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Anticipating an unwanted future: euthanasia and dementia in the Netherlands

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This ethnographic exploration of anticipation draws on fieldwork among people with dementia and their families in the Netherlands. I examine how requests for euthanasia by people with dementia offer insight into the work of anticipation, revealing it to be a temporal orientation through which the future is made tangible. Imagining a future with dementia may prompt some people to request euthanasia, but timing such measures is extremely difficult and often results in deferral. Contributing to an emerging anthropology of time, I argue that anticipation is a process of establishing, collapsing, and renegotiating the temporal distance between present and future, bringing the future into the present while also, and simultaneously, keeping the future at bay as a continuous ‘not yet’.

‘I do want euthanasia, but not yet’, said Ms Verbeek,¹ after she had taken a sip of her coffee. We sat at her dinner table by the window, looking out onto the street in a small town in the south of the Netherlands. We had been talking about her experiences of living with dementia, her outlook on the future, and the end of life. The topic of euthanasia came up in our conversation, as it often did during my research on the end of life with dementia in the Netherlands, in regard to anticipating an unwanted future. While that future had not yet arrived, it still inhabited everyday life, occupying the present as people with dementia and their family members tried to discern the ‘right’ time to prevent it from happening. The simple phrases ‘but not yet’ and ‘not now’, often uttered by those in the process of requesting euthanasia, were indicative of the difficulties of deciding when euthanasia should happen. This difficulty of finding the *when*, I argue, reveals that anticipation is a continuous process of negotiating the temporal distance between present and future, in which the future is both brought into the present, as demanding action in the now, and pushed away, as something that is not yet there.

Anticipation takes on particular importance as people with dementia orientate themselves towards a future of inevitable cognitive and physical decline that they fear and wish to avoid. The prospect of decline motivates the request for euthanasia, but it is also precisely what threatens the possibility to receive it, as the request must be made before one loses the ability to understand and confirm the request. The problem

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with this is that, at the moment of making the request, the person typically has not (yet) reached the point when they consider life not worth living. In public debates in the Netherlands, this is often referred to as the ‘five-to-twelve problem’, meaning the need to request euthanasia ‘too early’ before it is ‘too late’ (The 2017: 65-6).² In this sense, dementia forms an exceptional condition with regard to euthanasia (Bolt, Snijdewind, Willems, van der Heide & Onwuteaka-Philipsen 2015; Snijdewind, van Tol, Onwuteaka-Philipsen & Willems 2014), showing the difficulties of anticipation as a way of relating to and acting upon an unwanted future.³

Bringing death into view as an impending future, and seeking to bring this future closer to the present via euthanasia, effectively forms an intervention to avoid a perceived loss of dignity. Expressions such as ‘too early’ and ‘too late’ point not only to the experience of time at the end of life but also to underlying processes of evaluation. Analysing discourses on euthanasia with dementia shows one way that people in the Netherlands cope with what they consider the prospect of a life not worth living and the efforts that go into maintaining dignity.

The discussion presented in this article is based on eighteen months of ethnographic fieldwork conducted in 2014 and 2015 in nursing homes in the Netherlands. Although participant observation in the daily life of closed wards included many hours of ‘being there’, I focus here on observations made during healthcare meetings of people with dementia, their family members, and general practitioners (GPs) wherein requests for euthanasia were discussed. I also draw on in-depth interviews with people with early-stage dementia who were living at home and in the process of requesting euthanasia, as well as with their family members, professional caregivers, and spiritual counsellors. Finally, I consider the discussions among a focus group of volunteers for the Dutch Association for Voluntary End-of-Life (NVVE), one of the principal advocates for euthanasia in the Netherlands, which is mainly committed to consultation and lobbying.

I begin with an overview of the recent scholarship in the anthropology of time, in order to give insight into the workings of anticipation as a way of bringing the future into the present. As anticipation is embedded in local value systems, I then briefly consider the Dutch cultural and legal context before turning to my ethnographic accounts. Discussing the image of an unwanted future that dementia evoked for many of my interlocutors, I connect this anticipated future to culturally rooted notions of dignity and control, and show that it builds on people’s previous experiences with dementia. I then turn to the question of how anticipation is ‘done’, by detailing how the unwanted future is acted upon in the interactions of people with dementia and their family members and professional caregivers. In doing so, I show the negotiated nature of this anticipatory process. Finally, by paying attention to deferral – how boundaries of what people consider ‘worth living’ shift in the process of anticipation – I conclude that anticipation should be understood not only as bringing a fixed moment from the future into the present but also as a continuous renegotiation of the temporal distance between that future and the present.

Anticipation and the anthropology of time

Anticipation has mainly been analysed within future studies and in planning and engineering disciplines (e.g. Poli 2010; 2014), only recently becoming of interest in anthropology as part of the so-called ‘temporal turn’. Anthropologists increasingly pay attention to time and temporalities (Bear 2016; Fabian 2014 [1983]; Munn 1992)

and take the future as an object of study (Appadurai 2013; Bryant & Knight 2019; Pels 2015; Salazar, Pink, Irving & Sjöberg 2017). Anthropologists have shed light on alternative ways of being in time that challenge linear thinking, emphasized temporal diversities and inequalities, and attended to temporal forms of agency (e.g. Nielsen 2011; 2014; Ringel 2014; 2018). The present, in these lines of thought, is always already infused with both pasts and futures, in the sense that future orientations as well as past experiences are integral to the meanings of present experiences (Bryant & Knight 2019; Crapanzano 2004; Mattingly 2014; Munn 1992). Working with this scholarship, I stress that anticipation is a particular orientation through which the future is made tangible, making it a valuable conceptual tool through which the relationships among past, present, and future can be further illuminated.

