

## Conclusion

### Time, Value, and Death

It's twelve o' clock and residents are being gathered for lunch. On the far left end of the table sits an elderly woman with gray hair. Our eyes meet, and she smiles and asks: "What are you doing?" as I was just making some notes at the kitchen counter. I respond that I am a researcher and that I will be spending some time with them. To which she says: "Oh, but you wouldn't write anything bad about us, would you?"

This encounter has stayed with me throughout my research, reminding me that the words I write are about real people's lives, and of the importance to do justice to the stories and experiences they shared with me. I have in this dissertation been in search not only of a way to understand the loss my interlocutors experienced but also how to write about it in a way that goes beyond the stereotypical imaginaries of dementia.

My interlocutors often referred to life with dementia as a life that was undignified, or was expected to become undignified in the future, as the person with dementia was perceived to gradually lose their grip on life and self. In this dominant discourse, which resonates with negative representations of people with dementia in policy and media, life with dementia was often construed as a life not worth living. More positive accounts of how to live well with dementia tend to be disregarded, which means that negative imaginaries of dementia have a significant impact on how death with dementia is anticipated and experienced. Based on eighteen months of ethnographic research in nursing homes and interviews in the home setting, I have sought to present a different, more nuanced narrative of dementia, without romanticizing it, by unravelling the complexities and contradictions in experiences of decline and loss.

In *Timing Death: Entanglements of Time and Value at the End of Life with Dementia in the Netherlands*, I have elaborated on how people with dementia, their family members, and professional caregivers sought to navigate, negotiate, and exert control over death and dying with dementia. These efforts, I have shown, constitute a striving toward a good death. In this research I addressed the questions of how life, death, and the future with dementia are imagined, valued, and anticipated in striving toward a good death, and what this reveals about the entanglement of time and value at the end of life. I have demonstrated that the moral evaluation of death—the extent to which it may be considered “good”—is dependent on the value ascribed to life and to experiences and projections of time. I have argued 1) that the management of the end of life is future-oriented, as it involves living toward death by constructing and acting upon images of the future, and 2) that in the entanglement of time and value, attempts to make sense of and influence the temporal dimensions of dying can change how life and death are valued. My aim, ultimately, is to underscore the intertwinement of the evaluations of life, death, and time.

## **Finitude and Future-Making**

This research sheds light on experiences of being toward death, how time is perceived and adapted in the process of dying, in the specific context of dementia—a context that has its particular configurations of duration, timing, and futurity. I was struck, during fieldwork, with how *future-oriented* many of the narratives I heard, and the end-of-life care practices I observed, often were. People with dementia, their family members, and professional caregivers were constantly speculating about and anticipating the future with dementia and the end of life. This sometimes involved grand gestures of establishing advance directives or a euthanasia request, but was more typically a part of everyday life, conversations, and caregiving. Even mundane conversations were saturated with references to the future. Also professional caregiving—and palliative care in particular—was infused with expectations of future

needs and estimations of the nearness of death, as much as it was based on observations of the person's condition in the present.

In my approach, I have followed debates in the anthropology of time that seek to understand not what the future *will* be, but how constructions of the future are produced and acted out in the present (Bryant 2016; Bryant and Knight 2019; Ringel 2016, 2018). Past and future are closely tied together and find expression in the present (Munn 1992), but not necessarily in a linear chronology (Nielsen 2011). As illustrated in how my interlocutors drew on previous experiences with dementia in how they envisioned the future (chapters one and two), and how the death of a nursing home resident evoked previous personal losses for care workers (chapter three), the present became intertwined with the future and evoked past experiences. The anthropology of the future that I have presented, in this sense, is as much concerned with understanding the present as with understanding the times to come.

