

## **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**

#### **KLAAR MET LEVEN**

**Een studie naar de geleefde ervaring van ouderen  
die hun leven als voltooid beschouwen  
en verlangen naar de dood**

(met een samenvatting in het Nederlands)

#### **PROEFSCHRIFT**

ter verkrijging van de graad van doctor  
aan de Universiteit voor Humanistiek te Utrecht  
op gezag van de Rector Magnificus, prof. dr. Gerty Lensvelt-Mulders  
ingevolge het besluit van het College voor Promoties  
in het openbaar te verdedigen  
op 22 november 2016  
's morgens om 10:30

Door  
Elizabeth Jacoba van Wijngaarden  
geboren op 29 december 1976 te Dordrecht

**Promotoren:**

Prof. dr. Carlo Leget, Universiteit voor Humanistiek

Prof. dr. Anne Goossensen, Universiteit voor Humanistiek

**Leden van de promotiecommissie:**

Prof. dr. Chris Gastmans, Katholieke Universiteit Leuven

Prof. dr. Bregje Onwuteaka-Philipsen, Vrije Universiteit Medisch Centrum

Prof. dr. Paul Schnabel, Universiteit Utrecht

Prof. dr. Evelien Tonkens, Universiteit voor Humanistiek

## SUMMARY

*I will not relinquish old age if it leaves my better part intact. But if it begins to shake my mind, if it destroys its faculties one by one, if it leaves me not life but breath, I will depart from the putrid or tottering edifice. If I must suffer without hope or relief, I will depart, not through fear of the pain itself, but because it prevents all for which I would live (Seneca, quoted in e.g. Werth Jr, 1996).*

*Without much doubt, I have the feeling that many older people would be greatly relieved knowing that there is a means to end life respectably at the moment suitable to them, based on what they can reasonably expect from that point on (Drion, 1991).*

Older people who consider their lives to be ‘completed’, who suffer from the prospect of having to live on and therefore prefer a self-chosen death: it is not a new issue. What is relatively new, though, is the current Dutch debate about whether we should legalize, facilitate and institutionalize assisted dying in such cases. Should older people who come to a well-considered conclusion that life is over have the right to assisted dying? In order to develop a careful and morally responsible policy, it is a prerequisite to first gain deeper understanding of this phenomenon. Essential questions should be addressed, such as: What exactly does it mean that life is considered to be completed? What are the underlying motivations and experiences? Remarkably very little empirical research has been done into this specific phenomenon of completed life in old age. Therefore, we performed the first empirical study worldwide into the lived experiences of older people who consider their lives to be completed and want to terminate their lives at a self-directed moment, without being severely physically or mentally ill. The central research questions were:

1. What is the lived experience of older people who consider their lives to be completed and no longer worth living (without evidence of a life-threatening disease or a psychiatric disorder)?
2. What does it mean to live in-between the intention to end life at a self-directed moment and actually performing a self-directed death (or not)?
3. How can the gained empirical insights (resulting from research questions 1 and 2) be connected with the ethical debate on completed life in old age and what considerations can be developed from a care-ethical understanding of emerging social dilemmas?

**Chapter 1** (the Introduction) outlines the socio-political context of this research project. The current debate about completed life is situated within the Dutch euthanasia debate that took place from 1969 till 2016. This period is divided into three main stages: Stage 1 (1969-1981) is characterized by breaking the taboo on euthanasia. Stage 2 (1982-2002) is the phase of the development and implementation of the Dutch Euthanasia law. Stage 3 (2002-present), concerns the period after the introduction of the Euthanasia law: the developments in the interpretation of the law. Besides, an explanation of the methodological framework of the empirical part of this study is provided in the Introduction. The chosen phenomenological research approach focuses on the lifeworld. The emphasis is on studying the phenomenon as it appears in human experience. This approach is consistent with the objective of this research, namely to understand the phenomenon of complete life in old age from an insider perspective.