Appadurai (2013) stresses the need to take imagination seriously when studying future-making. The power of imagination becomes clear when considering that a person may request euthanasia in response to an imagined unwanted future with dementia. However, anticipation is more than a temporal imaginary: it involves action (Bryant 2016; Bryant & Knight 2019). Adams, Murphy, and Clarke argue that anticipation is a mode of being in time, 'a way of actively orienting oneself temporally', that may include acts in the name of a future that otherwise could not be legitimized. They also conceptualize anticipation as an 'affective state' (Adams, Murphy & Clarke 2009: 247). As the future comes to inhabit the present, it not only informs actions but is also lived and felt. Ahmed's (2004) work further illuminates how anticipation, as an affective state, can generate possibilities for action. For Ahmed, emotions are essentially about movement: to be affected is not only to be moved but also to be moved in a direction. Emotions, she writes, 'involve (re)actions or relations of "towardness" or "awayness" in relation to ... objects' (Ahmed 2004: 8). To understand anticipation as an affective state, then, means recognizing that the future can generate urgency, anxieties, hopes, and fears, both at the level of individual subjects and collectively (Bryant & Knight 2019).

I build on this body of literature in the anthropology of time, futures, and anticipation to analyse the process of anticipation in requests for euthanasia among people with dementia in the Netherlands. Clarke argues that 'one largely ignored facet of anticipation is how much work it actually takes to "optimize", to "live in preparation", to anticipate – to gather information, calculate, consider, plan, foresee, decide, act, and so on' (2015: 90). This insight has prompted me to look in detail at *how* the future is anticipated through a euthanasia request, to study the hard work of orientating oneself towards an impending, finite, and unwanted future. Taking this approach shows that anticipation is not done individually but collaboratively, and that, even though the end of life is actively pursued, deferral plays a crucial role. Hence, anticipation is not an event that relates to a clearly demarcated moment in the future, but is rather a process in which perspectives change and boundaries shift in relation to a future that is always in flux. I conclude that while the unwanted future is brought into the present through anticipation, it is also actively kept at bay. Before elaborating on this, I provide a brief overview of some of the local values and norms that inform euthanasia, as a culturally specific form of relating to the future, in the Dutch context.

Euthanasia in the Netherlands

The work of anticipation in requesting euthanasia can be understood as an attempt to gain control over the future and the process of dying. The Dutch terms *zelfredzaamheid*,

zelfbeschikking, *eigenregie*, *onafhankelijkheid*, *controle*, and *autonomie* all refer, in subtly different ways, to what would translate in English as ‘control’ and ‘autonomy’, and are central to contemporary euthanasia debates. Having control over the timing and manner of death contributes to a large extent to its discursive framing as ‘good’, and maintaining control over the end of life is often a primary motive for requesting euthanasia (Buiting *et al.* 2012; Norwood 2009; Pool 2000; 2004). The gradual acceptance of euthanasia in the Netherlands coincided with a paradigm shift that took place between the 1960s and 1980s, when the ethics of the medical prolongation of life were questioned and patients’ self-determination became increasingly valued (Kennedy 2002: 67; The 2009: 153; van Wijngaarden, Klink, Leget & The 2017). Kennedy (2002), in his thorough historical and cultural analysis of how euthanasia policy emerged in the Netherlands, argues that attempts to remove the taboo around euthanasia and make it *bespreekbaar* (allowed to be openly discussed) not only allowed individuals to gain control over their own deaths but also made it possible for the state to control euthanasia through regulation. Norwood adds a level of nuance to this by arguing that control is exerted not so much through the act of euthanasia, but rather through what she calls ‘euthanasia talk’: ‘a discussion for the purpose of planning a person’s euthanasia death’ (2009: 30). The fact that euthanasia is discussed and planned, she suggests, reconfirms a person’s autonomy, even if they do not go through with euthanasia. Anticipating euthanasia might then even be more important than its realization.

Over the last decade, the Netherlands has seen an increase in both the total number of euthanasia cases and the specific number of cases with dementia. In 2012, the Regional Euthanasia Review Committees (RTE) received 4,188 notifications of euthanasia, including forty-two notifications concerning people with dementia. Six years later, in 2018, it received 6,126 notifications, and cases with dementia rose to 146, accounting for a little over 2 per cent (RTE 2013; 2019). While, in numbers, dementia may then seem a minor concern, public debates in the Netherlands have revolved primarily around euthanasia for people with dementia.⁴

By law, euthanasia in the Netherlands is not a right, but a request that can also be denied, as is stipulated in the 2002 Termination of Life on Request and Assisted Suicide Act, commonly known as ‘the Euthanasia Law’.⁵ According to this law, euthanasia can only be carried out by a medical doctor, who must comply with criteria of due care (*zorgvuldigheidseisen*). Additionally, the validity of the request must be confirmed by an independent medical specialist and all cases of euthanasia must be reported to an RTE, which reviews whether the criteria of due care have been met. As formulated in the Euthanasia Law:

The medical professional:

- (a) Holds the conviction that the request by the patient was voluntary and well-considered,
- (b) Holds the conviction that the patient’s suffering was lasting and unbearable,
- (c) Has informed the patient about the situation he was in and about his prospects,
- (d) And the patient holds the conviction that there was no other reasonable solution for the situation he was in,
- (e) Has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a-d, and
- (f) Has terminated a life or assisted in a suicide with due care.⁶

These criteria implicitly presume and require a rational subject, which creates tension in the context of dementia. Firstly, the requirement that ‘the request by the patient was voluntary and well-considered’ can become problematic due to cognitive decline. It is likely to become difficult or even impossible for the person with dementia to confirm their request. The GP can then no longer be certain that the request is well considered and if the person with dementia still wishes euthanasia. The euthanasia law does include the possibility of setting up a *wilsverklaring*: a written statement in which the request for euthanasia is expressed. The written statement could, in theory, replace verbal confirmation and thus make euthanasia more accessible for people with dementia. However, in practice, most physicians do not perform euthanasia when the person cannot certify that this is indeed still what they wish (Bolt *et al.* 2015; Rurup, Onwuteaka-Philipsen, van der Heide, van der Wal & van der Maas 2005). In 2018, of the 146 cases of euthanasia with dementia, only two were performed in an advanced stage of dementia and on the basis of a written statement, while the remaining 144 cases were performed in early stages of the disease wherein the person was still able to oversee their request (RTE 2019).

Secondly, the legal requirement that ‘the patient’s suffering was lasting and unbearable’ at the moment of euthanasia is highly subjective and to a large extent dependent on the assessment of the medical professional. People with dementia who request euthanasia often do so with reference to a future they consider unbearable. The evaluation of suffering is thus inextricably tied to images of the future with dementia that are associated with a loss of control and dignity.

An unwanted future

‘He is a zombie. He doesn’t respond to anything anymore. Nothing remains of his former self. My husband used to work; he is a historian, has a university degree. He can’t even read the newspaper anymore,’ said Margriet, as she turned and pointed at the wall behind her:

These paintings are his, but now he cannot paint, he cannot read. He used to be active in sports, ran marathons. He cannot do any of that any longer. [There’s] A long list of things that have been lost. All he has left is billiards, for what it’s worth, but he does seem to take some pleasure from it. But that’s all that’s left, and if that falls away, he won’t have anything.

Margriet and I sat at the long wooden table in her spacious country-style kitchen. She had poured us two large cups of tea. She talked fast, sometimes without finishing her sentences, which made me think she had a lot to say. Every now and then she got up and rushed to the living room, and came back with a newspaper article she had saved or a book to show me. She reflected on the last ten years in which her husband had been living with dementia, from the initial diagnosis to their current trajectory towards euthanasia. Besides narrating what had been lost over time, her story also conveyed losses that she anticipated were still to come. She lamented:

If I don’t put him in the shower, he does not bathe. If I don’t tell him to shave, he won’t. And there will come a time when he will no longer be able to do it himself. Well, I absolutely do not want that, because I find it unworthy of a human being. And he would also not have wanted it. We have talked about this, and I told him, ‘You are slowly sliding off towards Bloemenhof.’⁷ He then said, ‘I don’t want that.’

She looked back at the paintings and said, ‘I don’t think that is dignified. A human being is not meant to end as a lump of misery’.

It was common for those I spoke with, both those with dementia and their family members, to see a future with dementia as one involving a loss of dignity. Like Margriet, my interlocutors foresaw the future as a grim and ever-worsening scenario. A loss of dignity was imagined as even worse than death by some (cf. Behuniak 2011). This was also strongly voiced during a focus group conversation with NVVE volunteers who informed and guided people in their efforts to request euthanasia. When I asked them, ‘What is it that makes you consider that life unworthy?’ their replies quickly followed one another. ‘I think you are not a worthy human being anymore. Almost animal-like’, said Ben. Harold followed: ‘I don’t see it as a human-worthy existence. My former boss was always a gentleman. At some point I saw him drooling in a wheelchair, being pushed around town. I was certain: he would have never wanted this. And I would never want it either’. Dorien nodded, adding, ‘The emotion and frustration. He would not have wanted that’. Ben sighed, and explained: ‘And then we are not even talking about the changes in someone’s character. So it is not only about self-composure and losing your mind, but ending up in a different atmosphere and becoming a different person’. Julie immediately confirmed: ‘Yes. Not knowing what I will become. Because you don’t know that’. ‘Yes’, Tina concluded: ‘And becoming a burden for another. That is really difficult’.