Furthermore, I have suggested that the relation between the future and the present can be negotiated. I have paid particular attention to anticipation, through which the future with dementia is brought into view and given concrete form in the present. Not only does anticipation bring the future into the present, as various authors have suggested (Adams, Murphy, and Clarke 2009; Bryant and Knight 2019; Clarke 2015), it also involves, as I argue in chapter two, a dynamic of both drawing the future nearer *and* of holding it off. Drawing the future nearer, my interlocutors actively formulated images of the future and allowed it to infuse the present as they acted upon it. In other words, through anticipation, the future legitimizes the present (Adams, Murphy, and Clarke 2009). This is true even to the extent that future suffering can become suffering in the present. Anticipating a fearful, unwanted, and foreclosed future means being affected by it, living toward it, even if dreading to do so. When my interlocutors held the future off, they repeatedly had to adjust their own projections as the illness changed. This included maintaining that the imagined future had “not yet” arrived, effectively prolonging the present to keep the future at bay. The deferral of established boundaries for the moment of euthanasia, for example, is a clear point at which the temporal distance between the future and the

present is negotiated and renegotiated. Another instance of this may be seen in cases where death was welcomed, which conveys an acceptance that the future *as* death will become a reality, and entails a hope that this future will arrive sooner rather than later. Hence, a future-as-finitude is drawn nearer, but in doing so the unwanted future with dementia, conceived of as a future-in-suffering, is kept at bay or avoided altogether. Anticipation, I have suggested, involves an attempt to gain control over the future—aligning with the value placed on maintaining autonomy at the end of life—and to adjust its temporal distance by bringing imagined horizons into the present while also holding them at a distance. How the future is anticipated—how my interlocutors oriented themselves toward the future, constructed images of it, sought to influence it, waited for it, postponed it, and acted it out—I emphasize, reveals much about how life and death with dementia are valued and how this plays out in people’s daily lives.

While others (e.g., Bryant 2016; Nielsen 2011; Ringel 2014, 2018) have demonstrated that the relationship between present and future is not always linear, I have focused on experiences of time in a frame of finitude (cf. Irving 2017); this has allowed me to demonstrate that future-making is not necessarily ongoing and open-ended, but also works to define endings. The future that is the subject of this dissertation is of a particular kind. As I have shown, my interlocutors related to a future that is imagined as unwanted, feared, and uncertain, as well as foreclosed and finite. Nearly without exception, the future was imagined as worse than the present. Already in early stages of the illness, people with dementia and their family members formulated projections of the process of decline, foreseeing an ending “in a fetal position” when there would be “nothing left,” before, eventually, death. In this way, the most negative images of the end of life with dementia were brought into view in the present, where, construed as the impending future, they demanded action and preparation. With this negative imaginary, people with dementia and their family members braced themselves for what they considered was still to come, seeking ways to postpone the inevitable and holding on to what was still possible. Alternatively, they sought ways to

avoid future decline and its associated loss of dignity in welcoming, and sometimes hastening, death.

From Kafer's (2013) work, I have drawn the insight that the normative, ableist image of the rational human subject that frames much of the experience of life with dementia, also produces a foreclosed image of the future, or the idea that there is no future at all. In these images, the future becomes very narrowly defined, limiting the possibility of alternative experiences and imaginaries. I observed that there was very little room in the narratives and experiences of my interlocutors for positive, optimistic views of the future, which was dominated instead by images of deterioration, suffering, and loss. Nevertheless, as the chapters in this thesis show, people with dementia, family members, and professional caregivers were invariably involved in estimating and anticipating the future as part of the temporal and moral project of achieving a good death. My interlocutors paid much attention to the future in an effort to get a grip on the course of decline and eventual death. In many instances, death itself was seen as a relief to suffering that would put a limit on the unwanted future. As such, the future with dementia also required coming to terms with finitude. My interlocutors placed great importance on the expected moment of dying and were until the person's very last breath concerned with a moment that was still to come. Still, this did not necessarily culminate in fatalism. Rather than accepting the looming future as destiny, my interlocutors were actively involved in shaping it and the process of dying.

