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.

Remarkably very little empirical research has been done into this specific phenomenon of completed life in old age. In fact, this thesis is 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. It addressed essential questions such as: What exactly does it mean that life is considered to be completed? What are the underlying motivations and experiences?

Els van Wijngaarden (1976) graduated cum laude in Religious Studies at VU University Amsterdam with specialisation in (non-denominational) spiritual counselling in organisations. For three years, she worked as an existential counsellor. Since 2007, she has worked as a lecturer in ethics and existential counselling at two universities for applied sciences in bachelor and post-bachelor programs. In the last four and a half years, she combined her work as a lecturer with a part-time PhD project at the University of Humanistic Studies. Her research was funded by The Netherlands Organisation for Scientific Research.

A study into the lived experience of older people who consider their lives to be completed and no longer worth living

Els van Wijngaarden
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
The research presented in this thesis was performed at the University of Humanistic Studies, Department of Care Ethics, Utrecht, The Netherlands. This study was funded by The Netherlands Organisation for Scientific Research (NWO).

Cover: A calligraphic sound script, by Dineke Groenhof Blaauw. In this thesis, eleven calligraphic sound scripts of Dineke Groenhof Blaauw are depicted. These sound scripts are made in resonance with Sofia Gubaidulina's violin concerto Offertorium, and part of the performance Monument for Life.

Logo: The above logo is designed for this research project. It is based on the symbolism of the circle and the life cycle. The sketchily drawn lines refer to the process by which people give meaning to life.

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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 Medical Center
Prof. dr. Paul Schnabel, Universiteit Utrecht
Prof. dr. Evelien Tonkens, Universiteit voor Humanistiek
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PROLOGUE

In May 2015, I got in touch with Dineke Groenhof Blaauw. After some media attention to my research, she had become interested in my research project and contacted me. She wanted to give me a bundled email exchange (between her and her near family) about the last phase of her mother’s life. This little booklet was titled: ‘My mother, old and worn out.’ After that first contact, we had a mutual exchange of ideas about tiredness of life in older people.

Dineke turned out to be an artist as well and she invited me in her studio to see (and hear) her latest work. She paints with black ink on paper while she is carried along by music. Her work is about resonance. Music guides her. She tries to pre-reflexively respond to the sounds. Dedication, concentration and attentiveness are important pre-conditions for her way of work. As an artist, she must be free from fixation or pressure. The hearing, the seeing and the moving should synchronize. While painting, there is no time for reflection. Her work is about ‘knowing immediately’. This way of working requires of her to be empty and open. Open to sounds, vibration and silence. Open to whatever arises. If all of that harmonises, then a piece of art in which sound and ink coincide might be created, revealing an essence of the music.

When I first visited Dineke’s studio, she put on a performance of her calligraphic sound scripts [in Dutch: kalligrafische klankschriften] made in resonance with Sofia Gubaidulina’s violin concerto Offertorium. This performance was named Monument for Life. For me, this was a very intense occurrence. Gubaidulina’s music is full of impassioned expressiveness. In this specific musical piece, Gubaidulina gives expression to a tangle of ambivalent emotions: Quirky, uneasy, capricious, distorted, almost dark sounds are interspersed with beautiful, serene, contemplative tones. As a listener you feel torn between excitement and despair, between fear and resistance, between flight and fight, between urgency and silence, and be-
tween life and death. Opposites come together, they are united in a human
dimension: this is how life is often experienced. In my view, Dineke’s sound
scripts resonate this music in a very appealing way: the black-and-white, the
drama, the intensity, but also the emptiness, and the silence of light. While
I was listening and watching, her calligraphic sound scripts had the power
to bring this tangle of feelings alive.

After this performance, I had thought a lot about the striking resemblance
between Dineke’s way of doing art and myself doing phenomenological re-
search. The artist and the phenomenological researcher share a common
attitude in their efforts to study the world. They are both concerned with the
meaning structure of how phenomena are experienced and try to disclose
lived experiences. Just like evocative phenomenological descriptions, visual
art can give unique aesthetic expression to factors that are basic to percep-
tion and embody these factors in distinctive ways. It can be seen as a mode
of experiencing the world itself. To put it in the words of Merleau-Ponty:
‘Painting does not imitate the world, but is a world of its own’ (Merleau-Pon-
ty, 1962/1945). Or in the words of Meraud: ‘Art may mirror or mock life, but
above all it makes us question life. It pushes us out of the natural attitude’
(Meraud, 2010).

In my research, the main aim was to illuminate the essence of the phenomen-
on under research which is the common thread through the variety of
participants’ lived experiences; the essential characteristics of the phenomen-
on ‘without which it would not be that phenomenon’. The primary focus
was thus on the lifeworld: not an objective world out there, but a humanly
subjective and relational world, full of meanings (Todres et al., 2007). Rather
than explaining, our focus was on describing the lived experience (Finlay,
2011). Inspired by the philosophy of Merleau-Ponty, I hold the idea that es-
sences belong to ‘the world that is already there’. Thus essences are not a
researcher’s construct, nor an outcome of interpretation, but meaning that
should be ‘disclosed’ in the researching act. To allow the phenomenon
‘to present itself in its otherness’, researchers need an open attitude, be-
ing aware of pre-understandings. This phenomenological attitude is called
the ‘epoch’, described by Dahlberg et al. as ‘an open and bridled attitude’
(Dahlberg et al., 2008). The term ‘bridling’ covers all efforts made by the
researcher to restrain prejudice, personal ideas and scientific assumptions.
Only then, the phenomenon can be explored with a certain openness, sen-
sitivity, wonder and receptivity. It demands ‘a true willingness to listen and see and understand’ (Dahlberg et al., 2008).

After the performance of Dineke’s sound scripts on Gubaidulina’s Offertorium, I was not only touched by the resemblance between her way of doing art and doing phenomenological research. I was also deeply affected by the intrinsic similarities: for me, this musical work gives expression to the tangle of ambivalent emotions present in the narratives of our research participants: torn between fear and resistance, between flight and fight, between urgency and silence, and between life and death. That is why I have chosen to include some of Dineke’s art work in this thesis. Every chapter starts with a sound script on Gubaidulina’s Offertorium. Hopefully, these representations evoke a sense of resonance in the reader as well.
REFERENCES


CHAPTER 1

GENERAL INTRODUCTION
1. INTRODUCTION

The seeds for this thesis were planted in my mind in 2010. At that time, I saw a documentary on the television which was called *Incurably Old*. It was an intriguing film about Ans Nieuwenbrug-Bron (93). Despite her age, Ans was still quite healthy. Her biggest annoyance, though, was the fatigue that increasingly played tricks on her. More and more, she felt limited and frustrated in her daily activities. She was completely done with life. This experience strengthened her intention to end her life at a self-directed moment. In the documentary, she said the following:

*The weaker you are, the harder it is to make the decision. I always compare it with when you’re cold, and you know there’s a blanket. The colder you are, the harder it is to step out of your bed to get that blanket. At the moment I’m still fit, so it is easier for me to make the decision. When I will be less fit, well, I just won’t want that. (...)*

*For sure, it is very rational. It is a very rational decision, and that’s good, just to avoid all emotional distress. Of course I did cry because of emotional thoughts. You know, emotional that you become incontinent or that your body is deteriorating, or...*

*Therefore, I simply force myself to accept my decision to terminate my life: You made this decision, so just go for it!*

When I saw this movie, I was touched by the story of Ans. It made me wonder about the underlying motivations and experiences of people like Ans. What does it mean to feel that you have lived your life, that life is considered to be completed? Why does someone choose to end his life, while not suffering from a serious mental or physical illness? To what extent can this be seen as a rational choice? And what does Ans mean with the emotional distress to which she indirectly refers in the documentary? The story of Ans sparked my wonder about this phenomenon and can be seen as the starting point of this research project.

1.1. THE DUTCH CONTEXT

The documentary *Incurably Old* was broadcast in a period when the issue of older people and the self-directed death came into the public spotlight. In
2009, the initiative group Of Free Will [in Dutch: Uit Vrije Wil] was founded by Yvonne van Baarle in cooperation with the Dutch Humanist Association [in Dutch: het Humanistisch Verbond] and the Right-to-die NL [in Dutch: de Nederlandse Vereniging voor Vrijwillig Levenseinde]. This initiative group made a plea for the right to professional assisted suicide for people over seventy who consider their lives to be completed [in Dutch: voltooid] (Peters et al., 2011). The legal ground for the assisted dying should no longer be a medically classifiable condition. The initiative group argued that older people who suffer from the prospect of living too long, with no perceived quality of life, should be entitled to ‘die with dignity’ in a manner and at a moment in time that they prefer. In 2010, the initiative group filed a civil initiative with 116,871 signatures of support to legalize assisted dying for this specific group. With this initiative, the issue of ‘older people and the self-directed death’ was put high on the social and political agendas.

In the Netherlands, the issue of ‘older people and the self-directed death’ was not a completely new phenomenon. For many years, it has paralleled the related societal debate on the conditions to guarantee a lawful and careful euthanasia practice (Leget, 2010). In 1991 already, Huib Drion – who was a Dutch Supreme Court judge and a professor of civil law – wrote a letter to the editor of a Dutch newspaper called ‘The self-chosen death in the elderly’ (Drion, 1991). In this letter, he advocated a remedy for older people – without a serious medical illness – to end their lives at a self-appointed moment. He wrote:

*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).*

His letter started a debate about whether a so-called ‘Drion pill’ (later referred to as a last-will-pill) should be made available to enable older people to end their own lives if they wished to do so (Drion, 1992a; Drion, 1992b; Achterhuis et al., 1995). In the following years, this discussion about the self-chosen death would continue and go in a new direction after several court cases, the adoption of the Euthanasia Law (2002) and other issues that got wide attention. In Table 1, an overview of the Dutch end-of-life discussion is provided. This overview is not intended to be exhaustive in the description.
of cultural-historical developments, arguments or jurisprudence. Rather, it serves to provide an overall context for the discussion about older people and the self-chosen death. Some key moments in the public debate and the development and implementation of policy are briefly highlighted. For a more in-depth analysis, we refer to literature that specifically focuses on this i.e. (Thomasma et al., 1998; Kennedy, 2002; The, 2009).

We have divided the end-of-life discussion into three main stages. The first stage can be characterized as a period of breaking down the taboo surrounding euthanasia. In the 70s, the public debate about euthanasia began. The main motives used were compassion towards the suffering of fellow human beings, solidarity and mercy on the one hand, and the sanctity of life on the other hand. The debate centered around the developments in medical technology, life-extending interventions, and in particular the medical paradox about two contradictory duties, namely to protect human life and to relief suffering. Obviously, from the beginning the focus in the Dutch discussion was predominantly on a physician’s right-to-assist, not on a patient’s right-to-die (Kennedy, 2002; The, 2009).

The second stage in the end-of-life discussion concerns the period in which the Dutch euthanasia law was developed. While a polarity between the proponents and opponents can be easily recognized, it is striking how relatively smoothly the debate has took place (if compared to other countries). According to Kennedy, this can be partly explained by Dutch governance pragmatism and the consensus politics. Instead of discussing fundamental legal questions, the focus was mainly on the pragmatic question of to what extent euthanasia could be seen as an acceptable medical practice (Kennedy, 2002). Wessel-Tuinstra was the first to put forward a bill to decriminalize physician-assisted suicide. She argued the law should be aligned with social developments and the growing public support for legalization of euthanasia (NVVE, 1980). Opponents criticized her proposal for focusing too narrowly on self-determination and for not acknowledging the difficulty of justifying crucial medical decisions on the grounds of the highly subjective criterion ‘quality of life’. They also pointed out the vagueness of the term ‘euthanasia’ and stated that this concept referred to a multitude of topics, rather than to one topic. The use of such an undifferentiated concept would obscure important differences, each having its own ethical implications and responsibilities.
Between 1990 and 1997, much attention was paid to developing and institutionalizing measures to safeguard against undesirable euthanasia practices. Five landmark court cases have been of crucial importance in the development of the euthanasia law and the requirements, namely 1) the Postma case, 2) the Wertheim case, 3) the Schoonheim case, 4) the Chabot case and 5) the Brongersma case. In 2002, after a long and heated public debate, the Dutch euthanasia law came into effect. In the meanwhile, the public and political debate was broadened to other forms of euthanasia than just cases of terminal illness. Different categories of people were discussed, namely incompetent people (coma patients, newborns, severely demented people), psychiatric patients, and older people tired of living.

The third stage concerns the period after the introduction of the euthanasia law. Since 2002, there had been a broader acceptance and increased incidence of euthanasia. In the beginning, euthanasia was almost entirely restricted to terminally ill patients. Over the years, euthanasia has extended to chronically ill people, newborns, demented people and psychiatric patients and most recently older people suffering from an accumulation of old age complaints. While the focus of the law is on supporting physicians in their conflict in duties, the focus in the debate shifted from compassion, solidarity and mercy towards a focus on the right to self-determination and people's right to an assisted death. There is a growing tendency to favour the possibility of an autonomous decision without the interference of a physician and the availability of a last-will-pill. In court cases, a shift towards cases about assisted suicide by non-physicians can be recognized, i.e. the Muns case, the Hilarius case, the Vink case, the Schellekens case and the Heringa case.

The question as to whether there is empirical evidence for a slippery slope has been raised many times in public as well as in academia. While indeed there has been a clear shift of types of diseases and categories of people, it is important to note that currently there seems to be no evidence of a heightened risk for abuse of vulnerable groups, such as the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities (Battin et al., 2007). However, others argue there might be, at least in Oregon (Finlay and George, 2011).
In short, the controversial issue about older people and the right to an assisted death has been under debate for the last twenty-five years with varying intensity. The accompanied major policy challenges require an in-depth understanding of this specific phenomenon. To carefully address the needs and concerns of the older people involved, one needs to know what these older people actually mean when they say they consider their lives to be completed. However, it turned out that empirical research addressing experiences and motivations of people suffering from life in the absence of a life-threatening condition or mental disorder was very limited (van Wijngaarden et al., 2014; van der Heide et al., 2014; Leget et al., 2010). Thus, in the midst of a topical and often intense debate, this PhD project has empirically explored this research area in its infancy.

