



Dying 'on time' in dementia

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Abstract: The fear of suffering dementia may lead to people signing an Advance Euthanasia Directive to make provision for health care decisions in the event that he/she becomes unable to make those decisions. However, Advance Euthanasia Directives are rarely adhered to in the case of dementia because the symptoms of dementia conflict with the due care criteria; a person requesting euthanasia must be able to confirm this request at time of death and must be undergoing unbearable and hopeless suffering. Once dementia has progressed, the euthanasia 'wish' can no longer be confirmed, and assessing suffering in a person with dementia is nearly impossible. This means that for a euthanasia request to be successful you have to perform the euthanasia early enough, while the patient is still cognitively competent. The risk in doing so is that the patient may lose years of their life that could have been full of quality. Postponing euthanasia in dementia could result in euthanasia not being possible and the person with dementia living a life that they did not want. This paper addresses how to decide what 'on time' is when it comes to dying with dementia through literature review, information visualisation and public debate.

Keywords: *dementia, euthanasia, speculative design, information design*

1. Introduction

Dementia affects 47 million people worldwide with 9.9 million new cases each year (WHO, 2017) Dementia is a collection or consequence of many illnesses, including Parkinson's disease, vascular dementia and Alzheimer's disease. There is a set of similar symptoms in which there is deterioration in memory, thinking and behaviour; it is a terminal disease.

Euthanasia has many definitions from the Greek origins of 'good death' or 'easy death' (dictionary.com, 2017) to the Nazi euphemism for the deliberate killings of physically, mentally, and emotionally handicapped people, leaving the term with extremely negative connotations (Wikipedia, 2017). The definition used in this paper is "The act of assisting someone who is terminally ill and whose suffering is unbearable and untreatable, to be in control of the manner of their dying."

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As euthanasia is illegal in most of the world, this paper will use the Dutch guidelines and legal framework which states *“euthanasia is not punishable if the attending physician acts in accordance with the statutory due care criteria. These criteria hold that: there should be a voluntary and well-considered request, the patient’s suffering should be unbearable and hopeless, the patient should be informed about their situation, there are no reasonable alternatives, an independent physician should be consulted, and the method should be medically and technically appropriate”* (Dutch euthanasia Act, 2002).

Euthanasia for people living with dementia is a complex issue because the symptoms clash with the due care criteria for euthanasia; unbearable suffering is difficult to assess in dementia (Buiting et al., 2008); (Hertogh, 2009); (Rietjens, van Tol, Schermer, & van der Heide, 2009); (Emanuel, 1999), and it is hard for a person living with dementia to consent to euthanasia at the point of death because of the decline in their cognitive functioning (Rurup, Onwuteaka-Philipsen, Van Der Heide, Van Der Wal, & Van Der Maas, 2005). In 2017 only three people with advanced dementia received euthanasia versus 166 cases of euthanasia in early stages of the disease, out of a total of 6,585 euthanasia cases in 2017 (NRC, 2018).

Not many people are aware that their Advance Euthanasia Directives are ineffective once dementia has progressed to a stage where cognitive functioning is diminished. This paper investigates when a good time to die would be in dementia and aims to raise awareness about the complexities in choosing the right time to die. A graphic was developed which visualises many complex aspects of the euthanasia in dementia debate shown as a timeline for end-of-life in dementia. This timeline is a compilation of research data, bioethics, personal experience and speculation; as such it functions as a speculative design and is intended as a tool to stimulate dialogue between experts (Auger, 2013). The graphic addresses the transfer of control from the patient to the carer to the professional; it shows loss of quality of life for patients and carers; it makes clear that in dementia biographical and biological death are not simultaneous (Rachels, 1986); it marks the window of opportunity for a planned death in dementia and highlights that an early diagnosis is essential if euthanasia is the preferred way to die in dementia (Davis, 2014). The timeline was used as a discussion tool in a public debate about euthanasia in dementia.

