

Mortality

Promoting the interdisciplinary study of death and dying

ISSN: 1357-6275 (Print) 1469-9885 (Online) Journal homepage: <https://www.tandfonline.com/loi/cmrt20>

Escaping the 'unprepared generation' trap: discussions about euthanasia after a 'completed life' in the Netherlands

Priya Satalkar & Sjaak van der Geest

To cite this article: Priya Satalkar & Sjaak van der Geest (2019): Escaping the 'unprepared generation' trap: discussions about euthanasia after a 'completed life' in the Netherlands, *Mortality*

To link to this article: <https://doi.org/10.1080/13576275.2019.1585780>



Published online: 05 Mar 2019.




Submit your article to this journal [↗](#)



View Crossmark data [↗](#)



Escaping the ‘unprepared generation’ trap: discussions about euthanasia after a ‘completed life’ in the Netherlands

Priya Satalkar ^a and Sjaak van der Geest^b

^aInstitute for Biomedical Ethics, University of Basel, Switzerland; ^bUniversity of Amsterdam, The Netherlands

ABSTRACT

This article analyses discussions in the Netherlands about extending the current euthanasia legislation to include older people who are tired of living and want to end life without being sick or suffering unbearable pain. We look at these discussion from a generational perspective: the present generation of older people has learned from the experiences of the previous generation that life may last longer than they want and it might be challenging to die in a humane way. First, we briefly sketch the processes that led to the present call for euthanasia on the basis of ‘completed life’ and disentangle the meaning of ‘completed life’ in the existing literature. We then present the results of our qualitative research consisting of interviews with nine people who signed a petition in support of ‘completed life’ euthanasia and analyse their arguments and opinions in the context of a historical timeframe and personal biographies. We then elaborate on individual expectations regarding the enactment of ‘completed life’ euthanasia legislation. We analyse the intertwinement of the respondents’ experiences with other people’s end of life struggles and their personal end-of-life expectations from the perspective of being or not being prepared for the trap of living ‘too long’.

KEYWORDS

Completed life euthanasia; fatigue; loss of autonomy; unwanted dependency; unprepared generation trap; self-euthanasia

Introduction

Historical background

The Netherlands was one of the first countries to legalize euthanasia. Public discussion about euthanasia since the 1970s led to increasing popular support for euthanasia under certain conditions. In 2002 the government issued the ‘Termination of Life on Request and Assisted Suicide (Review Procedures) Act’, which stated that euthanasia and physician-assisted suicide will not be punished if the attending physician acts in accordance with criteria of due care. The new law stipulated that in order to allow euthanasia, there must be unbearable suffering without prospect of improvement, and a voluntary and well-considered request from the patient who is competent to express his/her will. A second physician must be consulted and the euthanasia has to be carried out with due medical care and attention. According to the Ministry of Justice, euthanasia is a life-

terminating action on the explicit request of the patient. Physicians who for religious or ethical reasons object to euthanasia have the right to refuse to perform it.

Most requests for euthanasia come from people whose suffering is unbearable and who regard a self-chosen death to be the only way out. The suffering is almost always physical in nature. In more than 80% of cases, this concerns cancer patients in the final stages of their illness looking for help to die with dignity.

Discussions about the legal criteria for euthanasia have not ceased, however. Some – mainly religious – groups disapprove of the practice. Some doctors consider their task in euthanasia a heavy burden and prefer the much less ‘aggressive’ method of palliative sedation. Others, however, criticize the limitations of the present regulation and plead for an extension of the rules, including older people who are not ill and who do not suffer any physical pain but want their life to end simply because they are tired of it or feel that ‘it is enough’. This article analyses the discussion about the request for euthanasia because of having lived a ‘completed life’ (in Dutch: *voltooid leven*).

The discussion about ‘completed life’ euthanasia became prominent with the launch of a petition by a group calling themselves *Uit Vrije Wil* (Of Free Will), which was signed by more than 100,000 citizens. Their aim was to extend the existing legislation to provide assistance in dying to older people who consider their lives complete. Our article addresses the motivations and expectations of signatories of the petition.

What is a ‘completed life’?

Although ‘completed life’ is a recent concept, the volume of literature discussing the issue is substantial. If we count the public press contributions (news and opinions in daily newspapers and weeklies), the number is more than one hundred. Limiting ourselves to research-based publications that focus on the cultural and political context in the Netherlands, we discern mainly two groups of authors who have carried out research on ‘completed life’ and its relationship to the wish to die. One group consists of Mette Rurup and co-authors, most of whom are based at the Free University of Amsterdam. The other group is headed by Els van Wijngaarden from the University of Humanistic Studies in Utrecht.

The publications by Rurup and colleagues are all based on research that took place in a period when the option of euthanasia due to life fatigue (without physical or mental disease) was being discussed, but before the nationwide petition had been launched. The discussion was ignited by the case of a well-known person who had received euthanasia from a medical doctor because he felt that his life had been ‘complete’. The articles by Rurup and colleagues describe what being ‘tired of life’ meant to their respondents and how these views affected their wish to die. Two articles (Rurup, Onwuteaka-Philipsen, Jansen-van der Weide, & Van der Wal, 2005b; Rurup, Deeg, Poppelaars, Kerkhof, & Onwuteaka-Philipsen, 2011a) were based on questionnaires and three on interviews (Rurup et al. 2005a; 2011b, 2011c). The term ‘completed life’ is not used in their studies. They speak instead of ‘tiredness’ or ‘fatigue’. The concept of life being ‘completed’, which became popular after the 2010 petition, suggests a rather more positive and rational attitude towards voluntary death than ‘fatigue’.