Table 1 – Overview of the Dutch end-of-life discussion in three stages

<table>
<thead>
<tr>
<th>Year</th>
<th>Issue</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>1858</td>
<td>The Dettemeijer case</td>
<td>In the Dutch legislative history, before the penal code of 1886 came into force, only in the Dettemeijer Case, assisted suicide was equated with complicity to murder (Vink, 2009).</td>
</tr>
<tr>
<td>1886</td>
<td>Introduction of euthanasia and assisted suicide in the Dutch Penal Code</td>
<td>Since 1886, Articles 293 and 294 of the Dutch Penal Code have prohibited euthanasia and assisted suicide. Article 293 states: “He who robs another of life at his express and serious wish, is punished with a prison sentence of at most twelve years or a fine of the fifth category.” Article 294 prohibits assisted suicide. This article states: ‘He who deliberately incites another to suicide, assists him therein or provides him with the means, is punished, if the suicide follows, with a prison sentence of at most three years or a fine of the fourth category’.</td>
</tr>
<tr>
<td>1940-1945</td>
<td>Aktion T4</td>
<td>Aktion T4 was the code name of the Nazi eugenic euthanasia and sterilization program. The aim of this program was to preserve the genetic purity of the German people by the systematic murder of people who were disfigured or disabled or suffering from some form of mental illness. An argument to justify this murder was that the existence (and the ascribed suffering) of these people was pointless and senseless. This so-called ‘mercy killing’ was presented as a human act of mercy to these people. After the second world war, as a result of Aktion T4, euthanasia was taboo for years and legalization was simply unthinkable (Binding and Hoche, 1992).</td>
</tr>
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Stage 1: From 1969-1981
Breaking down the taboo surrounding euthanasia

<table>
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<tr>
<th>Year</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>1969</td>
<td>Publication of <em>Medical Power and Medical Ethics</em> by H.J. van den Berg. With his book, Van den Berg broke down the taboo on discussing euthanasia. He strongly criticized the prevailing medical ethos that life-extending medical treatments were justified at all costs. He also attacked medical power by pointing out the paternalism of physicians who forced patients to undergo treatment and refused to let them die. Since this publication, the debate about euthanasia became embedded in the general debate on medical ethics. The resulting openness towards the issue of euthanasia is also partly attributed to the democratization movements in the 1960s (Kennedy, 2002).</td>
</tr>
<tr>
<td>Late 60s / early 70s</td>
<td>Breakdown of the taboo on performing euthanasia by Piet Admiraal. Piet Admiraal broke the taboo on administering morphine and performing euthanasia in his readings and lectures throughout the Netherlands. Admiraal was an anaesthetist from 1963 until his retirement in 1994. In the late 60s, as one of the first, he realized palliative care for terminally ill patients, inspired by the English Cecily Saunders. This palliative care was a joint effort of nursing, social work, a pastor and a doctor. He pleaded for euthanasia as being a last stage in the terminal phase.</td>
</tr>
</tbody>
</table>
| 1971-1973 | The Postma case. On October 19, 1971 the Dutch general practitioner Geertruida Postma-van Boven gave her ill mother a lethal injection of morphine, after her mother had asked repeatedly for her help to terminate her life. This case was brought to court and led to a heated public debate on euthanasia. The Court of Leeuwarden expressed that life-shortening actions could be justified if they meet certain requirements, namely:  
- The patient is sick because of an incurable illness or accident.  
- The physical or mental suffering is unbearable for the patient.  
- The patient has clearly expressed a desire to end his or her life.  
The Postma case was the first out of five court decisions that has been of crucial importance to the development of the euthanasia law and the formulation of the requirements of due care. |
| 1972-1973 | The institutionalization of the euthanasia movement. The institutionalization of the euthanasia movement got started. In 1972, a pro-euthanasia task force was founded by Jaap Sybrandy and his wife Klazien Alberda, both sympathizers of the general practitioner Postma-van Boven. In February 1973, the Right-to-die NL was established aiming at the social acceptance and legalization of voluntary euthanasia. |
1972-1983 The institutionalization of the pro-life movement

As a counter reaction to the institutionalization of the pro-euthanasia movement, an institutionalized pro-life movement arose, for example:

- 1972: Establishment of the Netherlands Physicians’ League (NAV). Distressed doctors split off from The Royal Dutch Medical Association. The NAV has advocated against legalizing euthanasia and abortion in the belief that doctors should be inspired by an unconditional respect for human life.
- 1982: Establishment of the Netherlands Patients Association (NPV).


In his medical guide for euthanasia, Piet Admiraal described what medications a physician should use for euthanasia. In 1980, the Right-to-die-NL sent this brochure to all general practitioners and pharmacists in the Netherlands.

1981 The Wertheim case

This case concerns Ms Wertheim, who assisted a 67-year-old woman in committing suicide, while not being a physician. At a clear request, Wertheim provided and administered the lethal drug. The woman who committed suicide had suffered severely from life from her childhood. She lived a very isolated life and additionally she was under the assumption of having cancer as well. The Court of Rotterdam ruled that in exceptional cases assisted suicide should not necessarily be unacceptable. They also held that for the suicidal individual (as well as for the significant others) it is important that there are possible ways to commit suicide in a non-violent way. However, the court ruled that, in general, this presupposes the help of another person. Therefore, they added new requirements, namely:

- The decision to assist should not be taken by one person.
- The lethal drug should always be prescribed by a physician; only a physician is allowed to assist.
- The physician should make a good prognosis and adequately inform the patient about alternatives.

The Wertheim case is seen as the second court decision that has been important in the development of the euthanasia law.
### Stage 2: From 1982-2002
#### Towards the Dutch euthanasia law

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<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1982</td>
<td>Establishment of the Netherlands State Commission on Euthanasia</td>
<td>The establishment of the Netherlands State Commission on Euthanasia to advise the Government on its future policy with regard to legislation of euthanasia.</td>
</tr>
<tr>
<td>1984-1986</td>
<td>The Schoonheim case</td>
<td>The Schoonheim case (also known as the Alkmaar case) concerned a 95-year-old woman who was seriously ill without a chance of recovery. As she suffered greatly from substantial deterioration, she had asked her physician several times to end her life. Finally, the doctor decided to act according to her wishes as he was convinced that her suffering was unbearable and hopeless. After several court cases, the Supreme Court held that the invocation of a situation of ‘force majeure’ (or necessity) – resulting from a conflict of duties – was justifiable. The court held that the physician had carefully balanced the duty to alleviate hopeless suffering and the duty to preserve the patient’s life and thus should not be convicted. This case can be seen as the third court decision that has been important in the development of the euthanasia law, because the conditions for invocation of force majeure in the cases of assisted suicide were formulated.</td>
</tr>
<tr>
<td>1984</td>
<td>Bill Wessel-Tuinstra</td>
<td>With this legislative proposal, Wessel-Tuinstra tried to amend the Articles 293 and 294 of the Penal Code. Wessel-Tuinstra proposed that assisted suicide should be decriminalized, and that the law should be aligned with social developments (NVVE, 1980).</td>
</tr>
<tr>
<td>1984</td>
<td>KNMG Position Paper on euthanasia</td>
<td>The Royal Dutch Medical Association (KNMG) published a position paper, in which they took the position that euthanasia and physician assisted suicide could be acceptable under certain circumstances. This paper also contains a formulation of due care criteria that should be taken into account by physicians involved in euthanasia. It has played a key role in the euthanasia debate in the Netherlands (Kennedy, 2002).</td>
</tr>
<tr>
<td>1985</td>
<td>Report of the Netherlands State Commission on Euthanasia</td>
<td>The Netherlands State Commission on Euthanasia proposed that the law should be amended in such a way that intentional termination of another person's life after his or her clear and repeated request would not be an offence, provided that it is performed by a doctor in the context of careful medical practice in respect of a patient who is suffering unbearably with no prospect of improvement (Gevers, 1987).</td>
</tr>
</tbody>
</table>
**1985** The Admiraal case

In 1983, Piet Admiraal reported euthanasia, which he had performed to a woman with multiple sclerosis. The woman suffered from life as she was totally paralyzed and had great difficulty swallowing. She lived in a nursing home, but her physician refused to perform euthanasia. That is why she went to the Hippolytus hospital, where Admiraal performed the euthanasia. He had not expected prosecution because in previous cases, the court had not taken any action. This prosecution was probably deployed since Admiraal’s advocacy of euthanasia received a lot of media attention. In 1985, the lawsuit ensued. The Public Prosecution [in Dutch: Openbaar Ministerie] was actually convinced of due care and demanded ‘guilty without punishment’. The court went one step further and ruled acquittal. No appeal followed.

**1986** Publication of *Mag een dokter doden?* by Prof. dr. Dessaur

In this publication, Dessaur and Rutenfrans discussed arguments opposing what they call ‘euthanasiasm’ and physician assisted suicide. They were of the opinion that an ideology of death should never be implemented in social policy (Dessaur and Rutenfrans, 1986). The public debate became more intense and emotional.

**1990** The Committee Remmelink

In 1990, the government installed a committee to investigate the current medical practice of euthanasia. On behalf of this committee, independent research was done into the medical decisions about end-of-life and the practice of termination of life (van der Maas et al., 1991b; van der Maas et al., 1991a).

**1990** National reporting procedure

Simultaneously with the installation of the Committee Remmelink, the national reporting requirements for physician-assisted suicide and euthanasia entered into force and were legally enshrined in a governmental decree. Ten years later, this reporting procedure was modified into the Dutch Termination of Life on Request and Assisted Suicide Act.

**1991** Drion’s letter *The self-chosen death in the elderly*

In 1991, Huib Drion – who was a Dutch Supreme Court judge and a professor of civil law – wrote a letter to the editor of the Dutch newspaper NRC Handelsblad titled ‘The self-chosen death in the elderly’ (Drion, 1991). This letter can be seen as the beginning of an ongoing discussion about older people and the self-chosen death. It fueled the public debate by advocating a remedy (often referred to as ‘Drion’s pill’) for older people – without a serious medical illness – to end their lives at a self-appointed moment (Drion, 1992b; Drion, 1991).

**1993-1999** Bill Van Boxtel

Van Boxtel introduced a bill in parliament saying that a physician who performed euthanasia with due diligence should not be prosecuted.
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Description</th>
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<tbody>
<tr>
<td>1994</td>
<td>The Chabot case</td>
<td>The Chabot case dealt with the assistance of a psychiatrist in suicide in the case of a person whose suffering was not of somatic origin, but only from psychic traumas. The Dutch Supreme Court came to the conclusion that in this case, there was evidence of unbearable and hopeless suffering, unregarded the cause of the suffering. It was the first time that a court separated suffering from an underlying medical illness and decided that suffering caused by psychological problems could also be unbearable. The Court also held that legally the wish to die of a person suffering from a psychiatric illness could be considered as a result of a substantially autonomous, competent and voluntary judgement (Griffiths, 1995). This case can be seen as the fourth court decision that has been of high importance to the development of the euthanasia law due to the formal distinction between physical suffering and psychological suffering.</td>
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<td>1994</td>
<td>Documentary <em>Death on Request</em></td>
<td>The documentary <em>Death on Request</em> – which was the opening film on IDFA and broadcast in October on the Dutch television – can be seen as one of the most controversial documentaries of the past 25 years. It has fueled the national and international debate on euthanasia. In this documentary, Maarten Nederhorst followed Cees van Wendel de Joode, who suffered severely from ALS. Nederhorst recorded the whole process towards euthanasia: from the first conversations between Van Wendel de Joode and his GP until the night the GP administered the lethal injections. The documentary put a great emphasis on the role of the GP. This euthanasia was the first case of euthanasia on television.</td>
</tr>
<tr>
<td>1995</td>
<td>The establishment of the Foundation De Einder</td>
<td>The establishment of the Foundation De Einder by Jan Hilarius. This foundation aimed to assist and support people with a wish to die to die at a self-appointed moment.</td>
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<tr>
<td>1996</td>
<td>The establishment of the Foundation for Voluntary Life (SVL)</td>
<td>The establishment of the Foundation for Voluntary Life (SVL). This foundation aimed to assist and support people with a wish to die. This foundation was abolished in 2015.</td>
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The case of ‘t Blauwborgje  

The case of ‘t Blauwborgje fueled a heated societal debate about dying as a result of abstaining from eating and drinking [in Dutch: versterven] [Pool, 2004; The, 2005]. A newspaper reported that a psychogeriatric nursing home called ‘t Blauwborgje had purposely allowed a 62-year-old man suffering from Alzheimer to ‘dehydrate’ in order to let him die a gentle death. The family (a daughter and an ex-wife) reported the case to the police and accused the staff of attempted murder. In the months afterwards, important questions were: To what extent is deliberate dehydration related to euthanasia? Is it a good death? Should it be seen as a natural and peaceful death or as a horrible death imposed on helpless psychogeriatric patients? To what extent could it be seen as voluntary? Was the patient in control? There was also a call for more external control and guidelines for nursing homes.

Guidelines for psychiatrists  

In 1998, the Dutch Association for Psychiatry (NVvP) developed a guideline for psychiatrists concerning how to deal with a request for euthanasia or assisted suicide by patients with a psychiatric disorder. The guideline requires that a patient’s request is voluntary, explicit and well-considered, the desire for death long-lasting and the suffering unbearable and hopeless. An independent psychiatrist should be consulted as well as former treating physicians, the general practitioner, family members and other people involved (Tholen et al., 1999). This guideline was renewed in 2004 and 2009 (Tholen et al., 2009).