2. Literature review

A major barrier for euthanasia in dementia has been pinpointing a time to act. In dementia there is only a small window of opportunity, after a diagnosis and before cognitive decline sets in.

2.1. Too early

Deciding the time of death is complicated in dementia; it seems impossible to die ‘on time’. *“Not so early as to lose many good years, but not so late that the subtle onset of dementia robs one of the ability to appreciate the situation and to act in*

accordance with one's goals" (Davis, 2014). Hertogh identifies a small window of opportunity in early dementia when cognitive functioning is still relatively intact (Hertogh, 2009). Euthanasia in dementia is rare, but it does happen in the early stages of dementia, this is often seen as 'too early'. There have been 166 cases of euthanasia in dementia in 2017, these all took place in the early stages of the disease when cognitive functioning was still in tact (NRC, 2018). Patients must carry out the impossible task of choosing the time of death, because there is no possibility to change one's mind once this has been decided (Gastmans & De Lepeleire, 2010).

2.2. On time?

There is not much awareness about having to speed up the euthanasia process in dementia, and some people try hard to postpone the moment of death. Author Henk Blanken is fighting for the right to die 'on time' and proposes that his wife should be the one to decide. He feels that a person with dementia must be able to authorize a loved one to find a physician to perform euthanasia, or in the worst case, allow the loved-one to perform the euthanasia themselves at the time that they deem is right (Blanken, 2018).

2.3. Too late

Once patient autonomy has diminished, this responsibility of deciding on euthanasia would be transferred to others which may cause stress (De Boer et al., 2011). In a study to see whether physicians could conceive of performing euthanasia under morally complicated cases such as people who simply tired of living, people with a psychiatric illness, or demented people, the timing issue arose: *"Many physicians state that it is impossible to determine at what moment an advance euthanasia directive is to be carried out if the patient can no longer specify this"* (Bolt et al., 2015). There have only been 3 cases of euthanasia in dementia at a late stage of the disease to date (2017), and these have been very controversial (NRC, 2018)

The key point on timing is:

- Deciding the moment of death is difficult. In dementia there is a small window of opportunity, after a diagnosis and before cognitive decline sets in.

3. Information design as a method to explore this debate

Design is usually seen as a problem-solving practice, however the focus of design is shifting and design often engages with broader social context, asking questions and opening issues for discussion (Mitrović, 2016). Dunne & Raby (2013) use the term Speculative Design to describe design used to stimulate discussion and debate amongst designers, industry and the public about the social, cultural and ethical implications of existing and emerging technologies (Dunne and Raby, 2013). Speculative design uses prototypes as a method of enquiry (Auger, 2013). In this research, within the context of euthanasia and dementia, design is used as an

anchor point between the different stakeholders; people with dementia, non-professional care-givers and professional care-givers. A piece of information design, the timeline, was created with the aim of making the debate more accessible (Figure 1).

