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Summary

This dissertation explores the entanglements of time and value at the end of life with dementia in the Netherlands. The end of life with dementia is often negatively imagined and associated with a loss of dignity. As such, the moral value that is attributed to life and death with dementia is at stake. Interested in what people with dementia, their family members, and professional caregivers found important at the end of life, I explored how they sought to achieve a good death. In this thesis, I show that the intertwinement of time and value played a crucial role in this process. Temporal experiences such as waiting, enduring, prolonging, and hastening all impacted how life and death were valued in moral terms. Future orientations in particular mattered, as attempts to reach a good death seemed to constantly involve living in a state of anticipation. To look at how time and value come together in the management of the end of life with dementia, I posed the following main research question:

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

To answer this question, I conducted eighteen months of ethnographic fieldwork in nursing homes in the Netherlands and additional in-depth interviews in the home setting. In the thesis, I focus on the narratives and experiences of people with dementia, their family members, and professional caregivers. Contributing to current debates in the anthropology of time, medical anthropology, and death studies, I argue that the pursuit of a good death with dementia is both a temporal and moral project.

In this inquiry, I conceptualize the good death as an idealized objective that substantiated the narratives, decisions, and actions of my

interlocutors. As frictions often emerge between this ideal and the reality of dying in the context of dementia, I ask how the good death is aspired, facilitated, and negotiated. I demonstrate that the moral value ascribed to death with dementia—the extent to which it may be welcomed or considered good—is rooted in the value ascribed to life with dementia. Negative imaginaries and public discourses of dementia, which are based on ableist norms that exclude people with reduced cognitive and physical capacities, can be dehumanizing and thus affect the moral evaluation of the end of life. Certainly, the perception of life with dementia as being undignified, or even as a state between life and death, underpinned the extent to which my interlocutors welcomed death and in many cases was identified as the motive behind euthanasia requests. Further, I show that achieving a good death is subject to a range of temporal experiences and orientations. My interlocutors sought ways to exert control over the process of dying by influencing its temporal aspects, which became particularly prominent in their efforts to either stave off or hasten death. The future takes on particular importance in this process, as much anticipatory work is done in aspiration of a good death. Managing the end of life then became matter of producing and acting upon possible, alternative, or sometimes unwanted futures, while maintaining a constant orientation towards the projected moment of death.

With this thesis, I aim to offer an in-depth understanding of both how people may become oriented toward death, and the importance of time and future-making in how the end of life with dementia is managed. Chapter 1, *Moral Frames for Lives Worth Living: Managing the End of Life with Dementia*, disentangles the construction of the end of life with dementia as “not worth living” and its relation to the welcoming of death. I demonstrate that the efforts of my interlocutors to influence the timing of death were premised on the value they attributed to life. Family members often associated the end of life with dementia with a loss of dignity and perceived it as a *lijdensweg* (literally a “pathway of suffering”), and sought relief to this suffering by negotiating the timing of death. They then tended to consider death to be more acceptable and sought control over the manner and timing of death. I then proceed to demonstrate that death was welcomed above all as a relief to suffering.

Although the creation of a category of lives that are narrated as “allowed to die” is problematic, this occurs not in a form of abandonment or indifference. Rather, in focusing on the narratives and experiences of family members, I argue that their welcoming of death does not arise from ill-intended neglect but can be seen as a form of care that brings relief from suffering. Death may be welcomed precisely because the person with dementia still matters, and it is accompanied with grief, sadness, and feelings of powerlessness as well as relief.

In chapter 2, *Anticipating an Unwanted Future: Euthanasia and Dementia in the Netherlands*, I explore the dynamics of anticipation by analyzing the process of requesting euthanasia in the context of dementia. I highlight that people with dementia requested euthanasia as a way to cope with an unwanted future with dementia. This unwanted future haunted the present through fearful anticipation, threatening the worthwhileness of life itself. As such, the possibility of euthanasia became associated with the possibility of a death on their own terms and without further degeneration. While euthanasia has been legalized in the Netherlands, meeting the legal criteria can be challenging in the context of dementia. Also its timing is extremely difficult due to the deferral of established boundaries of when to proceed with euthanasia. My interlocutors were then confronted with a temporal challenge of being either “too early”—when the person can still confirm the request but has not yet reached the point where they would want euthanasia—or “too late”—when the person has reached a point they would have considered undignified but have become unable to confirm the request for euthanasia. The efforts that go into planning and negotiating the request between people with dementia, their family members, and professional caregivers, offer insight into the work of anticipation as a temporal mode through which the future is made tangible. In this process of establishing, collapsing, and renegotiating the temporal distance between present and future, I argue, 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 3, *Competing Goods and Fallacies of Care: Moral Deliberations at the End of Life in the Nursing Home*, I discuss a case in which the death of a nursing home resident occurred unexpectedly. Unable to anticipate