Furthermore, perceptions of the person with dementia as "already gone" but also "still here"—the "gray zones" between life and death (Kaufman 2005, 2006)—reflect a temporal confusion in which projected loss is experienced as occurring before its time or the person's continued presence as superseding the normal order of time. Loss and grief, then occurred not only after the moment of death, but throughout the process. In this anachronistic experience of dementia, the end of life comes near while also remaining at a distance. Much of the ambiguity in the experience of dementia has to do with this uncomfortable collapse of future and present.

## Temporal and Moral Projects

This thesis suggests that achieving a good death with dementia is both a temporal and a moral project. The temporalities of death and dying matter to how a death might be considered “good,” as does the moral value ascribed to a life with dementia. In seeking to address both time and value, I have built on studies that, in different ways, critically address the question of the differential valuing of lives and deaths at the margins of society (Biehl 2005; Butler 2006; Kaufman 2005, 2006; Rose 2007; Stevenson 2014), as well as on studies situated in debates on the anthropology of time that ask how time is experienced, inscribed with meaning, and influenced, particularly in relation to the future (Bear 2016; Bryant and Knight 2019; Kafer 2013; Munn 1992; Nielsen 2011; Ringel 2016). This resonates with works that address the pursuit of a good life or self in everyday life and in unfolding temporalities (Garcia 2010; Han 2012; Mattingly 2014; Robbins 2004). My use of moral value, following Mattingly (2014), is not to determine to what extent people are (or do) “good,” but to highlight that the people involved in the end of life with dementia all take part in evaluating life and death in moral terms. They are all concerned with how to maintain the dignity and worthiness of life with dementia, and in negotiating how to facilitate life and death as well as possible. I have followed this thread further in exploring the pursuit of a good death in a context where the value of life itself is put under pressure. This ethnography makes clear that the moral evaluation (often devaluation) of life infuses how people with dementia, their family members, and professional caregivers relate to and act upon time. Their experiences and projections of time, in turn, influence the value ascribed to living and dying with dementia.

As the chapters in this dissertation illustrate, the entanglement of time and value can take various forms. It became especially apparent when my interlocutors sought possibilities to hasten death. Bringing death into view as a pending future, and seeking to bring this future closer to the present by negotiating the possibilities of (withholding) treatment or by requesting euthanasia, effectively formed an intervention in this perceived loss of dignity by means of working with the timing of death. Expressions such as “on time,” “too early,” “too long,” and “too

quickly” point to the experience of time at the end of life, as well as to underlying processes of evaluation. Sudden, unexpected death was often framed as an ideal way of dying, without protracted suffering and without an anticipatory confrontation with death. But being deprived of the possibility to anticipate death, could also, as discussed in chapter three, be distressing to family members and care workers who encountered a loved one or resident who died without forewarning and who thus had no chance to say a proper goodbye. In many cases, my interlocutors sought ways to spend the time they “still had”—the days and weeks lived in anticipation of death when time was considered precious and running out—in a meaningful way. For some, this period of vigil was infused with feelings of powerlessness and discomfort and experienced as simply waiting. To support family members during such moments, care workers in several nursing homes in the Netherlands composed a *waakmand*, a “vigil basket” with items such as hand cream to massage the hands of the dying person, CDs, scented candles, and crossword puzzles, both to comfort the resident and for family members to occupy themselves at the bedside. When death finally occurred, family members and professional caregivers not only evaluated it in terms of a moral “good” but also in terms of timing, whether death had come at the “right” time. Throughout, my interlocutors were assessing, negotiating, and reaffirming the value of life and death in light of their experiences of time and by adjusting their own temporal orientations.

My interlocutors sought to get a grip on time, narrating the trajectory of decline with dementia in an attempt to understand and estimate its projected course. In this way, “time-reckoning,” the activity of “telling” and “measuring” time (Munn 1992), was central to my interlocutors’ experiences and narratives at the end of life. However, they were not only observing and estimating time, but also engaging in a form of “time-tricking” (Moroşanu and Ringel 2016), which refers to attempts to influence the temporal dimensions of life and, in this case, death. My interlocutors sought to speed up and slow down processes; timed and planned future events, bringing them closer to or further from the present; and mingled past experiences with future imaginaries to decide how to act in the present. Time-tricking and time-reckoning—two