These responses each referred to different aspects of what it would be like, according to them, to live with dementia. The imagined future encompassed the idea of a loss of self, that the person with dementia would become someone they explicitly did not want to become, involving an anticipated loss of autonomy and control, which were often equated with a perceived loss of dignity.⁸

Such a view resonates more broadly, since negative imaginaries of dementia are recurrent in media representations and it is widely considered one of the most frightening diseases in Western societies (Johnstone 2013a; 2013b).⁹ For example, commenting on how dementia is imagined in the United States, Basting (2009) distinguishes multiple fears: of being a burden, of the unknown, of being out of control, of losing one’s self, and of a meaningless existence. Taylor (2010) discusses the harmful implications of this imaginary, as it can imply a denial of recognition of the person with dementia. Hellström and Torres, conducting research in Sweden, found that couples living with dementia viewed the future as ‘predetermined and rather gloomy’ (2016: 1571). The unwanted future reflects a worldview wherein certain lives are deemed dignified while others are not, creating a norm for a ‘life worth living’ (Lemos Dekker 2018). Anticipating the future with dementia as a life not worth living can, in many cases, be considered a driving force behind the request for euthanasia.¹⁰

The nursing home plays a key role in this imaginary (van Wijngaarden, Leget & Goossensen 2015). Even while institutionalization during old age is common in the Netherlands, and the quality of nursing home care is generally good, for many of my interlocutors the nursing home symbolized loss of independence and control, and thus came to be seen as the ultimate tragedy (cf. Leibing, Guberman & Wiles 2016). Ms Verbeek, for example, during a conversation with her GP about her wish for euthanasia, said:

Actually, I wish to stay at home as long as possible, until I don’t know it anymore and need to move to a nursing home. Then I want euthanasia. If I cannot stay at home, it’s done. To be closed in, in a ward, what kind of life is that?

The prospect of moving to a nursing home, for Ms Verbeek, Margriet's husband, and many others, threatened their autonomy to such an extent that several interlocutors insisted that 'euthanasia is the only alternative'.

Such images of lost independence and dignity were often further infused with personal experiences from the past. 'Both my father and brother used to live in a nursing home, so for me that is a limit', said Ms Verbeek, reminding us that how we perceive the past can guide how we anticipate the future (Bryant 2016: 26; Munn 1992: 115). My interlocutors also shared stories of having witnessed dementia among acquaintances, which influenced their outlook on a future with dementia. Harold, for example, was very outspoken about this, explaining why people opt for euthanasia:

Because too often we have seen things we don't want to be exposed to ourselves. That is why I want to maintain my self-determination. I have made that very clear to my GP. I have volunteered in a nursing home, and I would not wish what I saw there on anyone. Even though they are being cared for with love. But that's not for me. I never want to be encountered like that.

A similar sentiment was expressed by Dorien, who, one year after her mother's death, reflected on the final year of her mother's life and process towards euthanasia. She told me that her mother had witnessed her two older sisters, Jet and Cor, developing dementia and eventually moving to a nursing home. Dorien recalled: 'The shocking image that she kept was how, during family dinners, Jet and Cor were unable to join in conversations. So she knew what awaited her. And she always said: "I do not want to become like Jet and Cor"'. That was her doom scenario, becoming like that.

For those seeking euthanasia, the unwanted future thus haunts the present through fearful anticipation, threatening the worthwhileness of life itself. For my interlocutors, euthanasia appeared to be a way to avoid this unwanted future, the possibility of death without further degeneration, without becoming an unwanted version of the self. In this sense, euthanasia, as Hannig (2019) also shows in the context of assisted dying in the United States, is pre-emptive in nature, a means to avert an already imminent death.

As the accounts of my interlocutors demonstrate, the fear of a future with dementia already evokes the suffering associated with it. Ahmed makes this link between fear and anticipation more explicit, writing that 'fear involves an *anticipation* of hurt or injury. Fear projects us from the present into a future' (2004: 65, emphasis in original). To anticipate a future of suffering, then, means not only to imagine it but also to engage with that suffering in the present, to fight it, to postpone it, and, ultimately, to put an end to it before it arrives.

Through its affective force, anticipation demands action, bearing a responsibility to strive for the best possible future.¹¹ The options available to my interlocutors seemed limited but also clear. Ahead of them they saw a choice between further decline or euthanasia. However, as I will show in the following section, while requesting euthanasia can be a way to position oneself as an active agent in pursuing one's well-being towards the end of life with dementia, this process of retaining control still encompasses many uncertainties and is subject to negotiations among the person with dementia, their family members, and medical professionals. By elaborating on how the unwanted future comes to be acted upon through such negotiations, I emphasize that anticipation is a collaborative process.

Negotiating the *when*

While anticipation establishes a future imaginary, acting upon this future requires work and negotiation. Anticipating the end of life through a euthanasia request requires establishing the *when*. It asks the person with dementia, their family, and professional caregivers to plan and agree on the timing of death, which means it cannot remain a vaguely formulated reference to an unwanted future. The practical work of anticipation includes filling out forms, meeting with medical professionals, and, more generally, navigating legal and medical systems.

In most cases, meetings with the GP, the person with dementia, and their family members take place on a regular basis (cf. Norwood 2007; 2009).¹² While Ms Verbeek, her niece Hannie, and I waited for her GP, Martin Terbrugge, before one of these meetings, Ms Verbeek seemed restless, rubbing her hands together and shifting repeatedly in her chair. Then Terbrugge arrived, and we went into a small meeting room. The GP was a young and jovial man, casually dressed in jeans and a striped shirt; having witnessed his interactions with nursing home residents, I found he had an approachable demeanour that enabled him to create open conversations with his patients.