Two significant themes in Rurup et al.’s publications are (1) that the authors take a rather medical view of ‘fatigue’ and (2) that they conclude that medical doctors would

be the most suitable persons to take the final decision about euthanasia and to carry it out. There are several medical professionals among the authors and one article (Rurup et al., 2005a) is based on retrospective interviews with more than 400 (para-) medical respondents.

Van Wijngaarden and colleagues conducted their research when the public debate on voluntary death due to ‘completed life’ had intensified, after the abovementioned Of Free Will petition. The most complete overview of their study can be found in the published version of Van Wijngaarden’s (2016a) doctoral dissertation, but we shall mostly refer to the published articles as these will be more easily available to readers.¹ Van Wijngaarden responded to the topicality and urgency of the ‘completed life’ debate by publishing a more popular Dutch version of her study (2016b), thus contributing to the public and political discussion.

All of Van Wijngaarden and colleagues’ publications are qualitative, using a phenomenological approach (Van Wijngaarden, Leget, & Goossensen, 2016a). Their aim is to capture the views and lived experiences of older people who are confronted with the acute feeling that their life is complete. The various publications are based on diverse research techniques and ‘samples’ of people, for example in-depth interviews with 25 older people (Van Wijngaarden et al. 2015, 2016b), the analysis of two vignettes of older people (Van Wijngaarden et al., 2016a), and a focus on one case of an elderly couple (Van Wijngaarden et al. 2016c). In addition, the study includes an extensive literature review on older people’s wishes to die and assisted death in various forms, contexts and cultures (Van Wijngaarden et al. 2014).

It is impossible to summarize here the many and elaborate nuances that the authors present, but most prominent is their attempt to disentangle what their interlocutors imply when they use terms like ‘tired’ and ‘complete’. They discern five experiences that lead to the conclusion that life is ‘over’ and thus to the wish to die: ‘1) a sense of aching loneliness; 2) the pain of not mattering anymore; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion towards feared dependence’ (Van Wijngaarden et al. 2015, p. 257). In her concluding discussion, Van Wijngaarden (2016a, p. 256) highlights the experience of suffering in the various ways that these older people express their loss of connection with life as they want to live it. ‘Completed life’ thus appears a perhaps too cheerful and rational term for that experience, a euphemism for a painful and disturbing period at the end of life.

Robert Pool and Marije de Groot, anthropologists from the University of Amsterdam who carried out research among people who signed the 2010 Of Free Will petition, remarked that signing and supporting the petition has little predictive value with regard to whether people will actually opt for euthanasia due to life fatigue. Signing, they say, was first of all a political neoliberal statement that people should have the freedom to end their life if they think it is complete (oral communication).

We asked Van Wijngaarden if – and how many – persons from her 25 interlocutors had in fact made the decision to end their life. It should be noted that her respondents had been carefully selected as older persons who declared that they had in fact reached the phase of ‘completed life’. She responded that one person had acquired permission to have euthanasia, but had changed his mind because of the emotional reactions of his family. Others had discussed it with their general practitioner, but no decision had yet been made. As far as she knew, eight of them had, however, chosen some form of ‘self-euthanasia’

(without assistance of a medical doctor). It is this aspect of the 'completed life' discussion that forms the starting point of our article, which explores the reasons, decision making process and expectations of individuals who endorsed the 2010 Of Free Will petition.

The of free will petition

Launched in February 2010, the Of Free Will petition advocated amending the existing legal framework for euthanasia to create the possibility of a dignified death for Dutch elderly citizens based on the principle of self-determination and free will. The concept of 'completed life' in the petition applied to citizens 70 years or older who have a consistent and well-considered wish to die in the absence of unbearable suffering due to physical illness. Dutch law at the time did not acknowledge such requests, although several authors argued that the existing law could be stretched in its interpretation to include such requests (Huxtable & Möller, 2007; Ost & Mullock, 2011).

Within four months of its launch, the petition had been endorsed by 116,871 signatures. This massive public response was interpreted as a perceived need for legally approved assisted dying for the elderly who feel that their life is complete. The petition's main arguments were based on self-determination and free will. Its aim was to create a public discourse and bring about amendments in the existing Euthanasia and Physician Assisted Suicide Act. The petition was discussed in the House of Representatives, after a motion calling on the government to involve the citizens' petition in its evaluation of the euthanasia law. The government's reaction was that the citizens' petition did not relate well to the current system, but that further consideration of the issues raised by the citizens was important. It decided to conduct a study of the legal possibilities and social dilemmas of assisted suicide for people who deem their life 'complete'. A committee, chaired by the sociologist Paul Schnabel, was installed to carry out this study.