this moment, the ad hoc response of care workers, who lifted him from the floor onto his bed, reflected their concern with maintaining the dignity of the deceased. However, their response conflicted with nursing home protocol, which represented institutional demands for regulation and standardization, and stipulated that the body of the deceased should only be moved with explicit permission. While this highlights how dying is both infused with moral deliberations and subjected to paperwork and protocols, it also reveals how the very question of what is “good” may become unsettled. I analyze this as a fallacy of care, showing that recognizing such fallacies is a matter of recognizing not only the potentially harmful outcomes that may result from “good” care but also the friction that can arise between multiple “goods.” In this case, both care practices and protocols encompassed notions of good care and a good death, but these competed with and excluded one another. This produced moral distress, as acting upon one “good” produced an undesirable outcome for the other.

Chapter 4, *Standing at the Doorstep: Affective Encounters in Research on Death and Dying*, offers a methodological reflection on some of the emotional and moral aspects of ethnographic research on death and dying. By taking a close look at my own attunement to interlocutors and situations during fieldwork, I aim for a better understanding of the affect that comes with ethnographic encounters, and of how emotions feature in the ways ethnographers can position themselves in the field. Focusing on moments in fieldwork that required a particularly sensitive approach, discussing also some of my own discomforts and how I was affected by the research, I illustrate also more general implications of doing research in a delicate context such as the end of life. I reflect on how I navigated this and how, similar to family members, I engaged in anticipatory work to prepare for the death of a resident, highlighting also the difficulty of having to inquire about future losses. I frame this discussion through the metaphor of the doorstep, which came to symbolize the process of negotiating proximity and distance, involvement and detachment.

In the conclusion, I return to the overarching theme of this dissertation, namely the entanglement of time and value, and come back to the argument 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. 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, not only in terms of a moral “good” but also in terms of its timing—whether death came at the “right” time. Having shed light on how time is perceived and adapted in the process of dying with dementia, I argue 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. I underline, further, that future-making is not necessarily open-ended but it also works to define endings; that there are limits to how much the process of dying can be controlled or anticipated; and that the experience of the end of life with dementia entails negotiating with loss and grief. In the context of these challenges, the striving for a good death can be seen as an effort to maintain the moral value of the person with dementia in life and death.

Samenvatting

Dit proefschrift gaat over de verwevenheid van tijd en morele waarde bij het levenseinde met dementie in Nederland. Vaak gaat het levenseinde met dementie gepaard met negatieve beeldvorming en wordt het geassocieerd met een verlies van waardigheid. Zodoende komt de morele waarde die wordt toegekend aan het leven en sterven met dementie op het spel te staan. Vanuit mijn belangstelling voor wat mensen met dementie, hun familieleden, en zorgverleners belangrijk vonden bij het levenseinde, onderzocht ik hoe zij een goede dood probeerden te bereiken. In dit proefschrift laat ik zien dat de verwevenheid van tijd en waarde bij dit streven een cruciale rol speelt. Temporele ervaringen zoals wachten, verduren, bespoedigen, en afhouden beïnvloeden hoe het leven en de dood in morele zin worden gewaardeerd. Met name een oriëntatie naar de toekomst is van belang: pogingen om een goede dood te bereiken hangen samen met een constante staat van anticiperen. Om meer inzicht te krijgen in hoe tijd en waarde samenkomen in het vormgeven van het levenseinde met dementie, heb ik de volgende onderzoeksvraag geformuleerd:

Hoe worden het leven, de dood, en de toekomst met dementie verbeeld, gewaardeerd, en geanticipeerd in het streven naar een goede dood—en wat laat dit zien over de verwevenheid van tijd en waarde bij het levenseinde?

Om deze vraag te beantwoorden heb ik achttien maanden etnografisch veldwerk gedaan in verpleeghuizen in Nederland en diepte-interviews gehouden bij mensen thuis. Ik richt me op de verhalen en ervaringen van mensen met dementie, hun familieleden en zorgverleners. Ik beargumenteer dat het streven naar een goede dood met dementie zowel een temporeel als moreel project is, en draag daarmee bij aan hedendaagse debatten in de antropologie van tijd, medische antropologie, en dood studies.