concepts through which anthropologists have conceptualized people's relationship to, and agency in, time—as I have shown in this thesis, are not just about temporalities but also about the value of life itself. Reiterating part of my main argument, the different ways of making sense of and influencing the duration, speed, and significance of temporal aspects of dying, can change how life and death are valued. Bringing the future closer allowed my interlocutors a sense of control over the course of decline and the dying process, and was associated with the maintenance of dignity, while holding the future at bay could serve to postpone a projected loss of dignity and associated devaluation of life. Attempts to slow down the dying process could allow for a proper goodbye, while speeding it up could relieve suffering in the pursuit of a good death. As such, temporal orientation and moral evaluation together play a central role in striving for a good death. To put this differently, time at the end of life with dementia becomes a vehicle through which value is attributed to life, dying, and death. This involved building on past experiences, much anticipatory work, and continuous adaptation to changing circumstances.

## **Notes on Striving Toward a Good Death**

I have in this dissertation argued that managing the end of life with dementia is a future-oriented project in which time and value are closely tied together. Throughout, the notion of the good death has featured as a backdrop. The insight that the good death is the main objective of this future-making endeavor, here requires some nuance. Therefore, I present here a few notes on the implications, as well as complications, of what I have called “striving toward a good death.”

First, as discussed in the Introduction, I have approached the good death as a normative frame; it presumes an autonomous, rational human subject who can make decisions regarding the end of life, and circumstances of dying free of suffering and in the familiarity of the home. Dementia poses challenges to this ideal, as it can imply a loss of autonomy, is commonly associated with physical as well as existential suffering, and in most cases—at least in the Netherlands—involves



institutionalization. Rather than assuming that a good death with dementia would then be impossible, I asked how a good death is *strived for* in the context of dementia, and have shown that, in the face of these challenges, my interlocutors sought ways to facilitate dying as well as possible.

Second, I have stressed that death gains substance and meaning in relation to the value of life. I have shown from different angles how my interlocutors struggled with the good death: how they welcomed death in light of the perceived devaluation of life with dementia (chapter one), how they sought to anticipate and maintain control over it by requesting euthanasia (chapter two), and how they sought to do good even if this did not always play out well or conflicted with institutional systems (chapter three). Each instance reflected views pertaining to a perceived loss of dignity of the dying person, a form of existential suffering, but also showed attempts to humanize, to engage, and to care.

Third, as I outline in chapter three, different visions of the good death can coincide and clash. Managing the end of life in pursuit of a good death does not simply imply caring for the dying person; it also means taking into account systems and forms, the views and needs of family members and care workers, and the wishes and preferences of the person with dementia. Clearly, there are many versions and views of what a good death is and how it should be reached. While the notion of the good death thus raises the question “Good for whom?” (Howarth 2007), these chapters illustrate that approaches to a good death are *negotiated* among people with dementia, family members, professional caregivers, and institutional frameworks. And as I have underlined, individuals themselves can also have contradictory aims. While many people with dementia sought ways to control, or at least influence, the manner and timing of death, they also felt uneasy about knowing its concrete moment and often mentioned they would prefer a “natural” death, a death that occurred without their interference, and preferably in their sleep—the ultimate relinquishment of control and anticipation. Also many family members faced such contradictions, as they both wished to keep the person with dementia with them as long as possible and simultaneously welcomed death as a relief.