In January 2016 the committee remarked that the number of people who wish to die while in a relatively good state of health is probably very small; that wish, they argued, usually comes with an accumulation of physical and/or mental health complaints. They concluded therefore that the existing euthanasia regulation could also accommodate most older people above 70 who consider their life to be 'complete' and that no additional legislation was needed (Adviescommissie 2016). Nine months later, however, in October 2016, two ministers of the government proposed that new legislation should be made to help older people who wish to die after a 'completed life'. The advice of the advisory committee was apparently ignored. The proposal sparked passionate debate both for and against, and proved a thorny issue in the formation of a new government following the 2017 election.²

Research

Objectives

This exploratory qualitative study was carried out in 2011, shortly after the launching of the Of Free Will petition. It aimed to understand the reasoning and decision making of individuals who endorsed the petition. The enquiry was guided by a number of research questions, two of which are relevant for this article: (1) What factors, life events and values influenced the decision to support the Of Free Will petition? (2) What changes did

these supporters expect from being part of the petition in their personal lives and in society?

Methods

From January to March 2011, semi-structured in-depth interviews were carried out with nine English speaking³ Dutch citizens (between 48 and 65) living in the western part of the Netherlands, six women and three men. The respondents were not selected for a specific reason. Seven of them had a university degree, which is of course a very high percentage. The average education level of the signatories of the petition is not known, though it may have been rather high as well.⁴ More details and personal characteristics of the respondents are provided in Table 1. The first respondent was identified through personal contact. The other eight were enrolled using the snowball technique. All interviewees gave oral informed consent. The respondents were engaged in a conversation and had the freedom to speak about anything that they deemed relevant to the topic. Their narratives guided further questions. Each conversation lasted for about 90–120 minutes. All were audio recorded and transcribed verbatim. The transcriptions were sent to the respondents for their feedback, clarifications and comments.

The data was coded manually starting from a concrete to a more abstract level of coding to highlight the recurring themes. Data analysis was done by both authors independently and the themes of analysis were discussed, especially regarding differences in interpretation and to triangulate the relevance and the consistency of the themes. A consensus was reached between the two authors in case of a different interpretation. The research was carried out by the first author. The second author provided comments throughout the research and writing periods.

Table 1. Profile of research participants.

Gender	Male	3
	Female	6
Age	48–59 years	4
	60–70 years	5
Civil status	Never married	1
	Currently married	5
	Divorced	2
	Live-in partnership	1
Education (university degree)	Yes	7
	No	2
Work life	Presently working	4
	Retired	5
Religious views	Non-believer	6
	Believer	3
	Buddhist	2
	Liberal Jewish	1
Member of Netherlands Association of Voluntary Euthanasia (NVVE)	Yes	7
	No	2
Signed advanced directives	Yes	7
	No	2
Discussed euthanasia with the GP	Yes	4*
	No	5

* Two respondents have serious and chronic health conditions: one has multiple sclerosis and the other has co-morbidity of hypertension and childhood-onset diabetes mellitus.

First, we discuss the results and analyse the arguments and opinions of supporters of the petition in the context of the historical time period and their personal biographies. This will be followed by quotations in which the respondents explain their expectations of the enactment of 'completed life' euthanasia legislation.⁵

Life events and personal values shaping the decision to sign the petition

The respondents' views about what a dignified death meant to them had been shaped over many years, primarily by their experiences of the prolonged suffering and death of close family members and acquaintances. Through these experiences within their social environment, all of them had been confronted by what they perceived to be a restrictive interpretation of 'unbearable and hopeless suffering' in the existing euthanasia legislation. They felt the need to have control over the moment and process of dying, just as they believed in having control over their life decisions. The Of Free Will petition therefore had a strong appeal to these individuals, as it raised questions that had bothered them for many years. For all the respondents, the decision to endorse the petition seemed a natural course of action.

Prolonged suffering of parents, close family members or friends

Twenty-three detailed stories about prolonged suffering and death in their immediate family (in particular parents, grandparents and siblings) and among close friends were gathered from the nine respondents during the interviews. With the exception of two cases of suicide, all other deaths had been the result of a person's gradual decline and fading away. There were six people suffering from dementia, four had cancer, nine had atherosclerosis/cerebrovascular accidents leading to paralysis, and four suffered from chronic depression. All respondents were directly involved in the care of these dying persons and in their 'end of life' struggles.

The respondents described how the last years of their relatives and friends had been quite contradictory to the lives they had lived in terms of what they believed in and what was important to them.