The Muns case  

This was the first persecution of a counsellor of Foundation De Einder: Muns, who was a humanistic counsellor, was persecuted for illegitimately assisting in the suicide of a 81-year-old lady, as he was present at the moment she died, mixed the lethal drug with yoghurt and jam, and advised her how to fasten the plastic bag around her head.
1998-2002 The Brongersma case

The Brongersma case is the last court case that has been of crucial importance to the development of the euthanasia law and its requirements. It involved a doctor assisting in the suicide of a former Dutch senate member who was tired of life. Fundamental questions in this court case were: Does existential suffering (such as the experience of an empty and lonely existence and the hopeless fear that the situation may not improve) belong to the domain of medicine? And could a doctor legitimately perform euthanasia in cases where the suffering is primarily characterized by psychological factors in the absence of a physical illness? The Supreme Court held that questions about life and existential suffering (such as hopeless despair, loneliness and existential suffering caused by the inability to adapt to a new situation) are beyond a doctor’s professional competence. They further specified the notion of unbearable suffering caused by psychological problems (dealt with in the Chabot case) in the sense that suffering should originate from a medically classifiable disease, either somatic or psychiatric. The Court ruled that the doctor who helped this man die was guilty of assisted suicide (de Vries, 2004; Huxtable and Möller, 2007).

2001-2002 The Dutch Termination of Life on Request and Assisted Suicide Act

The Dutch Termination of Life on Request and Assisted Suicide Act was passed by a majority in 2001. It came into effect on 1 April 2002. It states that euthanasia and physician-assisted suicide are legal only if the criteria laid down in the law are fully observed. Only then, the physician is not punishable. The requirements of due care mean that:

a) the physician holds the conviction that the request by the patient was voluntary and well-considered;

b) the physician holds the conviction that the patient’s suffering was lasting and unbearable;

c) the physician informed the patient about the situation he was in and about his prospects;

d) the patient held the conviction that there was no other reasonable solution for the situation he was in;

e) the physician has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a – d;

f) the physician terminated a life or assisted in a suicide with due care (Leget, 2013).
### Stage 3: From 2002-now

**Developments after the introduction of the euthanasia law**

<table>
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<tr>
<th>Year</th>
<th>Event</th>
<th>Description</th>
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<tr>
<td>2004</td>
<td>The Committee Dijkhuis</td>
<td>The Committee Dijkhuis was established by The Royal Dutch Medical Association as a response to the rulings of the Supreme Court (2002) in the Brongersma case. This special committee was asked to further explore the ethical and practical implications of requests for euthanasia from older people who wish to die because they are ‘tired of life’. They also had to formulate some recommendations for the medical practice. The Committee was of the opinion that the legal demarcation of a medical cause does not always reflect the complexity of medical practice and that tiredness of life should not automatically be put outside of the medical domain (Dijkhuis et al., 2004).</td>
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<td>2004</td>
<td>The Groningen Protocol</td>
<td>In the mid-1990s, two Dutch courts considered two cases with regard to euthanasia in infants. One dealt with a physician who ended the life of a newborn with an extreme form of spina bifida. The other dealt with a physician who ended the life of a newborn suffering from trisomy 13. These cases have provided some guidance for both judges and physicians in end-of-life decisions, as the courts approved the procedures as meeting the requirements for good medical practice. However, many physicians repeatedly pleaded for clearer guidelines to assess such cases. As a reaction to this plea, Verhagen and colleagues developed the Groningen Protocol in 2002. This protocol contains general guidelines and specific requirements related to the decision about euthanasia and its implementation. Five medical requirements must be fulfilled; other supportive criteria were designed to clarify the decision and facilitate assessment (Verhagen and Sauer 2005).</td>
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<td>2005</td>
<td>The Hilarius case</td>
<td>This was the second prosecution of a counsellor of Foundation De Einder: Jan Hilarius was prosecuted for illegitimately assisting in the suicide of a 25-year-old lady, as he had decided to administer the lethal pills to her.</td>
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<td>2007</td>
<td>The Vink case</td>
<td>This was the third prosecution of a counsellor of Foundation De Einder: Ton Vink was persecuted for illegitimately assisting in a suicide of a 54-year-old lady. Her wish to die was not associated with her terminal illness, but with the fact that she was ‘finished with life’. For ten months, Vink had regularly spoken to her by phone in order to clarify her wish to die. In addition, he had sent some general information about suicide and what could be considered as appropriate lethal drugs.</td>
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2009-2012 The Schellekens case
This concerned a case against the Foundation for Voluntary Life (SVL) and its chairman Gerard Schellekens to face charges of providing assisted suicide in November 2007 to an 80-year-old woman who had suffered for fifteen years from Parkinson's disease. The doctor of the nursing home where the woman had lived for five years had refused her request for euthanasia. Therefore, her family went to the SVL for advice. In February 2012, the court in Arnhem imposed a suspended prison sentence of 12 months on Schellekens, because he was not a medical professional and thus found guilty of assisted suicide.

2009-2010 Civil initiative Of Free Will
The initiative group Of Free Will filed a civil initiative with 116,871 signatures of support, making a plea for legalizing assisted dying for older people who suffer from the prospect of living too long with no perceived quality of life (Beekman, 2011).

2012 Foundation End-of-Life Clinic
Right-to-Die NL founded the End-of-Life Clinic in 2012 to provide euthanasia or physician-assisted suicide for patients who meet all legal requirements, but whose regular physicians rejected their request.

2012-now The Heringa case
The Heringa Case also dealt with non-physician-assisted suicide. Albert Heringa was prosecuted for assisting in the suicide of his 99-year-old stepmother who suffered from the ailments of old age. He provided her with enough pills for a fatal overdose. In 2013, a Dutch court ruled that Mr Heringa was guilty of assisted suicide, but he received no punishment since the court was convinced that Heringa's assistance had been motivated by love for his mother. In 2015, an appeal court cleared Heringa of all criminal responsibility. In its decision overturning the 2013 court decision, the appeal court stated that Heringa should not be prosecuted for assisted suicide by noting that he had to decide between his duty to obey the law and his ‘unwritten moral duty’ to help his mother die in the manner she wished for. The Public Prosecutor has asked to bring the case to a court of cassation. The case is thus not closed yet.

2013 Foundation of the Cooperative Last Will
In 2013, The Cooperative Last Will was established aiming to enable a legal and dignified suicide for those who consider their lives to be completed without any intervention of another. The cooperative is committed to making the last-will-pill available to people aged over 18.
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<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>2014</td>
<td>Establishment of The Committee of Wise People</td>
<td>The Committee of Wise People was established by the Dutch Government to explore the legal possibilities and the societal dilemmas with regard to assisted suicide in cases of completed life. This was done in response to a growing group of Dutch citizens in favour of the possibility of an assisted suicide when they consider their lives no longer worth living, the civil initiative Of Free Will and The Heringa Case.</td>
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<tr>
<td>2015</td>
<td>Guideline Written request for euthanasia</td>
<td>In December 2015, a special task force with members of the Royal Dutch Medical Association, the Ministry of Security and Justice and the Ministry of Health, Welfare and Sport presented a new guideline: ‘Written requests for euthanasia’. The guideline was developed to inform patients and physicians about the possibilities and difficulties surrounding the use of written requests for euthanasia. It should provide clarity about the (im)possibilities of euthanasia in cases of dementia and on how to deal with written euthanasia requests of incompetent patients suffering from dementia.</td>
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<td>2014-2016</td>
<td>Advice report of The Committee of Wise People</td>
<td>In February 2016, The Committee of Wise People ‘on assisted suicide to people who consider their lives to be completed’ presented its report in which it gave the advice not to change the current law. Instead, they described the existing possibilities within the current law to perform euthanasia in cases of a serious accumulation of old-age problems. They also highlighted the need for a social understanding of the problem of completed life (Schnabel et al., 2016).</td>
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1.2. OBJECTIVES AND RESEARCH QUESTIONS
The main objective of this study was to provide an in-depth understanding of the phenomenon of ‘life is completed and no longer worth living’, as it is lived and experienced by older people who live with the intention to end their lives at a self-directed moment. Next, we aimed to further the ethical deliberation on the issue of older people and self-directed death by a care-ethical reflection on this phenomenon. 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 ques-
tions 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?

1.3. METHOD: A PHENOMENOLOGICAL APPROACH

In part 2 of this thesis, we have attempted to clarify the lived experience of ‘completed life’ in older people in order to gain an attuned understanding: How is this phenomenon lived; what do the day-to-day struggles, experienced contingencies, and the crisis in meaning exist of? Because this research project aims to give insight in the experiences of people from an insider perspective, a phenomenological approach – free from pre-fixed theories or frameworks – seems to be the best way to achieve this. This approach is characterized by an open, non-judging and wondering attitude (van Manen, 2014; Dahlberg et al., 2008; Finlay, 2011) and it advocates the need for complexity rather than abstract knowledge. It uses evocative and rich descriptions in an attempt to disclose the manner in which humans constitute the meaning of lived experience. In this section I describe some important paradigm stances underlying this thesis.

The choice for a phenomenological approach consists of philosophical, ontological assumptions about the nature of reality and its characteristics. Following Husserl’s criticism of the reductionist and atomistic approach of positivism (Dahlberg et al., 2008), phenomenology concerns the study of the structures of lived experiences. The focus is on studying phenomena as they appear in the human experience from the perspective of the individual, ‘bracketing’ taken-for-granted assumptions and usual ways of perceiving (Finlay, 2011; Dahlberg et al., 2008). In other words, phenomenology focuses on the world as it is lived, not as it is thought about (Merleau-Ponty, 1962/1945; Dahlberg et al., 2008; van Manen, 2014).

**Embodied knowledge:** Epistemologically, phenomenology is based on a paradigm of personal knowledge and subjectivity, and emphasises the importance of meaning and interpretation. It tries to grasp the lived experience (van Manen, 2014) and foster an embodied epistemology (van Manen, 2014). Knowing and knowledge are considered to be essentially subjective, because the subject is inseparable from the body and the world (Merleau-Ponty, 1962/1945). There is no thinking separate from the body. Indeed, the
body, the subject, and the world are intertwined. Embodiment is seen as an existential condition of being-in-the-world. Only as a body we have access to the world, and only as a body we can relate our experiences (22). We can never separate ourselves from this embodiment, never detach ourselves from our subjective bodies (Dahlberg et al., 2008). Consequently, in a phenomenological understanding all knowledge is embodied knowledge (Dahlberg et al., 2008), depending on the lived experience and interpretation of the people involved (Svenaeus, 2000).

**Contextual lived experiences**: As mentioned, in phenomenology humans are seen as embodied and intentional beings. Thought and language are essentially interconnected with bodily existence and bodily experiences. Therefore, phenomenological researchers are explicitly encouraged to put the emphasis on an exploration of what is experienced and of how the phenomenon under research is lived. Rather than focusing on thoughts and feelings, the focus is on what people do and what the context of this ‘doing’ is. Researchers should pose questions about actions, situations, habits, and events: ‘tell me about your experience’; ‘what does it mean to you?’; ‘in what kind of situations?’; ‘what happened?’; ‘what did you do?’; ‘how did that go?’; ‘who else was involved?’, and ‘in what way?’ (Slatman, 2014; Dahlberg, 2006b).

**Essence**: Phenomenology does not simply aim to describe the world from a first-person perspective, but it rather attempts to systematically and conceptually explore meaning structures of being-in-the-world (Svenaeus, 2011; Svenaeus, 2000), revealing a common human understanding of the world (van Manen, 1990). The focus is on the illumination of the essence of the phenomenon which refers to a common thread through the variety of participants’ experiences; the essential characteristics of the phenomenon “without which it would not be that phenomenon” (Dahlberg, 2006a; Dahlberg et al., 2008). We hope that our descriptions of older people’s experiences enable the reader to gain a better understanding of what it is like for someone to experience that life is completed and no longer worth living.

**Intentionality**: Phenomenology denies all dichotomies or dualisms between the individual and the world. Rather, it is a philosophy of in-betweenness. The idea of the lifeworld unites the individual, the body and the (social) world: the individual is of the world as much as the world is of the individual (Dahlberg, 2006b). Being is always understood as being-in-a-context.
This implies that an object or person cannot be fully understood apart from its situatedness in – and its directedness towards – its world context. In its directedness towards the world an object or person exhibits a certain ‘intentionality’. This phenomenological idea of intentionality refers to the fact that when a person's experience is directed towards something, it is experienced as something which has meaning for us. Humans are intentional beings.

**Integrating the empirical and the normative:** Chapter 8 of this thesis deals with research question 3. It describes the phenomenon in a normative way. Empirical research attempts to describe the world as it is, while normative research seeks to describe the world as it ought to be. But why and how should we integrate the empirical and the normative? We follow the idea that for normative judgments empirical support is needed, as the use of abstract norms without empirical evidence creates the risk of losing touch with, or misinterpreting, the lived morality (Leget et al., 2009; Molewijk et al., 2004; Widdershoven et al., 2009; Kon, 2009). The social phenomenon of older people and the self-directed death should thus not be judged in a deductive, top-down way by prescriptive moral principles only, because in-depth knowledge of a given social practice is relevant for deciding what is right or wrong. Indeed, we take the view that normativity is always socially situated and ideas about right and wrong are shaped by social context (Leget et al., 2009; Molewijk et al., 2004; Widdershoven et al., 2009; Kon, 2009). However, using only empirical data and conceiving the morality of a social practice as ‘the final moral arbiter’ might result in moral relativism (Molewijk et al., 2004). Thus, judging whether the self-directed death in older people is morally right or wrong by just presenting the opinion of a representative sample of members of society as essential for this justification, neglects the critical voice of external criteria.