## **PART 1: THE STATE OF THE ART**

**Chapter 2** concerns a literature review which provides an overview of the state of the art in the literature on older people with a wish to die. It describes the experiences and motivations underlying the dying wish of older people who are tired of life without suffering from severe depression or a life-threatening illness. Scientific databases were examined for publications between 1991-2011. Studies specifically focussing on a death wish (without a direct medical cause) were rare. Eventually, we found nine studies that met our inclusion criteria. These studies provide insight into the existential impact of the loss experiences associated with ageing; loss of control, connectedness, meaning and identity. These loss experiences play an important role in the development of a wish to die. Other influencing factors are personality traits, biographical factors (such as traumatic events), the social context, and personal beliefs and values. The interpretation of the wish to die differs widely: some studies describe the wish to die in terms of pathology, while others consider a death wish in old age a 'natural' phenomenon. The wish to die is explained as a result of a rational and understandable assessment of the decreasing quality of one's life. One study argued to replace the pathological paradigm with an existential paradigm and explain the death wish in terms of existential grief.

## **PART 2: THE LIVED EXPERIENCE ILLUMINATED**

**Chapter 3** describes the first part of the results of our phenomenological interview study into the lived experience of older people who consider their lives to be completed and no longer worth living. Participants were 25 Dutch mentally competent older people (mean age 82 years) without evidence of a terminal or mental illness. Open, exploratory phenomenological interviews were conducted to study the phenomenon from an insider perspective. Emphasis was not put on perceptions and thoughts, but on the way the phenomenon was lived in everyday life. Our research shows that the essence of the phenomenon can be understood as '*a tangle of inability and unwillingness to connect to one's actual life*', characterized by a permanently lived tension: daily experiences seem incompatible with people's expectations of life and their idea of who they are. While feeling more and more disconnected to life, a yearning desire to end life is strengthened. The experience is further explicated in its five constituents.

The first constituent is *a profound sense of existential loneliness*; older people feel separated from others. While in some cases they still have contacts, those contacts are being seen increasingly sporadically and do not compensate lonely feelings anymore. Despite people being around, they feel a lack of reciprocity and support. The second constituent is *the pain of not mattering*; older people feel sidetracked. They view themselves as dispensable, redundant and not important to people or society. The third constituent is *the growing inability to express oneself*. They are no longer able to carry out the activities they were committed to in life. The loss of these identifying

activities means a loss of the self. The fourth constituent is *existential and physical fatigue*. Some are tired because of physical age-related problems, but in many cases there is also an experience of existential weariness and boredom. People feel old and full of days. The fifth constituent is *a sense of aversion to feared dependence*. This refers to the fear of losing control and the uncertainty as to whether others will guard your interests if you are dependent on them. Most participants expressed a deep shame and disgust of their own deteriorating bodies. A notable finding of this study is that the phenomenon under research appears to have clear socio-positional grounds; feelings of social exclusion and uselessness play an important role in developing a wish to die.

**Chapter 4** describes a phenomenological case study that investigates the lived experience of a Dutch elderly couple who strongly wished to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression. It describes their subjective experiences and considerations prior to their self-chosen death. While the couple was part of the sample described in chapter 3, their case was also separately analysed and described. For this analysis, we used the following lifeworld dimensions: self and project, embodiment, temporality and sociality. This case study shows that the decision for a joint self-chosen death was largely based on the anticipatory fear of further deterioration, further loss of control, and not being able to control the moment and manner of death in the future. The couple's agreement to end their lives together appeared to have reached a deadlock, as their concerns, sense of time and logic differed significantly. Although the couple had talked about their agreement for years, they were unable to discuss the emotional impact with each other and their children. The agreement to end their lives together exercised a hold on them, as they had very different concerns and a very different sense of time and logic. The case ends in a paradox: on the one hand, they die together at a self-appointed moment according to their mutual agreement; but on the other hand, their story indicates that it is very difficult for each of them to keep pace with the other without a form of coercion. The case clearly reveals the ambiguity of people's volition, as choices can shift over time. It also highlights the difficulty of distinguishing between voluntary action and coercion in real life.