My father was not a man to complain. He would bear a lot of pain without a word. He was really suffering and he was in pain, but the doctors didn't believe him. They said they never heard him whimper in pain. We all knew he was in pain and I tried to explain to the doctors that my father is not a man who complains easily. So if he says he is in pain, he is in agony. They made it so difficult for him to get morphine. The dermatologist came to check his ulcers on the leg and he enthusiastically wanted to try some new treatment, while my father was clearly hardly interested in being treated in parts and fragments. We could not understand the insistence on treatment. He wants to die, please leave him alone. (Woman, 60 years old, R4TK)⁶

I told myself, this is what I never want for myself. I do not want to die like this. This thought has always remained with me since the struggle of my father to die. *I don't want that* [firm tone of voice]. If there comes a time... that my grandchildren will visit me maybe once a month, all my organs are functional and quite ok; my life has ended at that moment for me. I have lived my life and I don't want to wait till my heart or my brain stops. *I am responsible for my life and my body.* When I feel that I can't walk the stairs, I can't cook my own meal and I am lonely and can only move from sleeping room to living room or I have

to be dependent on the nurse or caregiver, what the hell is that life? (Woman, 65 years old, R1JVB)

Having witnessed these struggles to die, the respondents had come to believe that the current euthanasia law is too physician-centred, especially in its interpretation of unbearable suffering, and excludes those who have a well-considered and persistent desire to die without an underlying serious physical illness. Ironically, four respondents therefore believed that a diagnosis of cancer might sometimes feel like a 'boon' because then one is more likely to be able to convince the physician of unbearable suffering and hence to receive assistance to die.

Doctors' insistence on continuous medical treatment

The power of medicine over life and death has been a predominant theme in the euthanasia debate in the Netherlands. Respondents of this research echoed the same feelings. According to them, modern medicine and technological advancements treat human beings as multiple organ systems rather than as a person. They felt that failing organs in an older person's body can be kept functional with the help of new treatments and machines, while the person's desire to live has long since depleted. They argued that doctors tend to treat patients overzealously, since their expertise and skills are evaluated in terms of lives saved or years added, rather than focusing on quality of life in these added years. Patients' wishes are rarely taken into account in treatment decisions, particularly in old age (cf. Van der Geest & Niekamp, 2003).

The frailty that comes from old age was perceived as acceptable by the respondents, but not the prolongation of meaningless life due to a doctor's denial of a person's suffering, as they phrased it. The respondents were aware of their increased life expectancy, but they did not wish to suffer in old age like their loved ones had. They hoped to have the means to die with dignity while they are still capable and competent to make such a decision. They had experienced the limited power of advanced directives in the case of their loved ones. They believed that their requests for euthanasia would not be considered under the existing euthanasia legislation if they did not have a physical illness with no hope of relief or treatment. The petition, with its concept of 'completed life', therefore had a great appeal to these individuals, since it drew attention to the needs of those older persons who would not benefit from existing euthanasia legislation. This was further reinforced by their argument of 'free will' and self-determination, which is described in the next section.

All respondents of the study were aware that one does not have a right to die unless a physician is convinced of one's unbearable suffering due to a physical illness.⁷

Yes they have a law, but it is only limited to a few people, only those who are sick and who are able to convince the doctors. It is mainly for terminal patients with cancer. It is not for everyone. (Woman, 48 years old, R6MH)

For me that is the same, physical and mental suffering, but it is not the same for the law. Unbearable pain, what is that? My arm hurts? My head hurts inside? For me it is the same, but for the law it is not that same.... What is unbearable suffering? Is it physical, psychological, social or spiritual? And who should judge this suffering for others? (Woman, 53 years old, R5LA)

Respondents realized that the professional perspective of doctors makes it very hard for them to not treat a patient.

We are talking about someone who wants to cure someone else. He has been trained for it and he lives by that training. How can he let go of a person when his inside wants to cure him? It is an extremely hard decision for doctors to let go and not try new things.... The other problem is how the doctors are being evaluated. They are evaluated for the number of patients they have cured. That is crazy, but that is how the system is. Health care statistics are all about patients treated, lives saved. No one tries to measure the quality of life of those patients who were saved. When the doctor himself or herself goes through such disease conditions, they realize that life is not always worth living, but they can understand it only through their own experience. As long as it is the suffering or experience of the patient, doctors want to try all treatments possible. (Man, 61 years old, R4BK)

Four respondents shared strong concerns about doctors making 'heroic efforts' to keep patients alive, often against their wishes. Here are quotations from two of them:

I don't want to be dependent on the medical profession. I do not agree with the fact that the doctors decide whether I should live for another week because they do not want to pull out the plug [life support]. We live longer... because the doctors keep us alive. That is not my decision, it is their decision. They don't want to discuss it with me. If they won't do anything, most of us will die and it will save lots of money. Half the cost of health care goes to the last few weeks of life. Eighty-year-olds being in intensive care units for another week... Total nonsense, in my opinion. (Woman, 64 years old, R2MJG)

The technical way of keeping people alive is progressing. So people don't die when they break a leg or just because they are old. We are able to restore and fix their bodies. It is urgent to not just look at technical ways of keeping people alive but also to think about whether the life still has meaning, a sense of belonging. Your body might be fixed but your mind can't cope with life anymore. You are tired. Your energy to go on is finished. But you are expected to go on living because your body is still functioning due to technology. Your body is alive but you have lost the meaning of life, you have lost the energy and spirit to go on living. Keeping yourself alive remains a task because the meaning that you attach to your life cannot keep pace with the progress of medical technology and fixing bodies. (Woman, 65 years old, R1JVB)

The above quotations show that the respondents were quite emotional and very outspoken about the hegemony of doctors over people's lives and deaths. They did not always distinguish clearly between patients with physical or mental disorders and older people who are simply tired of life. For them, the medical interference with and theft of people's autonomy is the root of the problem, which has now cumulated in doctors' refusal to recognize fatigue as a legitimate reason for voluntary death. The respondents' experiences with the enforced prolongation of unwanted, meaningless lives had shaped their views about a dignified death and a more person-oriented legislation, including cases of life fatigue.