In the ensuing conversation, Ms Verbeek, Terbrugge, and Hannie sought to clarify at what point the time for euthanasia would arrive. Ms Verbeek repeated what she had told me when I had visited her at home: she wanted to stay at home as long as possible, and she wanted euthanasia if she had to move to a nursing home. 'Why is having to leave your home the limit for you?' Terbrugge asked her. 'Well', she answered, 'I might walk onto the street and not find my way back home. You hear that sometimes, of people who start wandering. I would not want that.' Terbrugge tried to rephrase her answer: 'So for you, admission to a nursing home means you will have degenerated to a point where you think you will be doing things you don't want to do?' 'Yes', she answered, 'then life has no point anymore, has it?' 'So what makes that the limit?' Terbrugge repeated his question, seemingly trying to get a more concrete answer. 'What are you afraid of? Is it the fact that you would have to leave your home, or further degeneration?' 'Well, those two come together', said Ms Verbeek, and, after a short pause: 'This situation will only get worse. I am sometimes a bit forgetful, and then I will not be able to discuss it anymore. So I felt I had to start this on time'. Terbrugge took a deep breath and said: 'The point is that when the moment arrives when you would no longer be able to live at home, you will likely have regressed cognitively to a degree that it will be hard to oversee the request'. To which Ms Verbeek answered: 'Well, I do want euthanasia, but not now'.

Meetings such as this often revolved around the motives for the euthanasia request, as well as the moment at which suffering would become unbearable. The anticipated, unwanted future was fundamental to such requests for euthanasia, often expressed in rather ambiguous and subjective terms, such as 'when it becomes undignified' or 'when I am no longer myself'. But when meeting with their GP, the person requesting euthanasia needs to make these notions explicit, concretely defining what they consider unbearable suffering, in order to meet the legal criteria. As noted, my interlocutors often mentioned having to move to a nursing home as such a limit, as they associated it with an advanced loss of autonomy. Another boundary often mentioned was no longer recognizing family members.¹³ In this light, Terbrugge was urging Ms Verbeek to state concretely at what point, and why, she would want to receive euthanasia.

The repetition of such meetings makes it possible for the GP to evaluate the consistency and continuity of the request.¹⁴ To comply with the criteria of due care, the person with dementia has to demonstrate that their choice is deliberate and

well considered, and not a hasty thought. This temporal dimension, the requester's consistency over time, contributes to the legitimacy of their request. Dorien explained that her mother's GP had initially been hesitant, 'but by now the GP has come to a point in which he says he may eventually do it. But that is only because we have had a meeting every month for the last half a year, and my mother is persistent in what she wants'. During this period, Dorien had been proactive, realizing her mother would not have been able to navigate the process of requesting euthanasia by herself due to her dementia. She told me her mother was able to engage in conversations, but afterwards could not remember what had been discussed and agreed upon. Dorien said:

She can no longer do this by herself. She needs someone who can structure the process so as to give her a chance to, when the time comes, receive euthanasia. And, with hindsight, that has been crucial. Because I remembered what had been discussed, and made sure that a new appointment was made and that she would attend it.

Taking her role seriously as the one responsible for 'structuring the process', Dorien sought to have many medical professionals involved who would be able to confirm that her mother had indeed expressed a wish for euthanasia, an approach she referred to as 'building a portfolio'.

Similar to Dorien, Margriet also worked to compile a track record of the euthanasia request. She explained, 'We agreed with the GP that my husband and I would meet every four weeks with her, to guide him through this difficult process'. Margriet then got up from the kitchen table and came back shortly with several documents: euthanasia requests for her husband and herself. Two forms, dated 1990, showed signs of folding and unfolding, one of them torn halfway at the fold, so that the page barely hung together. 'These forms are falling apart as we speak', Margriet said, and continued:

So this spring we have filled out and signed new forms. It is not as if you can say, 'I want euthanasia tomorrow'. It's a long trajectory. It sounds strange, but it is about providing evidence – the burden of proof that this is what I want and have wanted for a very long time.

While, as discussed above, past experiences influence images of the future, these efforts of 'building a portfolio' also demonstrate how the ability to exercise control over the future depends on the establishment of a past that consistently reflects the same views and wishes for the future. Anticipating the future through a request for euthanasia thus encompasses a complex negotiation of legal and social structures, involving the person with dementia, family members and friends, and medical professionals. Clearly, euthanasia is not requested in social isolation; Norwood emphasizes that 'euthanasia is a family matter' (2009: 183; cf. Buchbinder 2018; Snijdewind *et al.* 2014). This makes anticipation not merely an individual process of envisioning and acting upon a future; it also involves building upon knowledge of how to navigate a specific system.

And yet this pragmatic approach, though necessary for a request to be considered by a GP, cannot cover the personal and social complexities of preparing for euthanasia. 'In my mother's case', Dorien said, 'it is fully prepared. The only thing is that my mother has not said "yes" yet. If she would set a date, it would happen'. And as I show in the next section, it is one thing to establish the timing of one's death on paper or in conversation, but it is quite another to decide when that point is reached in daily life.