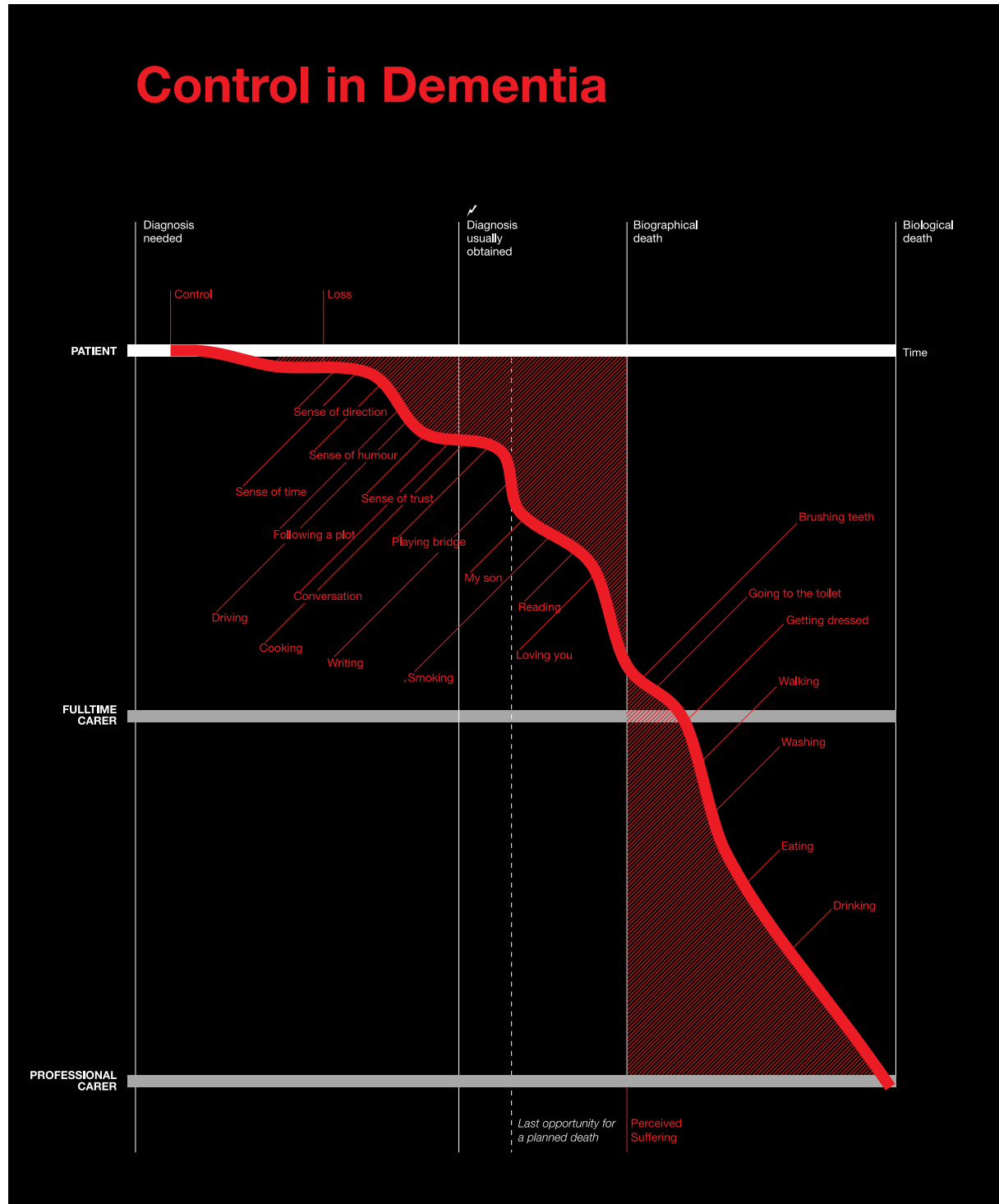


Figure 1. An interactive timeline produced for a public debate at Pakhuis De Zwijger in Amsterdam 10 December 2018 (version shown here adapted to English and a portrait format for readability in this paper).

4. Design decisions: How the timeline was constructed

This section explains how the timeline was constructed to illustrate the problem space. The graphic (Figure 1) was used to seek responses to the question: *When is a good time to plan death in dementia?*

4.1. Concept

Euthanasia in dementia is complex. In order to navigate the various issues related to this dilemma a kind of map was needed. Medical data, bioethical thoughts and personal accounts were mapped into one visualisation to be easier to understand and negotiate. The map took shape as a timeline identify the essential 'players' in the euthanasia for dementia debate. The timeline shows patterns and connections between the patient, the carer/loved-ones and the physician. It shows the various roles these individuals play in the progress of dementia. The information is presented as a timeline to highlight the fact that pinpointing the 'right time' to die in dementia is hard, and varies for the different players.

4.1.1. Medical data

The timeline's main visual element is the line of control. Control over the life of the person living with dementia transfers from the patient to the carer to the professional carer over time, meaning that the responsibility of this life is also transferred.