Ik conceptualiseer de goede dood als een geïdealiseerde doelstelling die een onderbouwing geeft aan de verhalen, beslissingen, en handelingen van mensen met dementie, familieleden, en zorgverleners. Aangezien er vaak wrijvingen ontstaan tussen dit ideaal en de realiteit van het levenseinde, stel ik de vraag hoe men een goede dood nastreeft, faciliteert, en erover onderhandelt. Ik laat zien dat de morele waardering van de dood—de mate waarin de dood wordt verwelkomd of als goed wordt gezien—samenhangt met de waarde die aan het leven met dementie wordt toegekend. De negatieve beeldvorming van mensen met dementie in het publieke debat, die vaak gebaseerd is op een normatieve uitsluiting van mensen met verminderde cognitieve en fysieke capaciteiten, kan dehumaniserend werken en zodoende de morele waardering van het levenseinde beïnvloeden. Zeker een perceptie van het leven met dementie als onwaardig, of zelfs als een staat van zijn tussen leven en dood, beïnvloedt de mate waarin het levenseinde verwelkomd wordt en vormt in veel gevallen ook het motief achter het aanvragen van euthanasie.

De mensen met dementie, familieleden, en zorgverleners in dit onderzoek zochten naar manieren om controle te behouden over het stervensproces door temporele aspecten ervan te beïnvloeden. Ik laat hiermee zien dat temporele ervaringen en oriëntaties van invloed zijn op het bereiken van een goede dood. Dit wordt vooral duidelijk in hun pogingen om de dood dan wel af te houden of te bespoedigen. De toekomst speelt hierin een belangrijke rol, aangezien er veel anticiperend gehandeld wordt in het streven naar een goede dood. Het vormgeven van het levenseinde wordt dan ook een kwestie van het creëren van—en handelen naar—mogelijke, alternatieve, en soms ongewenste toekomsten, vaak gericht op het verwachte moment van sterven.

Met dit proefschrift bied ik inzicht in hoe mensen zich komen te verhouden tot de dood, en in het belang van tijd en toekomst in hoe het levenseinde met dementie wordt vormgegeven. Hoofdstuk 1 bespreekt wijzen waarop het levenseinde met dementie als onwaardig wordt gezien en hoe dit zich verhoudt tot het verwelkomen van de dood. Ik laat zien dat de pogingen die familieleden deden om de *timing* van de dood te beïnvloeden gemotiveerd werden door de waarde die zij toekenden aan

het leven. Familieleden associeerden het levenseinde met dementie vaak met een verlies van waardigheid en zagen het als een lijdensweg. Zij neigden meer naar acceptatie van de dood, en zochten verlossing van dit lijden door controle uit te oefenen over de manier en *timing* van het sterven. Hoewel het problematisch is bepaalde levens te construeren als levens die “mogen sterven”, komt dit niet voort uit onverschilligheid. Door me te richten op de verhalen en ervaringen van familieleden beargumenteer ik juist dat het verwelkomen van de dood niet voorkomt uit slechte intenties of nalatigheid, maar als een vorm van zorg gezien kan worden. De dood wordt verwelkomd juist omdat de persoon met dementie er nog toe doet, en gaat, naast een gevoel van verlossing, gepaard met rouw, verdriet, en machteloosheid.

In hoofdstuk 2 onderzoek ik de dynamiek van anticiperen in het aanvragen van euthanasie door mensen met dementie. Ik belicht dat mensen met dementie vaak euthanasie aanvragen omdat ze een toekomst met dementie zien als een bedreiging van de waardigheid van hun leven. Door te anticiperen komt ook de tegenwoordige tijd in het teken te staan van de ongewenste en beangstigende toekomstverwachting. De mogelijkheid om euthanasie aan te vragen werd veel geassocieerd met een mogelijke dood onder hun eigen voorwaarden en zonder verdere achteruitgang. Echter, hoewel euthanasie in Nederland legaal is, blijft het in het geval van dementie erg moeilijk om te voldoen aan de zorgvuldigheidseisen. Met name de *timing* van euthanasie is zeer gecompliceerd doordat mensen vaak hun reeds vastgestelde grenzen verleggen. Mensen met dementie, hun familieleden, en artsen, worden geconfronteerd met de temporele situatie waarin euthanasie dan wel “te vroeg” (wanneer de persoon met dementie de aanvraag nog kan bevestigen maar nog niet het punt heeft bereikt waarop zij euthanasie willen) of “te laat” (wanneer zij een punt bereiken dat zij als onwaardig zouden hebben beschouwd maar waarop zij niet langer in staat zijn de aanvraag te bevestigen) aangevraagd zou moeten worden. De inspanning die het kost om op deze toekomst te anticiperen wordt duidelijk in de onderhandelingen omtrent het plannen van euthanasie. In dit proces wordt de afstand tussen heden en toekomst steeds opnieuw vastgesteld, ingekort, en uitgerekt. Ik betoog dan ook dat anticiperen een manier is

om de toekomst tastbaar te maken en naar het heden te halen, maar die tegelijkertijd ook op afstand te houden, als een tijd die er “nog niet” is.