Taking this into account, we follow the position of a two-way relation between the empirical and the normative theories, standing in tension and in relation to one another (Leget et al., 2009). A social practice should be judged by taking into account both empirical data and normative ethics, being interrelated in mutual interaction between the internal (or lived) morality (attitudes and behaviour of research participants within a specific social practice) and external morality (moral principles and theories) in order to critically determine the moral issue at stake (Molewijk et al., 2004). We
presume that our empirical phenomenological descriptions of the wish to die in older people reflect the lived experience and lived morality. These descriptions can perform what is called ‘proto-ethical work’ by forming thicker accounts of the ethical issues that are investigated and judged by normative ethics (Cohen, 2011; Olafson, 1998) and constitute a ground for ethical reflection (Olafson, 1998).

1.4. DEFINING THE TERMS

In the field of research about the wish to die in older people who suffer from life, there is a lack of consistency in conceptualization. For example, the wish to die and the desire to hasten death or the terms ‘suicide’ and ‘a self-chosen death’ are used interchangeably. Sometimes a reference is made to someone ‘considering’, ‘intending’ or ‘deciding’ to die without clear consideration of the possible nuances involved. Other times a request to die or to hasten death is used to indicate a request for assisted suicide or euthanasia without making a clear distinction between those practices. This lack of clarity in the terminology reflects the complexity and the ambiguity of the issue at stake. Firstly, due to the subjective nature of the wish to die in older people not only individuals experience different meanings, but these individual meanings might also be ambiguous for a given individual. One person may experience numerous, partial or even contradictory wishes. Another thing is that terms such as suicide, self-chosen death, assisted dying, or completed life are all examples of politicized language with moral implications. The use of certain terms, the change of terms, and the omission of terms may also be an indication of a certain emphasis the author wants to make, a preference, or even a normative appreciation. In Box 1, the most important terms used in the debate are defined.

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**BOX 1: Definitions of the terms**

**The wish to die:** The wish to die is defined as a ‘desire to die or lack of desire to live’ (Raue et al., 2010; Beck et al., 1979). The Beck scale distinguishes the following differences in intensity in the wishes to die: 1) a weak wish to die and moderate-strong wish to live; 2) a weak wish to die and weak wish to live; 3) a weak wish to die and no wish to live; 4) a moderate-strong wish to die and weak wish to live; and 5) a moderate-strong wish to die and no wish to live (Beck et al.,
In our research, we define the wish to die as a moderate-strong wish to die and weak wish to live; and as a moderate-strong wish to die and no wish to live.

**Tiredness of life** (or weariness of life or life fatigue): This term concerns the idea that ‘life is not worth living, or that you’d be better off dead’ (Barnow and Linden, 1997; Dennis et al., 2007) Some argue that that tiredness of life, the wish to be dead and suicidal ideation are indicators for the same phenomenon reflecting the severity of suicidal intent (Barnow and Linden, 1997). Tiredness of life is associated with depression (Barnow and Linden, 1997; Barnow and Linden, 2001). In 2010, the Dutch Right-to-die organisation came up with a new term to replace tiredness of life, namely ‘completed life’. For example in Belgium, the term ‘tiredness of life’ is preferred (van den Noortgate et al., 2016).

**Suffering from life:** In 2004, the Committee Dijkhuis – which was established to investigate the ethical and practical implications of requests for euthanasia from older people who wish to die because they are tired of life – came up with a the following description of this phenomenon: ‘Suffering under the prospect of having to continue life at a profoundly diminished level of quality, which results in persistently recurring longing for death, without being able to determine a somatic or psychological reason’ (Dijkhuis et al., 2004).

**Completed life:** Simultaneously with the civil initiative Of Free Will in 2009, the Right-to-die NL introduced the concept ‘completed life’ [in Dutch: voltooïd leven]. It is defined as ‘suffering under the prospect of having to continue life at a profoundly diminished level of quality, which results in persistently recurring longing for death, without being able to determine a somatic or psychological reason’ (Peters, 2010). The terminology of ‘tiredness of life’ (or ‘suffering from life’ or ‘finished with life’) is closely associated with a death wish, but Peters argues that by using the term completed life, people go one step further. The older people involved have decided not to wait for a natural death process, but decisively (with or without assistance) take steps to end their lives (Peters, 2010; van Rein, 2013).

**The wish to hasten death:** Some argue that the term ‘the wish to hasten death’ should be used only for a reaction to suffering in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being
asked about it, but – according to Balaguer et al. – it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon (Balaguer et al., 2016). However, others also use the term for individuals who – outside the medical domain – hasten their deaths by voluntary refusal of food and fluid while receiving some palliative care or by independently taking a lethal drug or by the helium method. These dying trajectories are more or less under the control of the individuals themselves and not at all restricted to terminally ill people (Chabot and Goedhart, 2009; Chabot, 2015).

**Suicide:** In scientific research, suicide is generally characterized as a symptom of depression, insanity or another psychiatric disorder. It is defined as ‘the deliberate termination of one's own life by self-initiated, injurious behaviour; with the intent to die; with a fatal outcome resulting in death’ (van Orden et al., 2010).

**Rational suicide:** Several authors argue that rational suicide should be distinguished from ‘pathological’ suicide (see for a thorough discussion Chapter 5 of this thesis). They define rational suicide as ‘a rational decision to terminate one’s own life based on a realistic and understandable assessment of one’s situation, and unimpaired by psychological illness or severe emotional distress’ (Lester, 2014; Lester, 2006). According to Battin (Battin, 1999), there are five ‘crucial’ criteria to determine whether a suicide might be rational: 1) ability to reason; 2) realistic world view; 3) adequacy of information (lack of information on palliative care); 4) avoidance of harm; and 5) accordance with fundamental interests.

**Balance suicide** (or balance sheet suicide): This term refers to a well-considered suicide (see rational suicide) that is based on balancing the pros and cons of living on or choosing to end one’s life. The suicide is seen as a logical, understandable outcome of a balance sheet: as one ages, the negative points accumulate to such an extent that death becomes preferable to life. This term is also used to distinguish such a well-considered choice from a desperate psychologically driven suicide (Drion, 1992a; Drion, 1992b).

**Epicurean suicide:** An epicurean suicide is one where death is considered rationally and with dispassion (often used with reference to the (Stoic) suicide of Seneca) (van Hooff, 2004; van Hooff, 2015).
**Surcease suicide** (or self-deliverance): This term refers to ‘a suicide to complete or avoid a severe stressor’. Characteristic to a surcease suicide is a person who seeks peace, relief, freedom from pain: death may be seen as alluring, inviting, liberating (Battin, 1999). It is sometimes considered as a form of rational suicide.

**Self-euthanasia** (or auto-euthanasia): With this term, authors want to make an explicit distinction between suicide and a self-chosen death. They reject the idea that a self-chosen death is suicide because of the association with self-harm and insanity. Self-euthanasia literally means: ‘a good death directed by the person concerned, to the person concerned’. It is defined as ‘an intentional act of a person independently ending one’s life without help of a physician, decided after a clear assessment conducted in a careful manner, preferably after having discussed it with meaningful others’. It should avoid what is called ‘undignified’ dying (Chabot, 2007; Vink, 2013).

**Self-chosen death** (or self-determined / self-directed death): This term is used to refer to an intentional choice to end life at a self-appointed moment (Peters et al., 2011; Beekman, 2011). In the Dutch debate, three routes to a so-called self-chosen death are distinguished, namely:
1) the medical route; this route is covered in the euthanasia law.
2) the autonomous route; this refers to a self-chosen death directed by the person concerned (also referred to as self-euthanasia).
3) the caregivers-route; this refers to dying assistance performed by a so-called ‘counsellor in dying’. However, at present this is not permitted in the Netherlands.

**Self-directed dying in dignity**: While Chabot formerly used the term ‘auto-euthanasia’ in his latter work he prefers the term ‘self-directed dying in dignity’. It also refers to the intentional act of a person independently ending one’s life in a humane way outside the medical domain (Chabot, 2015).

**Dignicide**: This term is used and promoted by William Simmons, attorney and founder of Final Exodus (US). Dignicide is seen as a substitute for the term ‘suicide’ when applied to a rational, dignified and self-chosen death. ‘It does get the concept across that such a death is much different than suicide, and it is a one word counter to that undesirable word’ (Simmons, 2016).
An elective death: Another term to define a so-called well-considered act to end one’s life is an elective death. It is defined as ‘a peaceful, anticipatory death organized by the person concerned, via appropriate (and legally available) lethal drugs that one can take by one self’. This term is especially used by proponents of the legalization of such a self-chosen death for people who want to end their lives early and provides them with every professional support that they need to make the decision. Proponents assume that as responsible decision makers in all other areas of their lives, people can make responsible decisions about their deaths.

Euthanasia: Literally, euthanasia means ‘good death’. In the current medical context, it is defined as ‘the intentional termination of life performed by a physician administering a fatal dose of a suitable drug to the patient in a condition of constant and unbearable physical or psychological suffering, without reasonable alternatives or treatment’. It should be on his or her explicit, voluntary and well-considered request.

Physician-assisted suicide: ‘The voluntary termination of one’s own life by administration of a lethal substance with the direct or indirect assistance of a physician’, based on the same conditions as mentioned above.

Physician-assisted dying: this term is used to refer to both euthanasia and physician-assisted suicide. It is also used to avoid the connotation with suicide.

Assisted suicide (or assisted dying): This term is used to refer to direct or indirect assistance in suicide by a confidant.

Yuill (2015) – among others – argues that recent neologisms – like ‘assisted dying’, ‘self-euthanasia’, a ‘self-chosen death’ – are problematic. These neologisms are considered to be euphemisms leading to confusion and vagueness. ‘The language is evasive rather than clarifying’ (Yuill, 2015). A change of term indicates a new meaning or emphasis, which, however, often remains implicit. With these terms, negative connotations are avoided and the debate is framed in an evasive way. They ‘hide’ political and moral ends, Yuill argues. For example, many people consider the term ‘suicide’ to be pejorative, implying a negative value judgment and a social stigma.
He states that using the term ‘assisted dying’ can be seen as a denial of the association with suicide. This is complicated, he argues, because the term ‘(assisted) suicide’ implies that the individual takes full responsibility. The use of the term ‘assisted dying’ tends to equate assisted dying and assisted suicide. This might fudge moral responsibility, he argues. Important moral distinctions between preventing death, or letting or assisting someone (to) die are getting more diffuse (Yuill, 2015).

During our research, we were aware of the politicized language and the underlying (implicit or explicit) moral implications of certain terms. What is important for this thesis is to underline that our main aim was to illuminate the lifeworld of the older people involved. Therefore, we tried to use the words our participants prefer, at least in Part 2 of this thesis. For example, in chapter 5 we use the word ‘self-euthanasia’. This word was not chosen for political or moral aims, but only because this term resembled most closely the language of the older couple in this case study. In Part 2, we also use the word ‘completed life’ for the same reasons, as this is the language in which the older people involved seemed to understand themselves.

1.6. THESIS OUTLINE
This thesis consists of three main parts. Part 1 (chapter 2) gives an overview of the literature about older people and the wish to die. In Part 2 (chapters 3-6) our empirical research is presented. In Part 3 (chapters 7-9), theoretical and ethical reflections are described. Chapter 2 describes the results of a literature review. We investigated what was already known about motivations and experiences underlying a wish to die in older people who are tired of life. The review acts as an empirical, theoretical rationale for our research and draws attention to strengths and limitations of earlier research (Creswell and Creswell, 2007; Finlay, 2011).

Chapter 3 presents the results of our phenomenological qualitative research by describing the lived experience of older people who feel life is completed and no longer worth living. Chapter 4 presents a phenomenological case study of an older couple who jointly chose to end their lives by spousal self-euthanasia. Chapter 5 describes from an insider perspective what it means to live between intending to end life at a self-directed moment and actually doing it (or not). Chapter 6 deepens our understanding of the anticipatory
fear that fuels the wish to die in the older people under research by presenting the images and metaphors they use to express their feelings and concerns about the feared future and old age.

In chapter 7, we reflect on the phenomenological approach we took. In the literature, the wish to die in older people is mainly understood from a medical, psychopathological paradigm. Drawing on insights from our empirical-phenomenological research, in this chapter we argue for a phenomenological perspective to counteract the medicalisation of death wishes. Chapter 8 presents a care-ethical reflection on the Dutch debate about older people and a self-directed death by using our empirical findings. In chapter 9, an ethical reflection upon our own research practice is provided by discussing some of the most complex and ambivalent issues that came up during this research project.

This thesis concludes with chapter 10, which provides a summary of the findings and a general discussion on the contribution of this study to the knowledge about and the insights into the wish to die in older people. Based on the empirical outcomes, the term ‘completed life’ will be criticised. Some (practical and moral) implications and recommendations for further research are outlined as well. At the start of every chapter in this thesis, a calligraphic sound script is depicted made by the Dutch artist Dineke Groenhof Blaauw. These evocative sound scripts might create a sense of resonance with the lived experiences of older people who feel ready to give up on life. For a more thorough explanation about the choice for this specific artwork, we refer to the Prologue.
REFERENCES


Peters M. (2010) *Completed Life. What are we talking about?* Amsterdam: NVVE.


It may not be dying we fear so much, but the diminished self. What diminishes the self is no longer desiring for itself. Falling out of love with yourself means ceasing to consider yourself desirable to yourself.