**Chapter 5** describes the second part of the results of our phenomenological interview study into the lived experience of 25 elderly people who consider their lives to be completed. The interviews were now analysed focusing on the question of what it means to live with the intention to end life at a self-chosen moment. The liminality or 'in-betweenness' of intending and actually performing a self-directed death (or not) is characterized by *ambivalent feelings of being torn*, expressed in words like: 'dilemma', 'doubt', 'a difficult balancing act', and 'a split position'. This paradoxical position is explicated in the following themes: 1) detachment and attachment; 2) rational and non-rational considerations; 3) taking control and lingering uncertainty; 4) resisting interference and longing for support; 5) legitimacy and illegitimacy. This study nuances earlier research into so-called rational suicides. It introduces empirical evidence to the largely theoretical debate on rational suicide. The period between intending and doing does not show itself as a coherent, calculating process of cognitive-rational judgment. Rather, it appears to be a major existential challenge in which people are caught between opposites within themselves. The findings clearly highlight the need for due consideration of all ambiguities and ambivalences present after a putatively rational decision has been made, in order to develop a careful policy and support for this particular group of older people.

**Chapter 6** describes the metaphorical images used by older people to express their feelings and concerns about (feared) old age. In this metaphor study, the 25 verbatims were reanalysed. All metaphors related to old age were collected and analysed using a phenomenological-hermeneutical method. The following ten central metaphorical concepts were found: 1) struggle; 2) victimhood; 3) void; 4) stagnation; 5) captivity; 6) breakdown; 7) redundancy; 8) sub-humanisation; 9) burden; 10) childhood. The metaphor analysis deepens our understanding of the experience of disconnection in older people with a wish to die (as described in chapter 3). It also furthers insight into the anticipatory anxiety associated with the death wish (which is described in chapters 4 and 5). In addition, the results of this study indirectly demonstrate the potentially negative power of commonly used social constructions of ageing. It empirically illustrates that wide-spread negative, stigmatized images of ageing not only might have added to the devaluation of old age in general, but also might have had an effect on how older people see themselves and might affect personal well-being.

### **PART 3: PHENOMENOLOGICAL AND ETHICAL REFLECTIONS**

**Chapter 7** reflects on the phenomenological approach underlying this research. In the literature, the wish to die in elderly people is often understood from a medical, psychopathological paradigm, referred to as cognitive impairment, depressive disorder, pathological bereavement, and suicidality. In this chapter we evaluate this paradigm by considering three serious limitations. The first is the risk of epistemic transformation: the medicalisation of language might prevent people from having suitable hermeneutical resources to interpret major (existential or moral) experiences and communicate about them. This might result in seriously limiting people's (existential self-)understanding, losing touch with the richness and heteronomy of life, and keeping them in ignorance of how to deal with serious life problems. The second risk of a medical-pathological paradigm is the allocation of the person into a category. Diagnostic classification schemes and symptoms are ways to classify the suicidal behaviour, providing explanations for disorders and diseases and developing effective and evidence-based therapies. This objectifying, instrumental and problem-oriented approach might undermine people's own logic and subjective truth, as the focus is not on the experience of life, but on a reducing model of life. The third risk is that a pathological paradigm tends to focus strongly on the wish to die as being a merely individual problem, deriving from a dysfunctioning mental state. This individualised interpretation has a risk of ignoring the social and cultural embeddedness of this wish. This is problematic because a phenomenon is never to be fully understood apart from its context, as social and positional aspects strongly influence human existence. Without trivializing the success of psychopathology, the need for good diagnostics, and the importance of an objectifying view in some cases, we argue in this chapter that a phenomenological approach can counteract the medicalisation of the wish to die. It provides a different kind of knowledge – so-called pathic knowledge – that functions harmoniously with human existence, because of its careful attention to the lived experiences of individuals, and their (social and cultural) situatedness.