In hoofdstuk 3 bespreek ik een casus waarin de dood van een verpleeghuisbewoner onverwachts plaatsvond. De zorgmedewerkers hadden niet op dit moment kunnen anticiperen, en hun ad hoc reactie was de overleden man van de vloer te tillen en in zijn bed te leggen, wat hun bezorgdheid om zijn waardigheid liet zien. Hun reactie ging echter in tegen het verpleeghuisprotocol, waarin stond dat het lichaam van een overledene alleen verplaatst mocht worden met expliciete toestemming. Terwijl dit geval belicht hoe het sterven zowel doordrongen is van morele overwegingen als onderhevig is aan papierwerk en protocollen, laat het ook zien hoe de fundamentele vraag wat “goed” is ontworcht kan raken. Ik analyseer dit als een drogreden van zorg, en laat daarmee zien dat het herkennen van zulke drogredenen niet alleen mogelijke schadelijke gevolgen van “goede” zorg blootlegt, maar ook de wrijving die kan ontstaan tussen verschillende vormen van “het goede”. In dit geval bevatten zowel de zorgpraktijk als het zorgprotocol een opvatting over goede zorg en een goede dood, maar deze verschillende interpretaties van het goede sloten elkaar uit en concurreerden met elkaar. Dit zorgde voor morele onrust, waarin handelen naar de ene interpretatie van het goede inherent de onwenselijke uitkomst van de andere veroorzaakt.

Hoofdstuk 4 presenteert een methodologische reflectie op een aantal emotionele en morele aspecten van het doen van etnografisch onderzoek naar het levenseinde. Door te reflecteren op hoe ik me tot onderzoeksparticipanten en -situaties heb verhouden, bied ik inzicht in het affect dat met etnografische ontmoetingen gepaard gaat en in de rol die emoties spelen in de positionering van etnografen in het veld. Door in te gaan op mijn eigen momenten van ongemak en de impact die het onderzoek op mij heeft gehad, illustreer ik meer algemene implicaties van het doen van onderzoek in gevoelige situaties zoals het levenseinde. Ik reflecteer op hoe ik omging met deze situaties en hoe ik me, net als familieleden van mensen met dementie, voorbereidde op het overlijden van verpleeghuisbewoners. Ik gebruik de metafoer van de deurdrempel

voor deze discussie, aangezien de drempel symbool kwam te staan voor de (methodologische) onderhandeling van afstand en nabijheid.

In de conclusie kom ik terug op het overkoepelende thema van deze thesis, namelijk de verwevenheid van tijd en waarde, en ga ik verder in op het punt dat de morele waardering van de dood—de mate waarin deze als “goed” gezien wordt—afhankelijk is van de waarde die aan het leven wordt toegekend en van ervaringen en projecties van tijd. Verschillende betekenissen die gegeven worden aan de temporele aspecten van het sterven, zoals de duur, de snelheid, en het verloop ervan, kunnen van invloed zijn op hoe het leven en de dood gewaardeerd worden, niet alleen in termen van het moreel “goede”, maar ook in termen van de *timing* van de dood—of de dood op het “juiste” moment komt. Na het belichten van hoe tijd ervaren en aangepast wordt in het stervensproces bij dementie, beargumenteer ik dat vormgeven aan het levenseinde toekomstgeoriënteerd is: mensen leven naar de dood toe door toekomstbeelden te creëren en daarnaar te handelen. Ik onderstreep verder dat een ingebeelde toekomst eindigheid kan definiëren; dat er grenzen zijn aan de mate waarin het stervensproces gecontroleerd en geanticipeerd kan worden; en dat de ervaring van het levenseinde met dementie samenhangt met het leren omgaan met verlies en rouw. In het licht van deze uitdagingen, kan het streven naar een goede dood gezien worden als een poging om de morele waarde van de persoon met dementie in leven en in de dood te waarborgen.