Arthur Frank (1995/2013, p.39) with reference to Anatole Broyard
CHAPTER 2

Experiences and motivations underlying wishes to die in older people who are tired of living:
A research area in its infancy

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ABSTRACT
The wish to die in older people who are tired of living and the possibilities to organize death are currently being discussed within the debate on self-determination and physician-assisted suicide. Until now, insight into the experiences and thoughts of people who are tired of life while not suffering from a severe depression or a life-threatening disease was lacking. Studies focusing specifically on this topic are rare. This review provides an overview of this research area in its infancy. The existential impact of age-related loss experiences plays an important role in developing a wish to die. Other influencing factors are: personal characteristics, biographical factors, social context, perceptions and values. Further research into the experiences and motivations underlying these specific age-related wishes to die and the existential impact of the loss experiences is necessary in order to deepen the understanding of this group of older people and for the development of policy and good care.
1. BACKGROUND

In the Netherlands, as well as in other western high-income countries, there is an increasing interest in the problem of aged people considering their lives to be no longer worth living and wishing to have access to medicine with which they can end life at a self-appointed time. Buiting et al. (2012) studied trends of older peoples’ attitudes towards an end-of-life pill. Respondents were asked whether they could imagine asking for a pill to end their lives if they became tired of living in the absence of a severe disease. For an end-of-life pill, these percentages were 31% in 2001, 33% in 2005 and 45% in 2008 (Buiting et al., 2012). Other and lesser-known measures for terminating life so as to avoid ‘undignified’ dying have been termed ‘auto-euthanasia’ (Chabot, 2007; Chabot and Goedhart, 2009).

In February 2010, the Right-to-Die NL started the sustained campaign ‘Completed Life’ and placed the discussion about ‘making self-determination of life’s end’ on social and political agendas. This campaign was based on the idea that many elderly people would be greatly relieved knowing that there is a way to end life respectably at the moment suitable to them. The Right-to-Die NL is of the opinion that elderly should be allowed to make a well thought-through choice and that such a choice is entirely up to them. Approximately 30% of Dutch citizens support a system based on autonomy, as proposed by the Right-to-Die NL (van Delden et al., 2011). This reflects a more open awareness of death and dying; a notable trend in the western world. Dying may still be separated from everyday social life, but an activist orientation towards the problem of dying is more common (Seale et al., 1997). The growing desire to control and plan the manner, the timing and the place of death is related to a dominant ethos of individualism and autonomy. The postmodern life is seen as a reflexive project: ‘a choice biography’. The course of life is individualized (Lange, 2007). People not only want to have control over their own lives, but also over their own deaths.

Research indicates that death thoughts and death wishes frequently occur among older people. In different studies estimates of 10%-20% have been found (Rurup et al., 2011a; Forsell et al., 1997; Scocco et al., 2001; Raue et al., 2007). Most of these epidemiological and prevalence studies found an association between death wishes and mental disorders. However, about 5-30% of the wishes to die in older people are not associated with psychiatric or depressive disorder (Harwood et al., 2001; Rurup et al., 2005; Rurup et al.,
Several other physical, demographic and social (risk) factors for developing a wish to die are mentioned in literature, such as physical impairment, relocation, bereavement and lower perceived social support (Forsell et al., 1997; Jorm et al., 1995; Harwood et al., 2006; Rurup et al., 2005; Rurup et al., 2011a; Raue et al., 2007).

This review is part of a larger Dutch study focusing on older people who are tired of living and have developed a wish to die, based on their subjective assessment that life is no longer worth living, while they do not suffer from a life-threatening disease. The main aim of this paper is to explore literature and to map out motives and experiences underlying the wish to die in this specific group of older people found in earlier research studies. Three steps will be taken to achieve this goal. First, we present an overview of empirical studies that address this phenomenon. By doing so, we provide insight into the degree to which the phenomenon is manifested in literature so far. Secondly, we summarise and describe the factors mentioned in the studied literature that give a deeper perception of the experiences and motives of this specific group of older people with a wish to die. Insight into these experiences is important for gaining a better understanding of this group of older people (which might grow in the near future) and their perspective on their own life and death. This is of primary importance for the development of good care tailored to their needs and is also relevant in the light of the public debate. Before political and social decisions can be taken deliberately, it is vital to have a thorough understanding of this specific group of older people.

Thirdly, this paper describes how the death wish is explained in the literature and whether the wish to die is labelled as pathological or as rational in the reviewed studies. This is interesting because there is an ongoing debate about whether the wish to die in older people in some cases is to be considered an outcome of a rational and understandable assessment of their personal lives. Some authors suggest that suicidal ideation in some cases can be explained as a natural phenomenon of old age (Moore, 1993; Osgood, 1985; Richman, 1992; Prado, 1998; Battin, 1999). Other authors strongly argue that suicide in the elderly can be seen and accepted as ‘un understandable, calculated and even normal decision’ (Barnow and Linden, 1997; Barnow and Linden, 2000; Barnow et al., 2004). These studies refer to suicidal ideation among the elderly as a phenomenon that should always be discussed
in terms of pathology and psychiatric morbidity and focus on identifying risk factors and the necessity of prevention, which challenges the idea that older people are able to make an autonomous, thoughtful, rational choice about the end of their lives at a self-appointed moment.

2. METHODS
Research into the wish to die in this particular group turned out to be relatively rare and is usually part of studies with a wider sample and a broader definition (Jorm et al., 1995; Harwood et al., 2001; Harwood et al., 2006; Rurup et al., 2011a; Rurup et al., 2005), including people with terminal diseases or psychiatric syndroms and incorporating all kinds of feelings and thoughts as well as different suicidal behaviour with several underlying causes. Therefore, the authors decided to take a broad approach in the search strategy by including all possibly relevant (quantitative and qualitative) research on the wish to die in this particular group. The value of the studies was not pre-determined. The underlying consideration was that studies – perhaps methodologically flawed in part, or with overall findings that do not appear important or relevant – might contain important findings in part. The authors also deliberately included studies from different contexts and with great diversity in methodologies for the same reason. This selection-approach is consistent with the Critical Interpretive Synthesis (Dixon-Woods et al., 2006). However, CIS was not used for the data-analysis, because our goal was not the development of theory. The development of concepts and theory by involving both induction and interpretation would be too ambitious because little research on this specific subject is available. A conventional systematic review is better suited for the goal to provide a first overview of studies about this specific group of older people and then summarize what is already known about their motives and experiences.

2.1. Search strategy
A systematic computer-based search of Cinahl, Embased, PsychoINFO, PubMed and Web of Science databases was conducted for the period between January 1991 and December 2011. Search terms used were: old* people or elderly or aged, wear* of life, finished with life, tired* of life, completed life, wish* to die, death thoughts, death wishes, suicidal ideation, suicide, auto-euthanasia, non-terminal, Drion-pill, last-will-pill, suicide-pill, end-of-life pill. Included papers were peer-reviewed English-language journal articles
within the search period. The reference lists of all identified papers were systematically checked for missing publications. Abstracts of papers meeting these inclusion criteria were independently screened by three reviewers. Disagreement between the reviewers was resolved by thorough discussion.

2.2. Search outcome

The initial database search identified a total of 673 potentially relevant papers. Reference search led to 36 more articles. Subsequently, a first selection was made based on title and abstract according to the inclusion/exclusion criteria. Citations and abstracts were included when the target population were elderly people (defined as age 60+) who had expressed the wish to die without being terminally ill or having a severe psychiatric disorder. Publications were excluded when the wish to die was expressed by people with a life-threatening disease, or when the papers focused on treatment issues or cultural aspects of the wish to die.

Full texts of 73 articles were retrieved. Findings of this selection were rather diverse: another 15 articles were excluded because they dealt with different thematic axes or were non-empirical studies. In addition, 13 qualitative studies and a substantial number of quantitative empirical studies were examined: 37 epidemiological, prevalence or case-control studies, 3 quantitative psychological autopsy studies, 4 studies researching attitudes about suicide and physician-assisted suicide in older people and 1 survey of self-directed dying attended by proxies.

The authors discussed the outcomes. Although the quantitative studies gave a good insight in demographic, physical, mental and social characteristics of older people with a wish to die, they focus primarily on prevalence rates and risk factors (Bonnewyn et al., 2009). Certainly, findings from these studies enabled further understanding of wishes to die and suicidal thinking and have made a valuable contribution to suicide prevention initiatives. Nevertheless, these outcomes give a limited explanation of the specific phenomenon under study in this review (Lakeman and FitzGerald, 2008) and did not give a deeper understanding of experiences and motivations underlying an age-related wish to die. Therefore these studies were excluded.

Thirteen qualitative studies remained. These papers were all scrutinised. Another four studies were excluded, but shortly mentioned below because
of an interesting emphasis. First, one study (Leichtentritt and Rettig, 2001) specifically focuses on revealing values and beliefs underlying end-of-life decisions in older people and their relatives. This is interesting because most studies only refer implicitly to sets of values as guiding principles, while values play an integral part in shaping personal attitudes and motives. However, the informants in this study were presented with four case scenarios, all examples of terminally ill patients. Values and beliefs underlying wishes to die in older people without life-threatening diseases were not addressed in this study, and therefore the study was not included. Another article (Moss et al., 2005) was excluded because the empirical part of the study primarily focuses on family responses to older people's wish to die. Although based on literature, Moss et al. mentioned some interesting implications of a forced relocation to an institution with regard to this wish to die in older people. A third paper (Lloyd-Williams et al., 2007) was excluded because this study explores general attitudes, views and experiences on issues surrounding death and dying from older people not necessarily having an actual wish to die themselves. And fourthly, a case study (Alexopoulos, 1991) was not included in spite of the fact that this study describes an inter-
esting suicide case within the context of ageing. The consideration for exclusion was that this study pays much attention to the pathological personality traits influencing the wish to die. The woman experienced several depressive episodes in her life and required various psychiatric hospitalizations during her lifetime for different reasons. Three days prior to her suicide she had had her last psychotherapy session, so it is difficult to determine the extent to which this suicide was pathologically driven. Although excluded, the case illustrates the multi-factorial nature of suicide and the interwovenness of factors playing a role in developing a wish to die. Beside the pathological factors it also pays attention to several age-related and sociological aspects – such as relocation to a nursing home and the loss of functioning, status and independence – as precipitants to suicidal thoughts.

One study turned out to be written in Dutch (Rurup et al., 2011c), but because of the fact that it was the continuation of an included study (Rurup et al., 2011b) and complementary as regards content, we decided to include it. After an intensive selection process, nine qualitative studies remained.

3. RESULTS

3.1. Identified studies

Table 1 presents the characteristics of the included studies. Six studies focus on an inner perspective of older people reflecting on their own wish to die (Moore, 1997; Lindner et al., 2006; Rurup et al., 2011b; Rurup et al., 2011c), their recent suicide attempts (Crocker et al., 2006) and the attitudes of elderly on how suicide becomes an alternative (Courage et al., 1993). Three included studies are qualitative psychological autopsy studies: proxies who were closely related to elderly who committed suicide were asked to describe the person who had a strong wish to die (Harwood et al., 2006a; Kjølseth et al., 2009; Kjølseth et al., 2010). Although these studies do not provide direct experiences of older people but proxy reports based on the interpretation of the experience from the perspective of others, they were included because these studies explicitly mentioned that the researcher tried ‘to hear the voices of the elderly people’ through the informants’ narratives. Despite the slightly different perspective of these studies, together they identify the research area on this topic and contribute to a better understanding of older people with a wish to die without having a life-threatening disease.
3.2. Reasons and factors
In literature the following factors were found to give more insight in the experiences of older people of living and the development of a wish to die: age-related losses, biographical factors, personal characteristics, social context, perceptions and values and feelings. These are presented and described below.

3.2.a. Age-related losses
In the reviewed qualitative research, the wish to die in this specific group of older people is characterized as a result of a subjective assessment of life quality and closely related to physical, social and mental losses. Without exception, the studies point out that age-related losses play an important role in developing a wish to die. The term ‘losses’ can either be used in a descriptive or in an evaluative way. The loss experiences found in the reviewed literature and mapped out below were described from an evaluative perspective and apply to a particular group of older people who already uttered a wish to die.

Loss of control: all studies listed in Table 1 point out that the wish to die in older people is associated with suffering from physical decline and the ongoing deterioration of walking, vision, hearing, speaking and sensory abilities, cognitive decline, incontinence and impotence. Several studies suggest that – as a consequence of these limitations – feelings of increasing powerlessness (Moore, 1997), growing dependency on others (Rurup et al., 2011b) and a loss of privacy and control over important aspects of their lives (Rurup et al., 2011b; Crocker et al., 2006; Kjølseth et al., 2009) are deepened.

Loss of connectedness: the extent to which older people feel connected with public life emerges as another aspect that influences the development of a wish to die (Moore, 1997; Kjølseth et al., 2010; Harwood et al., 2006a; Crocker et al., 2006). It is mentioned that some respondents suffer from a decreasing social status (Kjølseth et al., 2010; Moore, 1997). The sense of being no longer valued, needed or significant provokes feelings of worthlessness, invisibility to others and detachment from community. Research points out that they feel less personally involved in their environment, because they subjectively value their own contribution to society as diminishing. In addition, literature also gives descriptions of subjective feelings of alienation and disintegration caused by feelings of disinterest and separation from significant people in their lives who were supposed to care, but no longer cared about them (Rurup et al., 2011c; Moore, 1997).
Most elderly people have to face the diminution of their social circle, sometimes suffering several bereavements in succession. The loss of meaningful others is frequently mentioned as a reason for feelings of loneliness, less social support and a loss of connectedness (Moore, 1997; Harwood et al., 2006a; Kjølseth et al., 2009; Kjølseth et al., 2010; Rurup et al., 2011b). There is also a group of older people with a wish to die, who mainly create distance themselves. They do have contact with relatives or friends, but are not able to communicate about their inner feelings and struggles (Kjølseth et al., 2009; Kjølseth et al., 2010). Indeed, Kjølseth et al. conclude that although the majority of the respondents was not alone, their relationships were marked by distance and therefore less supportive.

The loss of connectedness is not only related to social relations but is likewise related to the physical environment. Relocation often seemed to be experienced as a forced breach of community ties and as a loss of habitual daily routines (Rurup et al., 2011b) and a familiar environment.