Deferring the future

In building a portfolio, and in repeatedly discussing a euthanasia request with medical professionals, anticipation emerges not only as a future imaginary but also as an

interactive process that brings the unwanted future into the present, where it is acted upon. Yet it also becomes clear that this future is made distant: rather than fully collapsing future and present, the process of anticipation also involves their conceptual separation. Some anthropologists, such as Nielsen (2011; 2014), have sought to dissolve the conceptual distance between past, present, and future, dismantling the supposed linear sequence. In seeking to understand how change may, counter-intuitively, occur in non-linear and non-progressive ways, Nielsen writes that ‘in a peculiar inversion of conventional linearity, the present becomes the effect of the future rather than vice versa’ (2014: 170). However, while focusing on anticipatory practices underlines the entanglement of past, present, and future, it also demonstrates the persisting distance between present and future: the future is coming but not yet here. So while I agree with Nielsen – moments that are chronologically distanced from the present moment can be tied together and related in meaningful ways – I also find that the (sometimes repetitive) affirmation of the temporal distance between present and future can be one of the ways in which both are made meaningful. In the conversation between Ms Verbeek and her GP, for example, she appeared less preoccupied with convincing him of her wish for euthanasia than with demonstrating that she was still capable of living by herself at home. Ms. Verbeek emphasized repeatedly that she was only a little forgetful at times, with statements like ‘It’s not that I cannot function’. In this way, she sought to hold off the future.

This dynamic of deferral is fundamental to anticipation in this context, as it establishes the unwanted future as ‘not yet’. This can be understood in the same line as Pols and Limburg’s (2016) work among people living with severe progressive disease (amyotrophic lateral sclerosis, or ALS, in particular), in which they show that people’s evaluation of their quality of life changes over time, and, particularly, that a situation that is dreaded in anticipation may be accepted once it becomes a reality. A similar process of re-evaluation occurs in relation to the imagined future and shifting experiences of living with dementia. The person with dementia might envision certain future circumstances as ‘unbearable suffering’, but once these circumstances are realized, their outlook on the situation may change and they may wish euthanasia to be postponed (Norwood 2009; The 2011). Initially, Dorien reflected, her mother had been quite decisive as to her wish for euthanasia and the moment she wanted it. She recalled:

We were celebrating her birthday, in August, and she said, ‘I want to have a conversation with you all’. At the end of that day it was clear. We were all startled – she told us she wanted to die before Christmas. She did not want to live for another winter. That was the worst, the winter. She also did not want to buy a new winter coat. Economical as she was.

Dorien chuckled, then, more seriously, she continued: ‘We then went to the GP, and there she repeated this. Not another winter. That was very clear’. However, even though Dorien’s mother voiced a moment in the future *before which* she would want to receive euthanasia, selecting a concrete moment for death would turn out to be challenging. Dorien continued:

So we proceeded to make appointments. However, in the meantime, my daughter went travelling and was to return mid-December. So we all assumed the euthanasia would take place while she was away. But then the postponing started. She wanted to wait for my daughter to come home. Then it was almost Christmas. And so she continued postponing. Then, 6 January was my son’s birthday and she did not want to die just before his birthday. Right after his birthday we had another appointment with the GP, so we thought, now she will set a date, but then she said my birthday was coming up. The

intervals became shorter each time, but she kept saying ‘not yet’. Eventually she lived until the next summer.

The story related by Dorien reflects the difficulty of establishing the moment to end life through euthanasia. In trying to find the ‘right’ time, people generally do not mention a concrete date, but at first tend to refer to a broader timeframe or relate it to particular (future) events. As one NVVE volunteer said: ‘My experience is that people always hold on to life and always shift their boundaries’. Many interlocutors also indicated that, even though they were requesting euthanasia, they would prefer a ‘natural’ death, which in this context referred to a death before the imagined, unwanted future had become a reality, but one that did not require an active intervention. Such a death would relieve the burden of knowing the timing of one’s death. One day, over coffee, Ms Verbeek said she would find it hard to know if this would be her last cup of coffee, and continued: ‘I would prefer to be sitting there on the couch and just go’. Quite similarly, Dorien remembered her mother saying: ‘I cannot decide. I find it so hard because it is a decision to be made. I wish I would just get the flu, so it would just happen’. For many, the idea of being ‘taken away’ by a ‘natural’ death seemed much less demanding than actively planning and deciding on death – the difficult work of anticipation.

While deferral can take the form of people consciously deciding to postpone action and changing criteria for that action, one recurrent aspect, specific to dementia-related euthanasia requests, is that the person with dementia often is not entirely aware of how the illness has been progressing (Keizer 2003; The 2017). This lack of insight into one’s own illness can result from cognitive losses: for example, a person may assume they are still able to perform the daily tasks they used to, and is unaware of having lost the capacity to do so. As NVVE volunteer Tina commented: ‘When *wilbekwaamheid* [mental competence] becomes insufficient, then you are too late’. Because one may cross this thin line without realizing it, it may not be evident when one has crossed previously established boundaries of unbearable suffering. Further, dementia does not progress linearly, and moments of clarity can alternate with moments of disorientation, and while dementia confronts us with certain losses, life is not lost all at once (Hellström & Torres 2016). When a euthanasia request increasingly depends on what family members referred to as ‘good’ or ‘clear’ days, moments when the person with dementia could have coherent conversations, the temporal distance between the unwanted future and the present becomes increasingly vague.

Ms Verbeek had established boundaries for when she wanted to receive euthanasia, but might not have been aware that she had reached, or was close to reaching, this point. When Terbrugge asked her about the things that were becoming more difficult in her daily life, she answered: ‘I am often forgetful but usually it does come back, you know’. Her niece Hannie frowned disapprovingly. ‘Well’, Hannie intervened, ‘some things are becoming more difficult, like hygiene. I find it difficult to confront her with that, but I find that I have to. Otherwise she thinks everything is fine, and it is not’. Without full awareness of her illness, Ms Verbeek may not realize whether she has progressed ‘too far’.