Respondents' expectations regarding the 'completed life' initiative

Arguing for self-determination and control over life and death

The social movement of emancipation, democratization and feminism in the 1960s and 70s was repeatedly mentioned by the respondents as a strong influence on their political ideology and worldview. Three of the six women had been directly involved in the feminist movement, particularly in the right to abortion in the Netherlands. During

this period, eight respondents had started challenging and critically questioning the influence and power of the church on their lives and had decided to move away from Christian morality. They believed that being a 'non-believer' made it easier for them to take strong steps towards ensuring a good death. Signing the petition was seen as one of these steps, along with membership of the Netherlands Association of Voluntary Euthanasia (NVVE) and the signing of advanced directives. This phase of social revolution had influenced their professional and personal choices regarding marriage, childbirth and other life decisions. Autonomy and self-determination were described as leading values of life. They believed in making their own choices and taking complete responsibility for these choices and their consequences. The prolonged suffering of family members and friends before dying made them determined that *they* should have autonomy and freedom over their own choices at end of life and not be totally dependent on a physician for assisted death.

The predominant focus of the respondents on self-determination and on having control over life events and death was evident at two levels in their narratives. First, we will explain the concept of self-determination, in terms of their decision making process and the kind of death they perceived as acceptable. The decision making process to endorse the petition was highly individual. The signatories' spouses and children had only been informed about their decision just before they signed it. Six respondents had discussed their views with family members, and the reluctance of these family members had not changed their opinion. They argued that after having completed all of their responsibilities towards their family, they had a right to decide on the moment and way of dying. The respondents not only wanted to decide about their death, but they also wanted to take complete responsibility for their actions, including the act of dying itself. All the respondents expressed their preference for a 'cocktail drink' or a pill to end their life, in contrast to a doctor giving a lethal injection, thus further reinforcing their desire for self-determination and 'doing it on their own'.

Independence is the most important value in my life choices. I do not want to be dependent on doctors who keep me alive when my body wants to die. I want to decide that for myself. I want to be more in balance [autonomous] instead of doctors having total say on how my life should continue or end. (Woman, 64 years old, R2MJG)

Nobody, not even my GP, can or may tell me if my life still has sense or not. He may know me very well but he can't make decisions about my life. That is the whole point. How dare he? (Woman, 65 years old, R1JVB)

Death is the final thing you want to have control over. It starts with life (abortion or not, marriage or not, children or not). Now it is time to include death in this list. (Woman, 60 years old, R4TK)

Avoiding extreme dependency and loss of dignity

Another expectation of the respondents that had moved them to support the Of Free Will petition was the fear of dependency on others and losing control over their life. Physical and mental deterioration during old age and gradual dependency on caregivers for everyday life activities were perceived as a violation of personal and private space and a loss of dignity. Five respondents stated that extreme dependency on others

during old age is the main reason for an individual to perceive life as meaningless. The respondents shared a palpable fear of being confined to a bed or wheelchair in a nursing home. These fears were strongest when they had cared for their paralyzed or demented loved ones who had been totally dependent on others for basic care.

This idea that someone will take the decision about how often to shower me or when to wash me, it doesn't make me feel dignified. I want to call it quits while I am still able to make my own choices and while I am able to die the way I lived. (Woman, 48 years old, R6MH)

Referring to a lady that this respondent had agreed to assist in several activities, she further elaborated:

She was 90. You get into her apartment and you get this feeling of [an] old, closed, lifeless life... Every day she would wake up and be scared of being used or being robbed. She was fragile and weak and all she could do was be scared. Her apartment was smelly and old. I don't see myself in this situation. I don't want to end up like that.

Another respondent expressed her aversion towards dependence as follows:

I do not like the prospect of gradual and irreversible deterioration of body and mind and not being able to do things anymore that I used to do conveniently. Why suffer the pain and agony for myself and for the others, like with the death of my mother and my father? I don't want to go into a home. People are living plants there, either demented or depressed. They are completely dependent on the help of others. If I am left to my own devices, slowly deteriorating and have to lie in diapers in my own filth... That is a horrible situation in my view. I'd rather be dead. I want to be my own author. (Woman, 60 years old, R4TK)

Of course, these outspoken and emotional rejections of dependency, long before the respondents themselves were likely to encounter it, cannot be taken as a definite predictor of a decision that they will in fact make in the future. Successful ageing is a process of continuous adjustment to new – restricting – circumstances (Von Faber et al., 2001). Growing disabilities and dependency that seem at first unbearable may gradually be accepted. This contradiction between what relatives and others are inclined to regard as unbearable and what the older person has come to accept has been termed the 'ageing paradox' in the literature (cf. Villar, 2012).