4.1.2. Bioethics

The timeline shows that an early diagnosis is essential to allow for essential end-of-life decision making while the patient is still in 'control' (Davis, 2014). The timeline introduces the concept of biographical and biological death as described by Rachels (1986): *"... when we speak of 'life', we may have in mind a very different sort of concept, one that belongs more to biography than to biology ... From the point of view of the living individual, there is nothing important about being alive except that it enables one to have a life."*

4.1.3. Personal accounts

The timeline is dotted with elements of loss. In the first stage, before the so-called biographical death there is loss of skills and personality traits, the elements that define personality. This 'loss' is individual and designed in such a way that viewers can imagine their own experiences. The items of loss after the biographical death have been labelled "perceived suffering", and are often mentioned by carers as the type of suffering they would like to avoid at all cost should they be diagnosed with dementia themselves. It is unclear however if this lack of decorum is experienced as suffering by patient's themselves (Hertogh, 2009).

5. Public debate and responses

The timeline was used as a discussion tool in a public debate about euthanasia in dementia in Pakhuis de Zwijger in Amsterdam, December 2018. This public debate was open to the general public but mostly attracted stakeholders in the debate. Participants were lawmakers, physicians, writers and people touched by dementia. The timeline was used as an interactive discussion tool (Figure 2), where the participants were encouraged to pinpoint the best time to die from the perspective of patients (magenta), loved-ones (yellow) or physicians (cyan) (Figures 3 and 4). Opinions were divided and no consensus was reached. It was clear that the individual experiences of suffering were essential to base decisions on. One element of loss, “loving you” received more pins than other specific moments. Time close to a biographical death seemed the most ideal, fewer times were pinned after the biographical death, though all three parties were represented there as well. An individual representing the NVVE [Dutch Society for the right to die] said: *“Every case is unique, you can not talk in general terms, it is impossible to create guidelines or say ‘this is how it should be done’, it means that close contact with a GP, patient and loved-ones is essential”*.



Figure 2. Two physicians discussing the timing issue in euthanasia in dementia at Pakhuis De Zwijger, 10 December 2018.

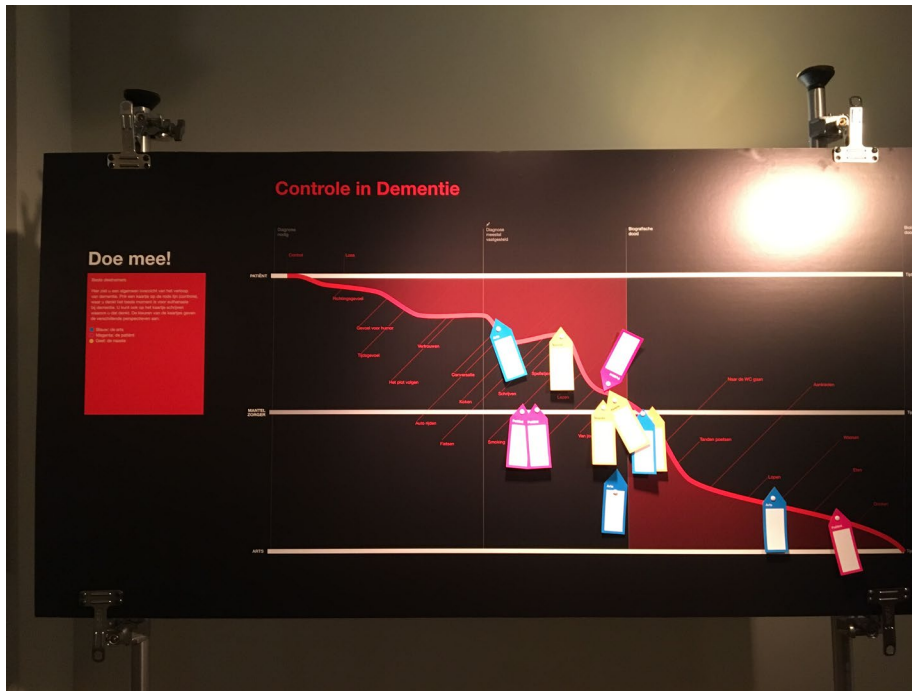


Figure 3. Overview timeline.