Loss of meaning: a strong subjective feeling that life has no meaning anymore is quite often mentioned by respondents (Rurup et al., 2011b; Rurup et al., 2011b; Moore, 1997; Kjølseth et al., 2010; Lindner et al., 2006; Crocker et al., 2006). The lack of sense has a negative effect on health and well-being. Rurup et al. (2011c) found that the irreversibility of the rapid (health) deterioration and the shrinking time perspective deepens the loss of meaning. Several studies explicitly report a negative future orientation. Elderly people give up trying to find solutions to improve their situation and experience the losses as absolute (Rurup et al., 2011c; Kjølseth et al., 2010; Crocker et al., 2006).

Loss of the self: decreasing self-determination seems to have a negative impact on self-esteem. Respondents themselves describe this process of losing control as a process of ‘losing themselves’ (Kjølseth et al., 2010). The loss of connectedness and social worth and the frustration about shifting roles is undermining older people’s self-efficacy and self-respect (Rurup et al., 2011b; Moore, 1997; Kjølseth et al., 2010; Crocker et al., 2006). The association between the loss of important life objects and the wish to die was found by several researchers. For example, not being able to paint anymore because of serious vision impairment can be experienced as a curtailment of self-expression (Kjølseth et al., 2010; Rurup et al., 2011b; Lindner et al., 2006).
3.2.b. Biographical factors

The impossibility to deal with non-age-related life struggles is another important finding. Several researchers describe traumas – at a young or senior age – as potential triggers for the wish to die in older people (Rurup et al., 2011b; Kjølseth et al., 2009; Lindner et al., 2006). They found that people were sometimes bothered by images of the traumatic event(s), which they saw all over again in their minds. Traumas mentioned by respondents are (sexual) abuse (Lindner et al., 2006), war or refuge-experiences (Lindner et al., 2006), posttraumatic stress disorder (Rurup et al., 2011b), (attempted) suicide in family history (Lindner et al., 2006), (early) loss of close relatives (Kjølseth et al., 2009), divorce, and loss of a job (Lindner et al., 2006). Distressful life events such as severe illness, a forced relocation, loss of a job or financial ruin (Harwood et al., 2006a; Lindner et al., 2006; Courage et al., 1993) were also linked with suicidal thoughts, but often in combination with other reasons accumulating over time.

3.2.c. Personal characteristics

All reviewed studies in Table 1 give implicit or explicit personal descriptions of elderly people with a wish to die. Harwood et al. (2006) took a psychological approach, aiming to identify characteristics associated with suicide in older people. This study report abnormal personality traits among elderly with a wish to die, such as strong anxiety, self-preoccupation, inflexible thinking and lack of adaptability as important contributing factors for committing suicide. Harwood et al. conclude that the way a person perceives and solves life problems is linked to personality and may be more important than the problem itself in determining suicide risk. This conclusion is supported by Rurup et al. (2011b), who relate the development of a wish to die to personal character, coping strategies and social support. The distinction between older people who express a wish to die and those that do not would thus be explained. Kjølseth et al. (2009) identified personality traits as a main topic but give a rich description and characterization of these traits, rather than a clinical description. The older people were described by the informants as ‘obstinate, strong-willed, stubborn, emotionally reserved and introvert’.

In several studies, the wish to die in older people is associated with anger and frustration uttered for not being given the attention and support they needed. It was found that elderly were disappointed in health care and their families (Lindner et al., 2006; Rurup et al., 2011b; Moore, 1997). Research
Table 1: Description of reviewed research on older people with a wish to die

<table>
<thead>
<tr>
<th>Reference</th>
<th>Research design</th>
<th>Research aim</th>
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<tbody>
<tr>
<td>Suicide in the elderly: staying in control</td>
<td>Qualitative interview study</td>
<td>To explore causative factors, identify deterrents, specific risk factors and causes for developing a wish to die; to explore how suicide becomes an alternative</td>
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<tr>
<td>Phenomenological study of meaning in life in suicidal older adults (Moore, 1997)</td>
<td>Qualitative interview study using the hermeneutical phenomenological research approach</td>
<td>To express the voices of eleven suicidal older persons by describing the depth of the experiences of these individuals</td>
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<tr>
<td>Giving up or finding a solution? The experience of attempted suicide in later life (Crocker et al., 2006)</td>
<td>Qualitative interview study using the interpretative phenomenological method</td>
<td>To capture and understand the subjective experience of older people and their pathway to their attempt, their thoughts, feelings and experiences in the aftermath and the way their experience of ageing impinge upon suicidal thoughts</td>
</tr>
<tr>
<td>Respondents</td>
<td>Results</td>
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<tr>
<td>18 elderly people living independently and performing their own daily activities, non-depressed (according to Beck Depression Inventory), aged from 67 to 84 years (USA)</td>
<td><strong>Attitudes towards participating in timing of death:</strong>&lt;br&gt;1) Death is to be considered as externally controlled (by God)&lt;br&gt;2) Death as a collaborative process between the individual, God and others&lt;br&gt;3) Intention to actively control the time of death (when life becomes intolerable)&lt;br&gt;<strong>Attitudes towards accepting suicide as an alternative:</strong>&lt;br&gt;1) Suicide is totally unacceptable&lt;br&gt;2) Suicide as an acceptable alternative to extremely intolerable life circumstances&lt;br&gt;3) Suicide as an acceptable and rational option&lt;br&gt;<strong>Other findings:</strong>&lt;br&gt;- Older people did not seem to discuss suicide with their peers&lt;br&gt;- Elderly in this study spoke of suicide as a logical way of controlling end of life</td>
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<td>11 elderly psychiatric patients who expressed suicidal ideation (no presence of psychosis or dementia) from inpatient psychiatric units, aged from 64 to 92 years (Canada)</td>
<td><strong>Psychache:</strong> their current emotional suffering, psychological pain&lt;br&gt;<strong>Nobody cares:</strong> the feeling that nobody cared for them, loss of human connectedness&lt;br&gt;<strong>Powerlessness:</strong> the loss of power, control and independence. Disappointments and losses increase feelings of powerlessness</td>
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| 15 elderly who recently made a suicide attempt within the context of ageing, aged from 65 to 91 years (UK) | **Struggle:** trying to come to terms with getting older. Discomfort, frustration, no longer any roles to fulfill, missed opportunities, losses, regrets. A hopeless, helpless state.<br>**Control:** the loss of control over life and functioning; reduction in independence and autonomy. Losses related to health, mobility, social status, social support. The suicide attempt made them feel more in control.<br>**Visibility:** the experience of becoming less visible to others (isolation, loneliness, sense of being distanced from / less connected with the outside world, a diminishing social circle, detachment from the wider community.
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<th>Reference</th>
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<th>Research aim</th>
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<tr>
<td>Psychodynamic ideal types of elderly suicidal persons based on counter transference (Lindner et al., 2006)</td>
<td>Qualitative interview study using the method of ‘forming types by understanding’ to develop ideal types of transferences</td>
<td>To understand the intra-psychic dynamics and psychosocial conditions that keep suicidal elderly people from seeking professional help; to understand factors influencing old age suicidality from a psychodynamic perspective</td>
</tr>
<tr>
<td>Understanding why older people develop a wish to die. A qualitative interview study (Rurup et al., 2011a)</td>
<td>Qualitative interview study</td>
<td>To learn more about the wish to die and get an insight in reasons, processes and backgrounds; to learn more about how and when the wish to die developed and about the intensity of the wish to die</td>
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<td>Older people who are ‘weary of life’: their expectations for the future and perceived hopelessness (Rurup et al., 2011b)</td>
<td>Qualitative interview study</td>
<td>To explore their expectations for the future and perceived hopelessness; to explore reasons for not ending their lives and perceived possibilities to improve their situations; to explore their opinions about the ‘Drion’s Pill’</td>
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### Respondents

| 30 elderly people who judged themselves as suicidal but had not talked about it in treatment; aged 60 or over (Germany) |
| 31 people with a wish to die without having a life-threatening disease; aged from 58 to 98 years (the Netherlands) |

### Results

#### Conditions to decrease suicidality:
- Difficulty with relationships because of life experiences
- Experiences of being uprooted, threatened and excluded
- Ashamed of being a burden to everyone, feelings of being at someone’s mercy
- The dependency and limitations difficult to cope with became unbearable
- An early experience of loss and desperation re-actualized
- Re-actualization of unconscious and unresolved early childhood conflicts
- The shame of being dependent on social welfare

#### Triggers of the development of a wish to die:
- Traumatic life events at a younger or senior age
- A life of adversity and distress
- Poor quality of life (age-related)
- Recurring depression (only three persons)

#### Recurring themes:
- Difficulties coping with a new situation of dependence
- Not being able to be useful, being a burden, not feeling needed
- High expectations of other people (family, children)
- Lack of social contacts
- Lack of control

#### Death wishes as a coping strategy:
- Reclaiming control by developing thoughts about death as a positive thing
- Balance between negative sides and positive sides of life and dying

#### Perceived burden:
- Wish to die itself is not perceived as a burden
- No fear of death, some outspoken, positive connotations
- Perceived difficulty to talk about wish to die with loved ones

#### Conditions to decrease the wish to die:
- Most respondents could not mention (physical or social) conditions to improve their situation
- Perceived hopelessness

#### Reasons not to end their lives:
- Significant others, burden to their loved ones
- Unacceptable fear to survive with damaged body
- Positive reasons; awareness of still having reasons to live for (partner, significant others or pets)

#### Attitude towards Drion’s Pill:
- Solution for their situation
B – Proxies interpreting the voices of older people with a wish to die

<table>
<thead>
<tr>
<th>Reference</th>
<th>Research design</th>
<th>Research aim</th>
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<tbody>
<tr>
<td>Suicide in older people without a psychiatric disorder (Harwood et al., 2006a)</td>
<td>Qualitative psychological autopsy interview study</td>
<td>To describe the characteristics of suicidal older people who do not have a psychiatric disorder to find out whether death had been influenced by the presence of a sub-syndromal psychiatric or personality disorder; to examine the types of life problems associated with suicide in this sample</td>
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“Why do they become vulnerable when faced with the challenges of old age?” Elderly who committed suicide, described by those who knew them (Kjølseth et al., 2009) | Qualitative psychological autopsy interview study using the systematic text condensation method for analysis, based on elements from both phenomenological analysis and grounded theory | To understand the process that led up to the individual suicide; to characterize these elderly people as persons and to investigate whether the descriptions of these elderly persons, given by those who knew them, provide common features that create recognizable patterns |

Why suicide? Elderly people who committed suicide and their experience of life in the period before their death (Kjølseth et al., 2010) | Qualitative psychological autopsy interview study using the systematic text condensation method for analysis, based on phenomenological analysis and grounded theory | To understand the way elderly experienced their existence towards the end of life in order to comprehend the act of suicide; to characterize each elderly person as a person; to identify external conditions that impacted on the elderly person in the final stage of life |
Respondents
Informants (relatives and friends) for 23 elderly people who had died by suicide and did not have a psychiatric disorder at the time of death; aged 60 years or over (UK)

Results
1) **Sub-syndromal depression** or other psychiatric symptoms are unlikely to have been a major factor contributing to suicide in this sample
2) **Physical health problems** were the most frequent type (57%) associated with suicide (life-threatening illness occurred in only a quarter of the sample)
3) **Abnormal personality traits** were common (half of the sample): inflexible thinking, lack of adaptability

Other life problems associated with suicide in this sample: bereavement (48%), interpersonal life problems (26%), social isolation (22%), financial problems (17%), problems with accommodation (9%)

63 informants (relatives, family doctors, home-based care nurses) for 23 elderly who had died through suicide; aged 65 years or over (Norway)

Results
1) **Life history: the ability to survive**: they were able to cope with stress in life
   *Action-oriented achievers*: self-realization and self-esteem linked to activity and achievement
2) **Personality traits**: strong personalities, obstinacy, strong-willed, controlling others, decision makers
3) **The relationship experienced by the informants**: main impression was that they showed strong self-control and were emotionally closed.

63 informants (relatives, family doctors, home-based care nurses) for 23 elderly who had died through suicide; aged 65 years or over (Norway)

Results
1) **Experience of life: this life has been lived**: closed time perspective; losses are absolute
   *Life as a burden*: because of illness, losses, a deep conflict with close relatives
2) **Perception of themselves: losing oneself**: damaged self-image; personal expectations can no longer be fulfilled
3) **Conceptions of death: acceptance**: death is imminent, no fear of death
also points out that some blame themselves because of missed chances, lost opportunities and unfulfilled aspirations (Crocker et al., 2006; Lindner et al., 2006; Kjølseth et al., 2010). Nevertheless, several studies point out that fewer respondents seem to suffer from depressive symptoms (Kjølseth et al., 2010; Rurup et al., 2011c; Rurup et al., 2011b; Kjølseth et al., 2009) than expected in the light of quantitative studies. Most respondents did not perceive depression as the (primary) cause of their wish to die.

3.2.d. Social context
Although all reviewed studies identified ‘the loss of connectedness’ and ‘a lack of social support’ as frequently mentioned experiences contributing to a feeling that life is no longer worth living, Rurup et al. (2011b) also mentioned the social context as a weakening factor of the wish to die. Having a partner, (grand)children or nice neighbours were indicated in both studies as important positive aspects and a reason to live on, despite having a wish to die.

3.2.e. Perceptions and values
A common image of older people not being frightened of death is provided in six reviewed studies (Rurup et al., 2011c; Rurup et al., 2011b; Kjølseth et al., 2009; Kjølseth et al., 2010; Courage et al., 1993). Not the thought of death itself, but the way of dying and the thought of living on in difficult circumstances seem to be experienced as burdensome. Associations of death mentioned were peace and quietness, being reunited with loved ones and the end of suffering. One study (Rurup et al., 2011c) suggests that the taboo on active death wishes is stronger in family members and physicians than in older people themselves. Older people in this study encounter a lack of understanding from relatives and carers.