Creating a possibility where none exists

Underlying the respondents' decision to sign the Of Free Will petition was a strong desire to create a possibility for themselves in the future to receive assistance in dying if needed and also to collectivize similar minded individuals to bring about legal and societal change. There was clear resistance towards politicians or professionals who want to decide about the end of life of individuals without taking into account their values or wishes: 'We want to create possibilities' or 'Give voice to the most vulnerable section of the society' were recurring themes in the interviews.⁸

As mentioned before, women in this study often highlighted their active participation in the 'right to abortion' movement in the Netherlands. Their support for this movement did not mean that they would necessarily have an abortion themselves, but they strongly believed that a woman who needs such a possibility should have the right to

one. They described a similar reasoning behind their decision to endorse the Of Free Will initiative. Personally, they may not choose to end their life even if they regard it as complete, but their participation – in terms of signing the petition and their involvement in the corresponding socio-political debate – aimed to create a possibility for people to receive assistance in dying with dignity if this is what they need. The least that respondents wanted from the initiative was to ensure that patients are seen as equal partners in decision making at the end of life, together with their health care professionals, and to have a say in when and how they die.

I imagine that for future generations we will have more hospices. Because it is all about end of life, whether it is voluntary end of life or involuntary, like in cancer patients. When you die, you can't do much about it. You either die at home or in an accident or you land in a hospital, or at some point when they can't care for you any more in a hospital, they prepare you for a nursing home or a hospice. I think... for future generations, the voluntary and involuntary death will come closer together. It will combine in some ways. Not in the immediate future, but it will definitely come. That is why you need initiatives like this one, to bring these subjects in discussion. You may not reach it in your lifetime, but you started the process, which is very important. It's about creating space for people who need it. It is like the fight for abortion law. It did not happen overnight; it was a movement and women coming together and fighting for it, and over years finally such provisions for abortion became possible. (Woman, 53 years old, R5LA)

What the respondents had seen happening with their loved ones and what they wanted for themselves when they grow old flow together in the above quotes: resistance to overbearing medical control, worries about a loss of autonomy, and fear of extreme dependence on others due to physical and mental frailty. Another somewhat confusing aspect of their responses was that very different types of euthanasia (for example, doctor-assisted and self-euthanasia) were sometimes lumped together, as frequently happens in public debates. In the conclusion, we focus on the intertwining of past and future concerns from the perspective of being or not being prepared. We present the concept of the 'unprepared generation' as a trap from which the present generation intends to escape because they have been 'warned'.

Discussion and conclusion: the unprepared generation trap

The conversations with the nine people who signed the petition in favour of completed life euthanasia are prominent examples of what Frances Norwood called euthanasia talk: 'Dutch people are using euthanasia talk to bring concepts of ideal death to play in the everyday reality of bodily decline and social loss' (Norwood, 2009, p. 124). The respondents talked about their experiences with dying relatives and friends to formulate a dignified death for themselves. They said that they had been closely involved in the care of family members and friends who had grown progressively dependent on their caregivers. They had witnessed their gradual decline and ultimate reduction to a living 'thing' confined to a bed. They also emphasized that they had been confronted by what they experienced as the minimal assistance one gets in such situations to achieve a dignified death. The respondents considered such living conditions and state of dependency unacceptable, and against their values of autonomy and self-determination. Thus they 'decided' that they did not want to get into such a situation themselves. We have placed 'decided' between inverted commas because decisions

about voluntary death are less clear cut than they may at first seem. By signing the petition, they made a political statement. They were lobbying for freedom and a means for what they regarded to be a dignified death. They argued that the personal sense of 'completed life' should be a starting point for end-of-life decisions. In contrast to the existing euthanasia law, where doctors must be convinced of a patient's unbearable suffering, these individuals pleaded for self-determination regarding a completed life and hoped to gain control over their future death.

The nine respondents said that they had learnt their lessons and drawn their conclusions from what their parents and others had gone through before them. The previous generation had been caught in the trap of not being prepared, of not knowing how difficult it could be to die in a humane way.

My generation was much more conscious about the freedom we got through the struggles of [the] 1960s and 70s. We could make choices, but that is because we had the possibility to make choices. My parents did not have those possibilities. We were the generation which was offered possibilities and we took them and we still know that in every situation we have a choice to make. (Woman, 57 years old, R3HVV)

Never before in history have people faced the paradoxical dilemma that the advances of medicine would turn against them and force them to continue 'living' against their wishes – at least not to this extent. As Van Wijngaarden et al. (2016b, p. 1) remarked, '... medical science has made it possible to sustain human existence past the point where a competent adult might rationally conclude that life is no longer worth living'. The experiences of the previous generation, who were caught both unawares and unprepared for this development, strengthened our respondents in their determination not to fall into this same trap.

Our view about life is that life must be worth living. That is not exactly what the generations of people [before us] lived for. Our generation wants the control over not only our life but also the moment and way of dying. (Woman, 60 years old, R4TK)

For some, religion was part of this trap.