**Chapter 8** reflects on the social-political challenges behind the issue of completed life in old age by connecting our empirical insights with the ethical debate. From a care-ethical stance, we discuss the notions of autonomy, vulnerability, independence, dependencies and dignity that came to the fore during the analysis. By drawing on our empirical work, we argue that the debate on completed life in old age should not primarily focus on the question of whether or not to legitimate the self-directed death.

Rather, it should be put in a wider perspective and focus on the question of how to build an inclusive society, (re)establish trust, and minimise the impact of inherent vulnerabilities and situational dependencies on the lives of older people. Perhaps improving the conditions of those older people might lessen their wish to die and be a more solidary solution.

**Chapter 9** focuses on research ethics. It reflects on the question of how to perform morally good research into highly intimate research topics with a possible impact on life and death. We argue for the need of reflective research ethics as an indispensable addition to procedural research ethics. Ethical guidelines and approvals form an important basis to start from. However, during the research process, ongoing reflection on all kinds of moral tensions is essential. In this chapter, we reflect on four complex ethical issues that came up during our research into older people with a wish to die. Drawing on our experiences, we first discuss the possibly establishing influence of our research on the wish to die (*moral experience of whether-or-not being guilty*); Could it be that the interview established participants' wishes to die? Could it be that joining this research project unintentionally strengthened their intentions to end their lives at a self-directed moment? Secondly, we discuss the suggested duty to intervene (*moral experience of transgressing the person's autonomy*); Should we have compromised their autonomy, freedom and self-determination and insisted on treatment, while they considered themselves as fully capable to handle their lives by themselves? Did we have a duty to intervene, knowing that participants were seriously ideating on a self-directed death? Thirdly, we reflect on the dilemma of intimacy (*moral experience of disappointing trust*); How to deal in a morally good way with the dilemma of intimacy? Is it justifiable to have a very intimate (and quite rare) conversation about the experiences of ideating on a self-directed death and then 'leave' a participant alone again? Lastly, the researcher's authority and power over the data is discussed (*moral experience of presumed misrepresentation*). How do we relate to the fact that participants tell their stories and that in many cases participants' stories turned out to be much more ambivalent and vulnerable than participants would have liked to present them in the first instance? To what extent is it justifiable that the researcher has the final authority and power over the data? After reflection, we conclude that being open about ethical uneasiness is crucial because in many borderline cases, there are only open-ended answers needing an enquiring mind, rather than clear and fixed guidelines. Acknowledgement of ethical uneasiness and open-ended reflexivity are indispensable to constitute a morally good research practice.

**Chapter 10** summarizes the main results of this thesis. We also reflect on our research methodology and discuss some of the strengths and limitations of this study. Our discussion ends with some suggestions for future research.

The first important key finding is the essential meaning structure of the phenomenon of 'life is completed and no longer worth living', which can be described as '*a tangle of inability and unwillingness to connect to one's actual life*'. This sense of disconnectedness is completely intertwined with the way people experience their identity, their body, their social relations, and their sense of time and space. The older people concerned lose the connection with themselves; their identity is threatened. They also lose the connection with their bodies. The process of bodily deterioration evokes feelings of uselessness, being a burden and indignity. They also lose the connection with the world around them. On the one hand, their world is getting

smaller; beloved people fall away. On the other hand, they withdraw themselves from others more or less consciously. Their sense of time also changes considerably. Time becomes an enemy, it stagnates, slows down, bores them. Frightening thoughts about the future and – in some cases – wistful thoughts about the past deprive the lust for life.

The second core finding is the meaning of the liminality of intending and actually performing a self-directed death (or not). This in-between period shows itself as an embodied dilemma, characterized as '*a constant feeling of being torn*'. People are caught between rational and non-rational considerations, conscious and more unconscious motivations, volition and compulsion, certainty and uncertainty, while both states coexist and appear as inextricably connected. Living with the intention to end life at a self-directed moment means constantly living within this penetrating tension.

