verified repeatedly. When recording interviews I always asked consent on record. If I sensed that my interlocutors were feeling uncomfortable with my presence, especially around the moment of dying and even if they did not say this explicitly—what Dewing (2007) calls signs of ill-being—I would withdraw immediately.

In preparation of this research, my colleagues at the University of Amsterdam and I organized a short intensive course titled *Voices Out of Order*,¹⁰ in which we addressed the question of how to include people in research who may not fit within dominant frameworks of data collection because they express themselves in nonlinear, incoherent, or otherwise non-normative ways, and whose voices are thus often silenced in scholarly work. During and after fieldwork, I discussed the research with our dementia research team and an inter-university group of colleagues working on death and dying, in order to foster reflexivity on our experiences and positioning as researchers in the field. I have found it highly valuable to be able to share my views and experiences with colleagues, to learn from their field involvements, and to reflect on these together.

Ethics approval for this research was granted by the ethics committee of the Amsterdam Institute for Social Science Research (AISSR).

¹⁰ This short intensive course was co-organized with Melissa Sebrecchts and Laura Vermeulen.

Throughout the thesis, the names and descriptions of the nursing homes and the people who lived, worked, and visited there have been anonymized.

Chapter Guide

In the first three chapters, I address the intertwinement of temporal and moral concerns at the end of life and in the pursuit of a good death. Focusing in the first chapter on temporal modes of waiting and hastening, in the second chapter on anticipation and timing, and in the third chapter on responses to the unexpected, I explore how my interlocutors sought in various ways to relate to, and gain control over, the temporalities of death and dying in response to the values ascribed to the end of life with dementia.

In the first chapter, I elaborate on the normative framing of life with dementia as “not worth living.” The objective of this chapter is twofold. First, I demonstrate that efforts to influence the timing of death are premised on the value attributed to life. When life is seen as undignified, family members tended to consider death more acceptable and to take decisions to no longer actively prolong life and in some cases even to hasten death. Second, in focusing on the narratives and experiences of family members, I show how their welcoming of death did not arise from ill intentions or neglect but can be seen as a form of care that brings relief from suffering.

In chapter two, I address a request for euthanasia as a mode of anticipation through which my interlocutors sought to gain control over an unwanted future as well as the timing of death. This projection of an unwanted future is based on negative imaginaries of life with dementia and experiences of cognitive decline and loss of autonomy. Timing euthanasia with dementia is however extremely difficult, which led to temporal modes of being either “too early” or “too late,” and often the deferral of established boundaries. Elaborating on the anticipatory work done in the process of requesting euthanasia, I show that anticipation is a process of establishing, collapsing, and renegotiating the temporal distance between present and future. I argue that anticipation brings the

future into the present while at the same time maintaining it at a distance, as something that is “not yet.”

In chapter three I discuss a specific case in which anticipation was not possible and death occurred suddenly and unexpectedly. This created friction between different perceptions of the “good,” as reflected in care workers’ attempts to provide “humane” care, and the procedures stipulated in the nursing home protocol. While highlighting how dying is both infused with moral deliberations and a matter of paperwork, protocols, and standardized procedures, I show how in this case both care practices and protocols encompassed notions of good care and a good death. However, these came to compete and exclude one another, producing moral distress and forming contested relations. I conceptualize such potentially harmful outcomes as a fallacy of care. Recognizing such fallacies is a matter of acknowledging not only the “bad” that may result from “good” care but also the frictions that can arise between multiple “goods.”

The fourth chapter offers a methodological reflection on doing ethnographic research on death and dying, exposing some of my own discomforts and illuminating how I also engaged in anticipation during fieldwork, seeking, as family members did, to know of and prepare for the death of a resident. Sensitive moments such as family conferences, wherein continuing or discontinuing treatment is discussed, or when sitting by a dying person’s bedside with family members, call into question the positionality of the researcher and research ethics. I frame this reflection with the metaphor of the doorstep, which came to symbolize the emotional and methodological negotiations of proximity and distance, involvement and detachment.

Finally, in the conclusion, I come back to the overarching concern of the entanglement of time and value at the end of life with dementia, reiterating the point that managing death and dying is, in a way, about future-making, even if this future is finite and foreclosed. Drawing upon the preceding chapters, I present recommendations for future research and practice.