I do not believe that my life was given by a god; I think I am convinced that I should be able to say, 'Stop it now'. I do not want to be like my aunt sitting in that room. (Woman, 65 years old, R1JVB)

We live much longer. We are more aware of our situation than the generations before us because we have more free time. Our parents were so busy raising children, fulfilling the responsibility of a householder, the physical work in everyday life was way more than what we have to put in. We are also not very religious anymore. (Man, 61 years old, R4BK)

Choosing voluntary death was also regarded as a service to future generations:

I feel that I should think about the others, mainly future generations. Make space for them. It is like those stories I studied in anthropology in hunter gatherer societies. It is not just because they want to sacrifice for the others, but it is also out of love. I see that the cost of health insurance is rising incredibly each year, and it is going to rise more in coming years, but the quality of life for such elderly people is not improving at all. (Woman, 48 years old, R6MH)

Thinking about others constitutes another aspect of the unprepared generation trap, the trap of the ‘sandwich generation’, in which some of our respondents found themselves. Being caught between caring for children and caring for ailing parents or grandparents provided another lesson to our respondents, which was, however, only referred to implicitly. By choosing death to prevent a long period of dependence on the younger generation (much longer than previously, when life expectancy was lower), they would help their children not to be ‘sandwiched’. Ethicists and politicians have stated over and over again that the choice for euthanasia should be free and not influenced by any pressure from others (e.g. Gastmans & De Lepeleire, 2010), but it is of course an illusion that anyone can make a decision in splendid isolation, without taking into account the ideas, worries, wishes and problems of their loved ones and others around them. ‘I don’t want to be a burden on my children’ is probably the most common expression of older people, certainly in the Netherlands. The children may protest and assure their ageing parents that they will never be a burden to them, but the parents know that they *are* a burden. For an overwhelming majority, this awareness will probably never lead to euthanasia, but it does augment their sombreness and worries in old age.

Finally, it should be stressed – as we mentioned before – that the firm statements made by our respondents about making ‘free will’ decisions regarding when their life will be ‘completed’ are not at all reliable predictions of what will in fact happen in the somewhat distant future. They should be interpreted as political statements in which they present themselves as enlightened, emancipated, modern people. Their future reality will, however, be a lot more complex, confusing and messy, as Van Wijngaarden and co-authors have abundantly demonstrated in their publications referred to in this article. Such decisions may turn out to be mere intentions that could not be realized due to a multitude of circumstances. Moreover, research has shown that people asking for euthanasia may at the same time opt for life-extending interventions and do other contradictory things such as borrowing a book from the library a day before the euthanasia will take place (Pool, 2000).

Postscript

Around the time we submitted this manuscript, ‘completed life’ became a hot topic in the international media. The renowned 104-year-old British-Australian geologist and botanist David Goodall travelled from Australia to Basel in Switzerland for an assisted voluntary death. Goodall had tried in vain to die in Australia, where euthanasia is illegal. He told journalists that his life had been rather poor for the past years and that he was very happy to end it, adding: ‘All the publicity that this has been receiving can only, I think, help the cause of euthanasia for the elderly, which I want’. During the interview, he wore a pullover with the inscription ‘Ageing Disgracefully’.

Notes

1. There is, however, the curious and confusing custom that the articles have multiple authors, whereas the thesis (the total of all articles) has only one author.
2. For a detailed overview of the processes that led to the Dutch euthanasia legislation and the Of Free Will petition between 1858 (!) and 2016, see: (Van Wijngaarden, 2016a, pp. 18–28).

3. The interviewer (first author) is English speaking.
4. Cf. Pool and De Groot (oral communication), mentioned before, who described the signatories as 'slightly elitist'.
5. For extensive discussions on methodological and emotional aspects of doing research about death and dying see among others: (Glaser & Strauss, 1965; Van Wijngaarden, 2016a; Visser, 2017; Woodthorpe, 2009).
6. For reasons of anonymity, the respondents are indicted by their code number. Some of the quotes in this article have been slightly edited to make them clearer. The contents were not affected.
7. Another aspect of a patient's dependence on his or her doctor is the doctor's right to refuse to perform euthanasia if he/she has ethical or religious objections. For a juridical discussion of this additional complication, see (Malpas & Owens, 2016).
8. Lemos-Dekker (2018) writes that Dutch family members welcomed the death of a loved one with dementia as a form of care.

Acknowledgments

We thank the respondents for their participation in the research, Els van Wijngaarden for her comments, and Zoe Goldstein for final editing.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributors

Priya Satalkar is trained in Medicine, Public Health, Medical Anthropology and Bioethics. She is currently a postdoctoral researcher in Biomedical Ethics at the University of Basel, Switzerland. This article is built on the research she conducted for her thesis during the Erasmus Mundus Master's in Bioethics.

Sjaak van der Geest is emeritus professor of Medical Anthropology at the University of Amsterdam, the Netherlands. He conducted fieldwork in Ghana and Cameroon and published books and articles on marriage and kinship and various topics in medical anthropology, including the cultural context of pharmaceuticals in non-Western communities, reproductive health, hospital ethnography, death and dying, perceptions of sanitation and waste management, and social and cultural meanings of care and old age in Ghana.