Similarly, Dorien’s mother made it clear she did not want to become like her sisters Jet and Cor had been when they had dementia. ‘Becoming like’ encompassed a future she did not want to end up in. ‘We know she always said: “I don’t want to become like Jet and Cor”’, reflected Dorien, ‘but the funny thing was that Cor’s children would say to me, “When I see your mother, she looks so much like our mother when she was

in that phase”. While Dorien’s mother placed ‘becoming like’ her sisters in the future, she was not aware to what extent she had already ‘become like’ them, how much she had already degenerated. This raises the question of when such a subjective boundary is reached. Margriet similarly commented on her husband’s limited awareness of his illness.

This summer he was telling the neurologist that he was going to pick up reading Greek again. But the books are gathering dust on his table. He cannot read anymore. And then he has been telling people about starting a Spanish course, which he has been saying for seven years now.

At some point, it may become ‘too late’ for euthanasia, as the person with dementia may become unable to confirm their request. This brings me back full circle to the dilemma I addressed in the introduction, wherein a person with dementia who wishes to receive euthanasia has to request it ‘too early’ before it becomes ‘too late’ (cf. The 2017). While this problem of timing can also occur in other illnesses (see, e.g., Hannig 2019), this dilemma is particularly pertinent for those with dementia. Progressive cognitive loss implies that the person with dementia will at some point no longer be able to confirm their request; if they can still confirm the request, it may be too early for euthanasia – too early for the person with dementia themselves, because they are still enjoying life, and too early for the GP, who will not perform euthanasia if they are not convinced the person with dementia is suffering unbearably. Margriet quoted her husband, describing his biggest fear: ‘If I decide [to do it] now, I will die too early. And who knows how many years or months I still have.’ Margriet continued: ‘He keeps saying, “What if I still had half a year left, then I would die too soon”. But he has shifted his boundaries so many times now. Soon there will be nothing left.’ Margriet realized that, as her husband kept postponing euthanasia, there could come a point where it would no longer be possible.

On the timing of euthanasia, NVVE volunteer Jan said: ‘On time is one minute to twelve. A quarter to twelve is too early. It’s impossible, because you never know when it’s one minute to twelve’. One of the difficulties, then, is that the ‘right time’ can in many cases only be clearly perceived in hindsight. Exactly *when* the time for euthanasia has arrived – the moment when the person with dementia is both still able to confirm the request and considers their suffering unbearable – is in many cases impossible to anticipate.

Conclusion

Acting in the present upon an imagined future establishes a tense relation to the future as a time that is yet to come. Ms Verbeek’s remark that she wanted euthanasia *but not yet* echoed not only how difficult it appeared for many people with dementia to establish the *when* of euthanasia, but also how anticipation did not unilaterally bring the future into the present, working instead as a mechanism for distancing the future from the present. A delicate process, it entailed an intimate, though often uneasy, correspondence between actions and affects in the present and the imagined future, each continuously shaping the other. In this process, perspectives can change and boundaries can shift. Thus, while Bryant and Knight define anticipation as ‘the act of looking forward that also pulls me in the direction of the future and prepares the groundwork for that future to occur’ (2019: 28), analysing anticipation in the context of euthanasia in dementia reveals that the future is already being lived but it is also held off. In anticipation, then, the temporal distance between future and present can be established, collapsed, and renegotiated.

While others (e.g. Bryant 2016; Munn 1992; Nielsen 2011; Ringel 2014; 2018) have demonstrated that the relationship between present and future is not always linear, and that both past and future can infiltrate the present, I have focused on experiences of time in a frame of finitude; 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 article 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. It was associated with a loss of autonomy, control, and dignity, and nearly without exception imagined as worse than the present. My interlocutors' emphasis on acting in advance to prevent this unwanted future from arriving demonstrates the work that goes into maintaining dignity, and how, for some, death can provide a means to do so. As I have described elsewhere (Lemos Dekker 2018), this struggle ties into fundamental questions of how life is valued, as it involves negotiating the boundaries of what is seen as a worthwhile life. Therefore, for an anthropology of the future it is, paradoxically, highly insightful to study the end of life.

The ethnography presented here further makes clear that anticipation is not an isolated, psychological process, but rather one that is culturally and socially embedded. Anticipating the future, then, is not only a matter of imagining it, but presupposes action (Adams *et al.* 2009; Bryant & Knight 2019); it requires work (Clarke 2015), which, I have demonstrated, is done collectively and in negotiation. As requesting euthanasia is a shared effort (Norwood 2009), not only the person with dementia requesting euthanasia anticipates the future: family members are deeply involved, as are GPs and volunteers. Collaboratively, then, people with dementia, family members, and medical professionals seek to navigate the agonizing trade-off between being 'too early' and being 'too late' for euthanasia, continually testing out images of the unwanted future against changing circumstances in the present. The 'right' time for euthanasia in many cases consists of overlapping timeframes wherein the person with dementia can still state their wish for euthanasia while also considering life not worth living anymore. Often, these timeframes exclude one another.