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List of Publications

Peer-Reviewed Articles

- 2019 **Lemos Dekker, Natashe**. Competing goods and Fallacies of Care: Moral Deliberations at the End of Life in the Nursing Home. *Journal of Aging Studies* 51.
- 2019 Leibing, Annette and **Natashe Lemos Dekker**. Fallacies of care – a short introduction. *Journal of Aging Studies* 51.
- 2019 Perfect, Devon, Alys W. Griffiths, Miguel Vasconcelos Da Silva, **Natashe Lemos Dekker**, Elizabeth H. Graham, & Claire A. Surr. Collecting self-report research data with people with dementia living in care homes: Benefits, challenges, and best practices. *Dementia: The International Journal of Social Research and Practice*.
- 2018 Borgstrom, Erica, **Natashe Lemos Dekker** and Sarah Hoare. What the social sciences have to offer palliative care. *European Journal of Palliative Care* 25(3).
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- 2017 **Lemos Dekker, Natashe**, Marjolein Gysels and Jenny T. van der Steen. Professional caregivers' experiences with the Liverpool Care Pathway in dementia: an ethnographic study in a Dutch nursing home. *Palliative and Supportive Care*. DOI: 10.1017/S1478951517000645.
- 2017 van der Steen, Jenny T., **Natashe Lemos Dekker**, Marie-José H.E. Gijssberts, Laura H. Vermeulen, Margje M. Mahler, and B. Anne-Mei The. Palliative care for people with dementia in the terminal phase: qualitative studies to inform service development. *BMC Palliative Care*. DOI: 10.1186/s12904-017-0201-4

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- 2020 **Lemos Dekker, Natashe** and Pols, Jeannette. Aspirations of home-making in the nursing home. In *Ways of Home Making in Care for Later Life*, edited by Bernike Pasveer, Oddgeir Synnes and Ingunn Moser (183-201). Palgrave Macmillan.
- 2019 **Lemos Dekker, Natashe**. Standing at the doorstep: Affective encounters in research on death and dying in *Affective dimensions of fieldwork and ethnography*, edited by Thomas Stodulka, Ferdiansyah Thajib and Samia Dinkelaker (201-211). New York: Springer.
- Lemos Dekker, Natashe**. Presence through absence: Experiences of motherhood through political action in Argentina. In *Mothering, time and temporalities*, edited by Abbi McNiven and Rachel Colls. London: Routledge (Studies in Human Geography). Forthcoming.

Other Publications

- 2018 **Lemos Dekker, Natashe**, Erica Borgstrom and Sarah Hoare. Researching end of life care from a social science perspective: Past, present and future directions. *Medical Anthropology Theory*.
- 2018 **Lemos Dekker, Natashe**. "I do want euthanasia, but not now." Timing a request for euthanasia with dementia in the Netherlands. In *Thinking with Dementia*, edited by Kristine Krause, Jeannette Pols, Annelieke Driessen and Emily Yates-Doerr. *Somatosphere*. <http://somatosphere.net/2018/i-do-want-euthanasia-but-not-now-timing-a-request-for-euthanasia-with-dementia-in-the-netherlands.html>.
- 2018 **Amsterdam Care Collective**. 2018. "Dementia and the Good Life: Collaborations with the Field." *Medicine Anthropology Theory*. <http://www.medanthrotheory.org/read/10021/dementia-and-the-good-life>.
- 2017 Vermeulen, Laura, Annelieke Driessen, **Natashe Lemos Dekker**, Els Roding, Silke Hoppe, Susanne van den Buuse, Kristine Krause, Anne-Mei The, and Jeannette Pols. 2017.

- “Goed Leven Met Dementie. Hoe Doen We Dat?” In *Goed Leven Met Dementie: Dialoog Tussen Wetenschap en Praktijk*, edited by Anne-Mei The, Jeannette Pols, and Robert Pool, 14–19. Amsterdam: Ben Sajat Centrum en Universiteit van Amsterdam.
- 2017 **Lemos Dekker, Natashe**. Goed sterven met dementie: Palliatieve zorg in het verpleeghuis. In *Goed leven met dementie: Dialoog tussen wetenschap en praktijk*, edited by Anne-Mei The, Jeannette Pols and Robert Pool. Amsterdam: Ben Sajat Centrum and Universiteit van Amsterdam.
- 2016 **Lemos Dekker, Natashe**. Standing at the bedside, Slam That #Ethnography! – Troubling Fieldwork. <https://allegralaboratory.net/slam-that-ethnography-troubling-fieldwork>.
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