ORCID

Priya Satalkar  <http://orcid.org/0000-0003-2769-8931>

References

- Adviescommissie Voltooid Leven (2016, January). *Voltooid leven: Over hulp bij zelfdoding aan mensen die hun leven voltooid achten* [Completed life: About assisted suicide to people who consider their life complete]. Den Haag. <https://www.bnr.nl/binaries/1000/26/01/rapport-voltooid-leven.pdf>
- Gastmans, C., & De Lepeleire, J. (2010). Living to the bitter end? A personalist approach to euthanasia in persons with severe dementia. *Bioethics*, 24(2), 78–86.
- Glaser, B., & Strauss, A. (1965). *Awareness of dying*. Chicago: Aldine.
- Huxtable, R., & Möller, M. (2007). Setting a principled boundary? Euthanasia as a response to 'life fatigue'. *Bioethics*, 21(3), 117–126. doi:10.1111/biot.2007.21.issue-3

- Lemos-Dekker, N. (2018). Moral frames for lives worth living: Managing the end of life with dementia. *Death Studies*, 42(5), 322–328.
- Malpas, P. J., & Owens, R. G. (2016). Given that physician-assisted dying is ethical, should it be part of a doctor's role? *Mortality*, 21(4), 295–304.
- Norwood, F. (2009). *The maintenance of life: Preventing social death through euthanasia talk and end-of-life care – Lessons from the Netherlands*. Durham NC: Carolina Academic Press.
- Ost, S., & Mullock, A. (2011). Pushing the boundaries of lawful assisted dying in the Netherlands? Existential suffering and lay assistance. *European Journal of Health Law*, 18(2), 163–189.
- Pool, R. (2000). *Negotiating a good death: Euthanasia in the Netherlands*. New York: Haworth Press.
- Rurup, M. L., Deeg, D. J., Poppelaars, J. L., Kerkhof, A. J., & Onwuteaka-Philipsen, B. D. (2011a). Wishes to die in older people: A quantitative study of prevalence and associated factors. *Crisis: Journal of Crisis Intervention & Suicide*, 32(4), 194–203.
- Rurup, M. L., Muller, M. T., Onwuteaka-Philipsen, B. D., van der Heide, A., Van der Wal, G., & Van der Maas, P. J. (2005a). Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: An interview study. *Psychological Medicine*, 35, 665–671.
- Rurup, M. L., Onwuteaka-Philipsen, B. D., Jansen-van der Weide, M. C., & Van der Wal, G. (2005b). When being 'tired of living' plays an important role in a request for euthanasia or physician-assisted suicide: Patient characteristics and the physician's decision. *Health Policy*, 74(2), 157–166.
- Rurup, M. L., Pasman, H. R., Goedhart, J., Deeg, D. J., Kerkhof, A. J., & Onwuteaka-Philipsen, B. D. (2011b). Understanding why older people develop a wish to die: A qualitative interview study. *Crisis: Journal of Crisis Intervention & Suicide*, 32(4), 204–216.
- Rurup, M. L., Pasman, H. R. W., Kerkhof, A. J. F. M., Deeg, D. J. H., & Onwuteaka-Philipsen, B. D. (2011c). Ouderen die 'klaar met leven' zijn: Toekomstverwachtingen en ervaren uitzichtloosheid [Older people who are 'weary of life': Their expectations for the future and perceived hopelessness]. *Tijdschrift voor Gerontologie en Geriatrie*, 42(4), 159–169.
- Van der Geest, S., & Niekamp, A. M. (2003). Ageism and euthanasia in The Netherlands: Questions and conjectures. *Mortality*, 8(3), 296–304.
- Van Wijngaarden, E. (2016a). *Ready to give up on life: A study into the lived experience of older people who consider their lives to be completed and no longer worth living*. Amsterdam: Atlas Contact.
- Van Wijngaarden, E. (2016b). *Voltooid leven: Over leven en willen sterven* [Completed life: About living and wanting to die]. Amsterdam: Atlas Contact.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2014). Experiences and motivations underlying wishes to die in older people who are tired of living: A research area in its infancy. *Omega Journal of Death and Dying*, 69, 191–216.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2015). Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. *Social Science & Medicine*, 138, 257–264.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2016a). Disconnectedness from the here-and-now: A phenomenological perspective as a counteract on the medicalisation of death wishes in elderly people. *Medicine, Health Care & Philosophy*, 19(2), 265–273.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2016b, Jan 18). Caught between intending and doing: Older people ideating on a self-chosen death. *BMJ Open*, 6(1), e009895.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2016c). Till death do us part: The lived experience of an elderly couple who chose to end their lives by spousal self-euthanasia. *Gerontologist*, 56(6), 1062–1071.
- Villar, F. (2012). Successful ageing and development: The contribution of generativity in older age. *Ageing & Society*, 32(7), 1087–1105.
- Visser, R. C. (2017). "Doing death": Reflecting on the researcher's subjectivity and emotions. *Death Studies*, 41(1), 6–13.
- Von Faber, M., Bootsma-van der Wiel, A., van Exel, E., Gussekloo, J., Lagaay, A. M., van Dongen, E., ..., Westendorp, R. G. (2001). Successful aging in the oldest old: Who can be characterized as successfully aged? *Archives of Internal Medicine*, 161(22), 2694–2700.
- Woodthorpe, K. (2009). Reflecting on death: The emotionality of the research encounter. *Mortality*, 14(1), 70–86.