In five articles respondents had the impression that the wish to die seemed to correspond with a ‘realistic world view’ based on ‘an understandable personal assessment of the situation’ (Kjølseth et al., 2010; Lindner et al., 2006; Rurup et al., 2011b; Kjølseth et al., 2009; Courage et al., 1993). Other respondents explained suicide as ‘a paradoxical act of autonomy’ and a way of regaining control (Rurup et al., 2011b; Lindner et al., 2006; Kjølseth et al., 2009). Death wishes seemed to be ‘a form of self-protection and comfort’ and a ‘final autonomous protection against the threat of continued living, feeling and thinking’.
Rurup et al. (2011b) describe a nuanced process of balancing feelings towards living and dying. Some respondents had a stable death wish, while others experienced a less stable balance between the wish to die and the wish to live. Although the wish to live was weak in most cases, the majority of respondents who had had a wish to die for many years still mentioned reasons to live on.

Most of the reviewed studies refer only implicitly to sets of values as guiding principles in developing wishes to die. Mentioned values underlying a death wish seem to be: quality of life and death (Rurup et al., 2011b; Rurup et al., 2011c), competence (Rurup et al., 2011b; Rurup et al., 2011c; Crocker et al., 2006; Moore, 1997; Harwood et al., 2006a; Courage et al., 1993; Lindner et al., 2006; Kjølseth et al., 2009; Kjølseth et al., 2010), wholeness (or integrity) of a person (Courage et al., 1993; Lindner et al., 2006; Kjølseth et al., 2009; Kjølseth et al., 2010) and loyalty (Rurup et al., 2011b; Rurup et al., 2011c). Only one study explicitates the fact that the extent to which elderly consider themselves as autonomous individuals who are permitted to participate pro-actively in timing of death, is influenced by ideological or religious backgrounds (Courage et al., 1993).

3.2.f. Feelings
Feelings and metaphors expressing feelings of older people, mentioned in the reviewed studies, give a closer impression of the way older people perceive life and the loss experiences. An overview of feelings and metaphors covered in the papers is presented in Table 2.

*Internalizing and externalizing feelings*: tiredness of living and the development of an age-related wish to die involve a great variety of feelings that are described in the retrieved papers (see Table 2). However, authors place different emphases on feelings. Crocker and colleagues (2006) found emotions influenced by resistance, struggle and control as a dominant theme, while Moore (1997) indicates ‘psychache’ as the most notable theme, described in terms of deep feelings of pain, suffering and loneliness: ‘overflowed with tears and sadness’. Courage et al. (1993) mainly address feelings of fear for the future: for suffering, for (cumulative) catastrophic life events and for the mode of death. Some studies describe metaphors derived directly from quotations from older people, giving expression to their inner feelings. They are described below.
**The burden impact:** the wish to die in older people is almost always accompanied by a fear of placing a burden on others; relatives, health care professionals or volunteers (Lindner et al., 2006; Rurup et al., 2011b). The term ‘burden’ was coined to describe the feeling of being heavily dependent – against one’s will – on others for help. Rurup et al. (2011b) not only refers to the burden impact on people but also to the burden on society. Some of her respondents feel uncomfortable by the financial burden they place on the community. Two studies (Kjølseth et al., 2010; Crocker et al., 2006) refer to the burden impact when it comes to reflection on the individual life. The sum total of all strains of old age meant that elderly perceived life as a burden.

**Fight metaphors:** in the reviewed papers, various fight metaphors are mentioned, used by the respondents to express their feelings and inner life: struggle, battle and war are mentioned several times (Crocker et al., 2006; Kjølseth et al., 2010). These metaphors indicate a strong resistance, defiance and difficulty with accepting life as it is.

**Uprootedness:** to be rooted seems to be an important need of the human soul. A human being has roots by virtue of a real, active and natural participation in life. The loss of rootedness, of connectedness and the lack of a sense of belonging is strongly given voice by using the metaphor ‘uprootedness’ (Lindner et al., 2006).

**Tiredness of living:** this metaphor is used to indicate the feeling of being completely exhausted by life, being physically and mentally fatigued, in a state of weariness, no longer able to give any resistance at all, in contrast with the fight metaphors mentioned before. Rurup et al. (2011b) indicates weariness of life also as a feeling of boredom, illustrating the weary hours spent waiting, because of a lack of meaningful daytime activities.

**Cul-de-sac:** this term is figuratively used (Rurup et al., 2011c) to point out the absolute feeling of a total impasse life has come to and not being able to see any possibilities for making progress anymore. The irreversibility and the perceived hopelessness (Rurup et al., 2011c; Kjølseth et al., 2010) are strongly expressed by this metaphor.
<table>
<thead>
<tr>
<th>Feelings</th>
<th>Description</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Externalizing regret</td>
<td>described as feelings of frustration, resentment and disappointment towards the children, family, health-care: blaming the outside world, uttered in accusation</td>
<td>(Crocker et al., 2006; Moore, 1997; Rurup et al., 2011c; Rurup et al., 2011b; Lindner et al., 2006)</td>
</tr>
<tr>
<td>Internalizing regret</td>
<td>described as an intense regret at the loss of possibilities and opportunities</td>
<td>(Crocker et al., 2006; Moore, 1997)</td>
</tr>
<tr>
<td>Perceived hopelessness</td>
<td>related to the irreversibility of ongoing deterioration</td>
<td>(Crocker et al., 2006; Kjølseth et al., 2010; Rurup et al., 2011c)</td>
</tr>
<tr>
<td>Powerlessness</td>
<td>described as having no control, feeling the victim of the situation, feelings of failing, yearning for what is no longer there</td>
<td>(Crocker et al., 2006; Moore, 1997; Rurup et al., 2011b)</td>
</tr>
<tr>
<td>Psychological pain</td>
<td>described as emotional suffering, hurt, anguish and sadness</td>
<td>(Moore, 1997)</td>
</tr>
<tr>
<td>Loneliness</td>
<td>described as feelings of being distanced from or cut off from the outside world. Feelings of exclusion, alienation, disintegration and separation of the self from others</td>
<td>(Crocker et al., 2006; Moore, 1997; Rurup et al., 2011b; Rurup et al., 2011c; Lindner et al., 2006)</td>
</tr>
<tr>
<td>Fear</td>
<td>related to the mode of death and intolerable life circumstances, fear of suffering</td>
<td>(Courage et al., 1993)</td>
</tr>
<tr>
<td>Shame</td>
<td>related to being a burden to others and being dependent on social welfare</td>
<td>(Lindner et al., 2006)</td>
</tr>
<tr>
<td>Metaphors</td>
<td>Tiredness of living</td>
<td>(Kjølseth et al., 2010; Rurup et al., 2011)</td>
</tr>
<tr>
<td>The burden impact</td>
<td></td>
<td>(Crocker et al., 2006; Moore, 1997; Rurup et al., 2011b; Rurup et al., 2011c; Kjølseth et al., 2010)</td>
</tr>
<tr>
<td>Fight metaphors</td>
<td></td>
<td>(Lindner et al., 2006; Crocker et al., 2006)</td>
</tr>
<tr>
<td>Uprootedness</td>
<td></td>
<td>(Lindner et al., 2006)</td>
</tr>
<tr>
<td>Cul-de-sac</td>
<td></td>
<td>(Rurup et al., 2011c)</td>
</tr>
</tbody>
</table>
### 3.3. Interpretations of the wish to die

Lastly, we try to get a grasp of the different interpretations of the wish to die, partly explainable by the various perspectives of the reviewed literature. Some studies (Lindner et al., 2006; Harwood et al., 2006a) interpret death wishes and suicidality in terms of abnormal personality traits and pathology. Two papers (Moore, 1997; Crocker et al., 2006) remain close to the lived experiences of older people in their interpretations of the death wish. Other authors (Rurup et al., 2011b; Rurup et al., 2011c; Kjølseth et al., 2009; Kjølseth et al., 2010) suggest that in some cases suicidal ideation in older people can be explained as a natural phenomenon of old age: a wish to die as an outcome of a rational and understandable assessment of their personal lives. One study (Courage et al., 1993) describes the interwovenness between a rational, logical wish to die and at the same time the influence of depressive feelings (see Table 3).

### Table 3: Explanations of death wishes and suicidality from different perspectives

<table>
<thead>
<tr>
<th>Reference</th>
<th>Perspective</th>
<th>Sample</th>
<th>Main explanation death wishes and suicidality</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Moore, 1997)</td>
<td>Phenomenological perspective: experiences and meaning</td>
<td>Elderly</td>
<td>- Death wish as a yearning for connection and a cry for meaning</td>
</tr>
<tr>
<td>(Crocker et al., 2006)</td>
<td>Phenomenological perspective: experiences and meaning</td>
<td>Elderly</td>
<td>Two contrast conceptualisations:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Suicide as finding a solution; after reaching a point of feeling trapped</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Suicide as giving up; a forced choice, epitomising their lack of autonomy, adding to feelings of helplessness</td>
</tr>
<tr>
<td>(Lindner et al., 2006)</td>
<td>Psychodynamic perspective; intra-psychic dynamics and psychosocial conditions</td>
<td>Elderly</td>
<td>- Suicide / suicidal thoughts as a paradoxical attempt to save the imagination of an autonomous existence</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Old-age suicidality as a result of intra-psychic disorders, in need for treatment</td>
</tr>
<tr>
<td>(Rurup et al., 2011)</td>
<td>Psychological perspective: triggers, reasons, processes and coping strategies</td>
<td>Elderly</td>
<td>- Death as a solution, freedom, reuniting with deceased relatives</td>
</tr>
</tbody>
</table>
(Rurup et al., 2011b) Psychological perspective: triggers, reasons, processes and coping strategies Elderly – Death wish is developed depending on life events / life problems, personal character, coping strategies and social support
- Death wishes as a coping strategy; reclaiming control by developing thoughts about death as a positive thing

(Courage et al., 1993) Psychological perspective: deterrents, specific risk factors and causes Elderly – Philosophically, elderly in this study spoke of suicide as a logical way of life. But when the inquiry moved to how they personally respond to their own suicidal ideation, they all described their experiences of coping in relation to depression
- At the experiential level depression and suicide are inextricably intertwined

(Harwood et al., 2006a) Psychological perspective; characteristics and types of life problems Proxies – Suicide as a result of abnormal personality traits and cognitive distortions, which seem to make a more important contribution to the decision than the (life) problem itself

(Kjølseth et al., 2009) Psychological perspective; personal characteristics Proxies – Suicide as a result of difficulty in accepting and adapting to age-related loss of function since the self-esteem is strongly associated with being productive and in control; this loss cannot be tolerated

(Kjølseth et al., 2010) Psychological perspective; experiences, personal characteristics and external conditions Proxies – Conceptions of death: acceptance: death is imminent, no fear of death
- Suicide as an understandable personal assessment of their situation, corresponding with a ‘realistic world-view’
- Suicide as a rational choice: a way of regaining oneself and becoming oneself. Through suicide elderly people acknowledge themselves and through choice they attain coherence in their lives

4. DISCUSSION
By describing the experiences and motivations of older people with an age-related wish to die – resulting from their subjective assessment that life is no longer worth living, while they are not suffering from a life-threatening disease – this article is the first to give an overview of studies on this specific subject. There is much literature on suicide in older age, but empirical studies that address the experiences of this particular group of older people
seem rare. Only a small body of research was identified paying (partial) attention to this topic. These studies give complementary findings from traditional quantitative studies that often report prevalence rates, risk factors and psychological symptoms. Quantitative studies frequently start from a psychiatric paradigm and demonstrate a tendency of medicalization of the wish to die in older people. In most cases, the assumption of an underlying pathology and the preference for clinical treatment is emphasized. Results in this review question this tendency and confirm the importance of making a distinction between a clinically defined state of ‘illness’ and existential ‘grief’, as Kjølseth et al. (2010) suggest.

We aimed to describe the experiences and motivations underlying an age-related wish to die. All studies listed in this paper point out that age-related losses play a crucial role in developing a wish to die: the loss of control, the loss of connectedness, the loss of meaning and in some cases the loss of the self. Most losses are closely related to the ageing process whilst others may be quite unrelated but were nonetheless experienced within the context of old age, making it difficult to disentangle them from this context. These loss experiences evoke a variety of feelings such as frustration, anger, loneliness, alienation, disintegration, powerlessness, worthlessness, hopelessness and tiredness.

Literature provides descriptions of personal characteristics, biographical events, social support and (implicit descriptions of) underlying perceptions and beliefs, which respondents subjectively assess as factors influencing the wish to die. Losses – particularly in advanced older age – are ubiquitous, so what distinguishes people who express a wish to die and those who do not? Several studies (Harwood et al., 2006a; Rurup et al., 2011b; Kjølseth et al., 2009) suggest that the way a person perceives and solves age-related life problems and loss experiences is linked to personal character, coping strategies and social support. For explaining the distinction between older people who express a wish to die and those who do not, personality may be more important than the problem itself (Harwood et al., 2006a).

Although these outcomes give a better understanding of this group of older people, their inner lives and interwoven factors and circumstances which elderly themselves believe as strengthening (and in some cases weakening) the age-related wish to die (see Figure 2), reservedness is required because
only a few studies are available and findings clearly point out the subjectivity of the individual consideration and the importance of making specifications as to differences in personal experiences.

As to the topic of how death wishes and suicidality were labelled in the reviewed studies, literature gives us an inconclusive picture as expected. The way the death wish is labelled seems to be partly dependent on the chosen sample and the perspective of the study. Some studies from a psychological perspective (Lindner et al., 2006; Harwood et al., 2006a) explain death wishes and suicidality in terms of abnormal personality traits and pathology. Two papers (Moore, 1997; Crocker et al., 2006) remain close to the lived experiences of older people in their interpretations of the death wish, which is quite logical because of their phenomenological approach. Other authors (Rurup et al., 2011b; Rurup et al., 2011c; Kjølseth et al., 2009; Kjølseth et al.,
suggest that in some cases suicidal ideation in older people can be explained as a natural phenomenon of old age: a wish to die as an outcome of a rational and understandable assessment of their personal lives. One study (Courage et al., 1993) claims to have found empirical evidence for the ambivalence and interwovenness between a rational life assessment and at the same time the influence of depressive feelings uttered by older people wishing to die. It seems that elderly in this study spoke philosophically of suicide as a logical way of controlling the end of life. But at a more personal level, all respondents described their experiences of coping in relation to depressive feelings. This finding challenges the idea that older people are able to make an exclusively autonomous, thoughtful, rational choice about the end of their lives at a self-appointed moment and calls for more research.