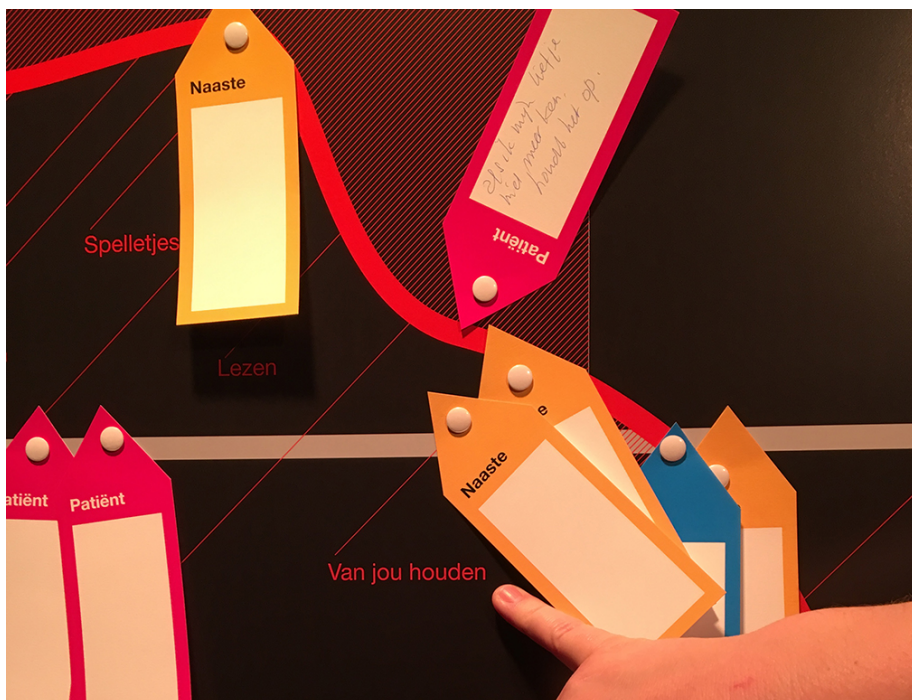


Figure 4. A topic of hot debate: "loving you" (or no longer loving you in the context of the timeline) as a moment deemed unacceptable loss of quality of life "If I can't remember my love, it stops".

6. Discussion

It is important in this discussion to be aware that euthanasia requests are rarely fulfilled in dementia, the only time euthanasia does happen in dementia is very early in the disease. The mapping of this complex problem into a comprehensible timeline was done with the aim of opening up debate.

In order to create a credible graphic a lot of research was done and the timeline's accuracy was confirmed with specialists (academics, physicians) (De Haas, Jun, & Hignett, 2019). The danger of condensing information in one visual representation is the potential loss of nuance and details. The benefits of creating access to the debate however outweighed its dangers and allowed to open up essential discussion around the complex issue of choosing the right time to die.

The timeline was photographed a lot and the authors have received many requests for a copy since the event. The timeline is due to be used at a workshop as part of a government initiative at "een tegen eenzaamheid" [together against loneliness] early 2019. The event organiser who requested a copy stated "*It is a wonderful tool for communication to aid discussion about the responsibilities of non-professional carers and essential values that make up quality of life*".

7. Conclusion

The euthanasia in dementia debate is at an impasse. The intention for producing a visualisation was to design a platform for reframing questions. This research has shown that there are benefits in presenting a dilemma, such as euthanasia in dementia, in a different format. The timeline visual has potential to aid discussion between various stakeholders, without each party needing to be a specialist. The use of a speculation was found to spark debate, but a caveat is the importance of boundaries whereby stakeholders are made aware of the greater context of the problem space so that inherent bias is addressed.

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