This process of negotiation decidedly evolved within the boundaries of a biomedical and legal framework. While the Dutch context is rather specific, being one of the few countries to have legalized euthanasia (it was the first actually to do so in 2002), the material presented illustrates how the affordances and limitations of legal and biomedical frameworks shape the ways in which the future can be apprehended, in which terms it can be formulated, and what actions are necessary or possible to achieve or prevent it. My interlocutors had to relate to the criteria of due care as formulated in the euthanasia law and to the expected trajectory of the disease, showing how biomedicine influences concepts of time.

For Dorien's mother, despite multiple deferrals, the timing of euthanasia eventually became clear. In early spring, she fell and broke her hip. She had established a written statement that explicitly stated she did not want to be hospitalized in the case of a broken hip, but wished to be cared for at home. Nevertheless, when it happened, she made it very clear to Dorien and the attending medical staff that she wanted to proceed with surgery. Dorien quoted her saying, 'If I do not have the operation, I would be choosing death, and I cannot do that now'. Following the surgery, Dorien's mother moved to the recovery unit in a nursing home. In the first few weeks after the surgery, she was delirious. Yet, little by little, and contrary to expectations, her condition improved. Dorien told me that her mother became very clear about her wish for euthanasia:

When I visited to tell her, 'Tomorrow we will have a conversation with the physician', she said, 'In that case I will tell him I want to die and that I want euthanasia. I have been letting it all sink in, and I don't want this. I am now like Jet and Cor and that's exactly what I didn't want'.

The next day, the elderly-care physician broke the news that she had to move to a psychogeriatric nursing home unit. Dorien's mother remained steadfast, and Dorien quoted her saying, 'But that is not what I want. I want euthanasia.' Knowing that her GP was willing to proceed with euthanasia, Dorien's mother went home, where her wish for euthanasia was granted.

NOTES

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¹ All names of interlocutors in this article are pseudonyms.

² Newspapers regularly publish articles with titles such as 'If I become demented, put something in my coffee' (Matthijssen 2017), portraying life with dementia as undignified and justifying euthanasia. Others highlight the legal and ethical challenges: for example, 'Euthanasia for mentally incompetent dementia patients is impossible to defend' (Kreulen 2018) and 'The woman who forgot that she wanted to die' (Reerink 2012).

³ The question of timing death through euthanasia has sparked intense ethical debates in the Netherlands as well as in many other societies. While taking into account these often highly polarized debates, in this article I do not advocate for or against euthanasia. Rather, I suggest that a careful analysis of the process of requesting euthanasia provides important theoretical insights into the workings of anticipation.

⁴ These numbers do not include withdrawn or denied requests. Euthanasia accounted for 4 per cent of the total number of deaths in the Netherlands in 2018 (RTE 2019). The RTE reports do not differentiate between euthanasia and assisted suicide when referring to dementia.

⁵ Legalized in 2002, euthanasia had previously been subject to jurisprudence. In 1973, a physician was given a symbolic sentence of one week's suspended imprisonment, and in 1984, another was acquitted. In 1984, due care criteria were formulated and the first euthanasia law proposed. The RTEs were established in 1998. See also Kennedy (2002); Pool (1996; 2000); The (2009).

⁶ From the Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Hoofdstuk II. Zorgvuldigheidseisen, Artikel 2.1. English translation in Norwood (2009: 238-9).

⁷ Fictional name of the nursing home where he received day care.

⁸ For a discussion of the related question of which 'self' (present, past, or future) merits priority in care and decision-making, see Dresser (1986); Dworkin (1993); Hertogh, de Boer, Dröes & Eefting (2007); Jaworska (1999).

⁹ While public debates commonly describe people with dementia as 'fading into nothingness', 'getting lost', and becoming 'undignified', or discuss bodily and cognitive decline, such as becoming incontinent or unable to recognize loved ones, there is also increasing attention to more nuanced accounts.

¹⁰ Here, I wish not to reinforce the negative imaginaries of dementia. Rather, I draw attention to this often powerful image as a crucial element in my interlocutors' narratives and in the process of anticipation.

¹¹ Adams *et al.* (2009: 256) term this striving for the best possible future 'optimization'.

¹² Usually, people with dementia who live at home have their own GP, while most nursing homes have an in-house, or an affiliated, external, elder-care physician.

¹³ See Taylor (2010) for a discussion on recognition in dementia and its relation to care.

¹⁴ The number of meetings between the person with dementia and the GP, as well as the timespan in which euthanasia is discussed, is highly variable between cases.

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Anticiper un avenir non désiré : euthanasie et démence aux Pays-Bas

Résumé

Cette exploration ethnographique de l'anticipation s'appuie sur un travail de terrain réalisé aux Pays-Bas auprès d'individus atteints de démence et de leur famille. L'article examine comment les demandes d'euthanasie formulées par des personnes souffrant de démence apportent des perspectives sur le travail d'anticipation, faisant de ce dernier une orientation temporelle par laquelle l'avenir devient tangible. La perspective de la démence peut pousser certaines personnes à demander à être euthanasiées, mais il est extrêmement difficile de déterminer le moment opportun pour prendre de telles mesures, qui sont souvent reportées. Contribuant à l'émergence d'une anthropologie du temps, l'auteur avance que l'anticipation est un processus consistant à établir, réduire et renégocier la distance temporelle entre présent et avenir,

plaçant ainsi l'avenir dans le présent, et le tenant également et simultanément à distance, le remettant continuellement à « plus tard ».

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