Fourth, while I have in this thesis shown how death was in some cases welcomed or hastened, and underlined that this is related to a certain devaluation of life with dementia, this is not to say that death in the context of dementia is easy or treated casually. Even if attempts are made to hasten death and it is more or less explicitly evaluated as a “good death,” it still can entail loss, grief, and struggle. This also has implications for theorizing the moral evaluation of life and death. I have approached the question of “lives worth living” as a question of valuing: a moral evaluation in relation to normative ways of apprehending life and death. In this approach I have built on Butler’s (2006) work wherein she draws an important distinction between apprehending the person as living, and recognizing their life as *a* life—a distinction between a devalued and a full life. I have seen this distinction at play in this research, as life with dementia was at times considered not worth living. However, Butler also argues that failing to recognize certain lives as lives that matter renders them “ungrievable.” This was not the case in my research: the devaluation of life with dementia did not necessarily make that life ungrievable. To the contrary, grief was very much present and part of the process of the end of life with dementia. The temporality of this process is such that along a protracted and gradual process of decline, my interlocutors were intermittently confronted with multiple losses. Consequently, grief was protracted and directed at current losses as well as at anticipated losses to come. Also the moment of death itself was surrounded by mourning rituals and emotionally charged with a mixture of sadness and relief. In other words, the willingness to let go of someone, a close relative in most cases, did not preclude grieving that loss. The striving for a good death that I have described in this dissertation precisely balances upon this point: even when life was seen as “already lost,” the person was not abandoned or disregarded but instead the object of much effort to maintain their moral value in life and death.

Finally, there are limits to the extent to which the process of dying can be controlled or anticipated. Even though my interlocutors were oriented toward the future in aspiring for a good death, the end of life was also elusive in that it remained hard to direct or predict. While

people sought to navigate this process to the best of their abilities, death in practice was often a messy process, which also means striving for the “good” is not linear or unambiguous, but a rather disorderly process.

### **Further Research and Implications for End-Of-Life Care**

In line with my exploration of how time is valued, it would be interesting to investigate in future research how time in the nursing home is indicated and structured through materiality, and ask how temporal rhythms and experiences are enabled or restrained in the materiality of the nursing home in all its care tools, administrative forms, and household items. The question of how time is organized through everyday activities, rhythms, and habits also merits more detailed analysis. Furthermore, as I have focused in this dissertation on how people with dementia, family members, and professional caregivers sought to hasten or delay the timing of death, this also raises questions regarding how people seek to influence the temporal aspects of dementia itself. How do people in early stages of the disease, or even before diagnosis, seek to delay a future with dementia? How are memory training, food consumption, and medication used to postpone an unwanted future with dementia?

During the course of this research, I observed changes and improvements take place in the nursing home. I cannot be certain to what extent this was due to my presence and conversations about end-of-life care, and could thus be attributed to the processual impact (Wahlberg, Lex, and Vigh 2018) of this research, or if these changes occurred independently of the research, since nursing home care is continuously changing and looking to improve. In one of the nursing homes where I did my fieldwork, for example, a palliative care coordinator was appointed, in order to put the topic of palliative care higher on the agenda; refurbishment plans for the home included a family room for family members to have a private space to stay near the dying person.

In terms of policy, I would stress the need to integrate current developments in end-of-life care better into the context of dementia. The

end of life, as apparent in this research, is a central aspect in the experience of dementia and the care provided. Currently, the knowledge of and experience with palliative care varies significantly between nursing homes and between individual care workers. A better integration of palliative and dementia care could allow care workers to receive more support and training in palliative care, as well as foster sharing and integrating knowledge between care workers and institutions. To achieve this, a more direct link could be made between dementia and palliative care policies, most notably the Deltaplan Dementie, the Dutch national policy regarding dementia, and the Kwaliteitskader Palliatieve Zorg, the state policy in which palliative care is discussed.

Finally, as I have argued in this dissertation, time plays a central role in achieving a good death. Related to this, time is of essence in the provision of good end-of-life care. Professional caregivers often expressed a serious lack of time. Hence, I believe it is important that time in end-of-life-care is not treated as a scarce resource that needs to be reported in lists and forms, so as to account for time spent, but as something to be fostered and made: time to be at the dying person's bedside, time to support family members and to listen to their experiences, and time for the ordinary actions and interactions that cannot be measured. Related to this, care workers also voiced a need to talk about the end of life and to share experiences among colleagues. While this sometimes happened informally in and between shifts, it is an important aspect of caregiving that deserves greater attention and dedicated time. Time is at the core of improvements to end-of-life-care and the possibility to achieve a good death.