The wish to die has a bodily dimension. On the one hand, the older people feel threatened by their own body. The unintentional and unwanted bodily changes often cause profoundly alienating feelings and strengthen a wish to die. On the other hand, that same body still gives most of them a sense of energy and vitality as well. The intersubjective dimension of the wish to die shows that while there is a strong desire to make an autonomous choice to end life without any interference of others, the older people simultaneously feel an aching loneliness because of the absence of support and the impossibility to share with anyone their struggle with the ultimate decision. There is also a temporal tension visible in the narratives: many participants are obviously in a kind of hurry, with an urgent drive to seek a way out before it is too late. On the other hand, though, the tendency to postpone hastening death – due to certain attachments to life – is also explicitly common in participants' stories. Lastly, the thought of death seems to create new space. Death is associated with the end of suffering, a release of distress and humiliation, a liberation and deliverance of being locked in in life. The self-directed death is pictured as an '*abiding expanse*', offering an exit. Ideating on death appears to be a way to regain autonomy, it seems to create a liminal space that gives a sense of relief regardless of whether one actually terminates one's own life or not.

The third key point is the description of the social-political challenges that emerge from our findings. Firstly, rather than the outcome of a calculative and rational weighing and balancing of the pros and cons of continuing or ending life, the wish to die appears to be a considerable, existential challenge permeated with ambiguities and ambivalences. Secondly, the evaluations of the older people have a distinct social dimension: older people's sense of indignity and unworthiness appears to be partly rooted in their experiences of societal ignorance, marginalization and exclusion. This is strengthened by the social imagery of the self-disciplined, independent agent, which falls short in appropriately recognizing the full humanity of every vulnerable human being. Thirdly, our empirical work has disclosed a profound sense of mistrust: the older people under study show a lack of trust in sufficient care arrangements, and a lack of assurance that others will take care of them properly when they become utterly dependent. While there is a strong lobby to legalize (medically or non-medically) assisted dying in cases of completed life in old age, our study questions whether this can be seen as a morally appropriate societal answer to the issue at stake. We pose that it might rather be a neglect of unmet needs.



We conclude by evaluating the terms ‘completed life’, ‘tiredness of life’ and ‘suffering from life’. All these terms fall short in describing the phenomenon at stake. Most importantly, our study has shown that a so-called completed life is not at all about ‘fulfilment’ or ‘completeness’; instead it is about existential suffering. Besides, the term completed life suggests a firm and well-established decision – clearly marked in time – that life is ‘over’, as if one has decided that ‘it is done’. However, in real life all kinds of ambiguities and ambivalences appeared to be present. The decision-making process is better characterized as a constant dilemma.

Finally, the term simply ignores the fact that someone is still living on. At least at a biological level, life is not completed yet. But also on the biographical level, life has not stopped yet. Actually, the older people ‘work on’ their own biography very consciously: for example, by active engagement in the political debate on completed life in old age; by joining our research project; and by organizing their death and their funeral in a way they personally prefer. The self-directed death seems not only a way to regain control, but also a way to ‘work on’ a coherent end of their biography. Besides, they also ‘work on’ their biography much more unconsciously, for example by planning another holiday; by opting for a knee surgery; or by moving to another place of residence. In real life, there is no such thing as narrative foreclosure, but rather an ambiguous attempt to foreclose a *certain* biographical end in which people fear to lose their identity. All in all, we conclude that completed life is a euphemism, an indirect phrase with a pleasant sound, used to refer to an experience that is often felt as highly unpleasant. There is a considerable inconsistency between the meaning of the term and the meaning of the experience it refers to. The term can be seen as a frame, an image or metaphor that does not resonate with people’s lived experience. Using the term completed life might not only be inadequate and confusing. Fundamentally, it might be a reduction of the lived experiences to which the term refers.