In addition, the reviewed articles explain the wish to die as closely related to physical, social and mental losses. Because of the accumulation of losses and the feeling of irreversibility, the experiences are characterized as absolute and hopeless. It seems that some respondents suffer from an ongoing mourning process. This might be some justification for the depressive feelings, so often found in older people with a wish to die. Possibly, the depressive symptoms should not predominantly be explained as a result of a clinical depression (Kjølseth et al., 2010; Rurup et al., 2011c; Rurup et al., 2011b; Kjølseth et al., 2009), but might in some cases be perceived as a (natural) part of a mourning process, reflecting the existential situation of the aged person. Therefore, findings of this review study might contribute to the debate of whether the wish to die in older people should be interpreted mainly as a pathological or as an understandable phenomenon in old age.

Some remarks must be made with regard to the limitations of this study. First of all, the selection procedure was quite complex, as described in detail before. Only nine studies remained, some of which are only partly related to this particular topic. This underlines the notion that this topic has not yet been thoroughly investigated and requires a very tentative and provisional description of results and conclusions. Furthermore, the included studies differ in philosophical and research tradition, research question, method and sample, which sometimes result in findings difficult to compare. In one study some respondents suffered from life-threatening diseases (Harwood et al., 2006a), in another study informants were living in a psychiatric unit (Moore, 1997). However, the authors carefully scrutinized these studies and
came to the conclusion that – despite being a grey area – both studies primarily focus on wishes to die in the context of ageing and question the possibility of a rational wish to die. A third limitation of this study lies in the fact that from the nine included studies, only six present results derived from older people’s narrations (Moore, 1997; Lindner et al., 2006; Rurup et al., 2011b; Rurup et al., 2011c; Crocker et al., 2006; Courage et al., 1993) and give descriptions of older people reflecting on their own wishes to die. The other three studies were based on the interpretations of the experiences of older people from an outside perspective and do not give direct insight in their experiences. Although these studies explicitly mentioned trying to hear the voices of older people through proxy narratives, the outside perspective might result in a different rating of personality and emotions.

Despite these limitations, this review provides a first insight in a research area in its infancy. The outcomes give valuable insights into how older people – who are tired of living, in the absence of a severe disease – may feel, think and experience their life. It clearly shows the existential character of the wish to die. The findings also indicate the need to consider the unique perspective of the individual and the surrounding social context. The outcomes are obviously complementary to quantitative studies and may build our understanding, which might be indispensable for further debate on this issue, clinical development and treatment. Considering the limited extent of qualitative research in the last twenty years on this specific group, the findings of this review mainly serve as an inspiration for further investigation from an inner perspective, focusing on the essence of the individual lived experience of older people with a wish to die who do not suffer from a life-threatening disease in order to get a better understanding of their life-world.
REFERENCES


Being-In involves immersing oneself in another’s world: listening deeply and attentively so as to enter into the other person’s experience and perception. I do not select, interpret, advise or direct. (...) Being-In the world of the other is a way of going wide open, entering in as if for the first time, hearing just what is, leaving out my own thoughts, feelings, theories, biases. (...) I enter with the intention of understanding and accepting perceptions and not presenting my own view or reactions. (...) I only want to encourage and support the other person’s expression, what and how it is, how it came to be, and where it is going.

Quote of Clark Moustakes in Patton (2002, p.8).
CHAPTER 3

Ready to give up on life:
The lived experience of elderly people
who feel life is completed and no longer worth living

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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: 257-264.
ABSTRACT
In the Netherlands, there has been much debate on the question whether elderly people over 70 who are tired of life and who consider their life to be completed, should have legal options to ask for assisted dying. So far there has been little research into the experiences of these elderly people. In order to develop deliberate policy and care that targets this group of elderly people, it is necessary to understand their lifeworld. The aim of this paper is to describe the phenomenon of ‘life is completed and no longer worth living’ from a lifeworld perspective, as it is lived and experienced by elderly people. Between April to December 2013, we conducted 25 in-depth interviews. A reflective lifeworld research design, drawing on the phenomenological tradition, was used during the data gathering and data analysis. The essential meaning of the phenomenon is 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 whom 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: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; 5) a sense of aversion to feared dependence. This article provides evocative and empathic lifeworld descriptions contributing to a deeper understanding of these elderly people and raises questions about a close association between death wishes and depression in this sample.
1. INTRODUCTION
In recent years, there has been a growing scientific interest in elderly people wishing to die without the presence of a life-threatening disease or a severe psychiatric disorder. Several quantitative studies have been undertaken to determine prevalence rates, characteristics and risk factors associated with the development of death ideation and death wishes in elderly people who are tired of living (Rurup et al., 2011a; Harwood et al., 2001; Jorm et al., 1995). In addition, some qualitative studies have been conducted to understand suicidal feelings in elderly people (Rurup et al., 2011b; Rurup et al., 2011c; Kjølseth et al., 2010; Kjølseth et al., 2009; Harwood et al., 2006; Crocker et al., 2006). These studies indicate that age-related losses, decreasing sociality, depressive feelings, personal characteristics and beliefs are associated with the development of a wish to die.

Most elderly people who wish to die ‘will wait until time fulfils their wish’ (Rurup et al., 2005) and would probably consider suicide to be unacceptable, associated with despair and mutilation. In the Netherlands, however, the general public seems to have become more open towards the possibility of a self-directed death (van Delden et al., 2011). With the ageing of the baby boom generation an ethos of neo-liberal values such as self-determination, autonomy and individualism has become more dominant and has stimulated an on-going process of a growing awareness of death and dying, not only in the Netherlands but in the Western world as such (Seale et al., 1997; Chabot and Goedhart, 2009). The debate on how to determine time and manner of death has become more common, as these aspects are considered as important indicators of a ‘good death’ in western countries (Chabot and Goedhart, 2009).

Chabot and Goedhart (2009) studied individuals who have a strong desire to control and hasten death by committing auto-euthanasia. Auto-euthanasia refers to an intentional act of a person independently ending one’s life; based on a persisting wish to die; decided after careful consideration, preferably after having discussed it with meaningful others; implemented in a careful manner, and without a physician performing euthanasia (Chabot and Goedhart, 2009). The term auto-euthanasia was previously used by Glaser and Strauss to indicate a way ‘to die gracefully, to manage one’s own death and arrange a painless, easy departure, to forestall an indefinite prolonging of medical treatments, before one may be powerless and no longer
capable of expressing one’s will’ (Glaser and Strauss, 1965). Although ‘the why and how of the hastened death’ has been studied by Chabot and Goedhart (2009), prevalence figures on elderly committing auto-euthanasia are not available.

In addition, several recent studies indicate that an increasing number of Dutch people can imagine appreciating having a physician assist them in the dying process, even if they do not suffer from a serious disease (van Holsteyn and Trappenburg, 1998; Buiting et al., 2012; van Delden et al., 2011). Although in the Netherlands euthanasia (EAS) and physician-assisted suicide (PAS) are only permitted in cases of unbearable and hopeless suffering that stems from a medical condition, a growing minority of the general public supports PAS or EAS in cases of elderly people who do not suffer from a medical condition but who are tired of living (van Delden et al., 2011; Raijmakers et al., 2013). Buiting et al. (2012) have demonstrated a significantly growing level of support for the availability of a last-will-pill from 31% in 2001 to 33% in 2005 up to 45% in 2008.

This growing support needs to be interpreted in the context of an on-going public debate in the Netherlands, questioning whether elderly people with a wish to die – without a life-threatening medical disease – should have legal options to ask for assisted dying. Since 2010, this debate is placed firmly on the Dutch parliamentary agenda by a citizens’ initiative called ‘Out of Free Will’, that collected 116,871 signatures to legalise assisted suicide for people over 70 who feel life is ‘completed’ and prefer death over life. Given these trends, a research agenda ‘Elderly and a self-chosen death’ (2014) was formulated at the request of the Dutch government, addressing several important questions in the end-of-life debate including the following: What are characteristics, prevalence rates and life-problems associated with this group of elderly people? How do shifting socio-cultural value orientations impact their wish to die? What is the role of a physician in these cases? What practical interventions may be suitable to diminish the wish to die and improve quality of life? What ethical and legal questions are raised and must be answered?

To answer these questions and to develop policy and effective health care services for elderly people who feel their life is ‘completed’ and wish to die, it is a prerequisite to first hear their voices and address their inner percep-
tions and subjective experiences. However, as described in a literature review undertaken by the authors of this paper (van Wijngaarden et al., 2014), very little qualitative research has been conducted so far into the experiences of this specific group of elderly people who wish to die without having a serious medical condition. It is thus necessary to supplement existing knowledge with in-depth knowledge about the lived experiences of these elderly people. The aim of this study was to develop an in-depth understanding of the phenomenon of ‘life is completed and no longer worth living’, as it is lived and experienced by elderly people who do not suffer from a life-threatening disease or a psychiatric disorder. This was done from a phenomenological approach to explore this experience with an open, non-judging and wondering attitude (van Manen, 2014).

2. METHODS

2.1. Reflective lifeworld approach

In order to describe the phenomenon in all its richness, an in-depth interview study based on Dahlberg’s reflective lifeworld approach (Dahlberg et al., 2008) was conducted. This approach, inspired by the philosophical phenomenology, was chosen because of its primary focus on the lifeworld: the world of lived experience. Rather than giving causal, behavioural explanations and using external theories and interpretive frameworks, the focus is on giving a description of the phenomenon as it is experienced by those who are studied (Finlay, 2011). The aim of the reflective lifeworld approach is ‘to illuminate the essence of the phenomenon’ under research. For Dahlberg (2006), an essence refers to a common thread through the variety of participants’ experiences; the essential characteristics of the phenomenon ‘without which it would not be that phenomenon’.

To enable the phenomenon to reveal itself, researchers need an open attitude. This phenomenological attitude requires the practice of ‘bracketing’, which includes all efforts made to restrain researcher’s personal ideas and scientific assumptions from having an uncontrolled effect on evolving understandings, in order to examine the phenomenon in a systematic, open and careful way (Finlay, 2011). It demands ‘a true willingness to listen and see and understand’ (Dahlberg et al., 2008). To practice this phenomenological attitude during this current research project, there was on-going reflec-
tion (by means of a reflective research journal and dialogue with co-authors and peers). This enabled the researcher to reflect on evolving understandings and to bracket 1) scientific theories and explanations, 2) truth or falsity claims made by participants, 3) and personal views and experiences of the researcher (Finlay, 2011).

2.2. Participants and sampling
Twenty-five people over 70 years of age, who considered their life to be ‘completed’ and no longer worth living, and who strongly wished to die while not being terminally or mentally ill, participated in an in-depth interview exploring their lived experience. Persons were recruited between April and September 2013. Advertisements were placed in four Dutch magazines and on three Dutch websites all targeting elderly people. In these advertisements, the context and aim of our research project were described. One hundred forty-four people responded by post, email and telephone, giving a description of their personal situation. Every respondent received a response with a short personal acknowledgement followed by general information about the selection procedure.

Participants were purposefully sampled in two rounds: the first selection was based on respondents’ short personal description. Sample criteria were: richness of experiences; differences in (physical) health; different ideological and demographic backgrounds; and nationwide coverage. Next, potential participants were called by the interviewer to ensure the first selection. Some potential participants were then excluded, as they turned out to be so-called ‘if-then respondents’: if their situation declined further, then they would prefer to have legal options for assisted dying, rather than having an actual wish to die at that moment. Others were highly politically driven. Their response was focused on advocating legalization of self-directed death, instead of giving a personal, experiential account. In a few cases, the respondents withdrew. One participant, who was aged 67 at the time of the interview, was included because of her unique religious background. Table 1 shows all background characteristics of the selected participants.

Regarding the safety of people who disclosed a death wish, it is important to underline that participants were targeted among mentally competent citizens, and not (psychiatric) patients. Excluded respondents had the possibility to contact the first author for referral to professional help at anytime.
2.3. DATA COLLECTION

The interviews took place from April to December 2013, were conducted by the first author in the participants’ everyday home environment, and lasted from 1 to 3.5 hours (median = 1:56). In two cases, the interviewer returned for an additional interview to complete the data. The adopted reflective life-world approach resulted in the use of open in-depth interviews to increase our understanding of how the phenomenon of ‘life is completed and no longer worth living’ is experienced in the interviewees’ everyday life. Although a phenomenological interview is characterized by an open approach, the interview was structured in (three) sequences: 1) completed life; 2) the wish to die; and 3) organizing a self-directed death. In this paper, we focus on the first two sequences as these correspond with the aim of this article. Guiding interview questions were: ‘Can you describe what it means to experience that life is completed?’; ‘Can you describe what it means to have a strong desire to die?’; and ‘Can you describe as fully as possible how this experience influences your daily life?’ In order to encourage participants to articulate their experiences in detail, the interviewer kept on posing questions such as: ‘Can you elaborate a bit more on that?’ Furthermore, to minimize any impact on informants’ expressions and responses during the interview, the researcher used open, non-directive formulations and expressions consistent with the participant’s language as much as possible.

Interviews were audio-taped and transcribed verbatim. To be able to understand the interview text in relation to its context, observational field notes were made during and immediately after the visits about contextual characteristics, atmosphere and relevant non-verbal expressions. Before the interview, a personal information form was sent to all participants. They were also asked to fill in this form and return it to the interviewer. Next, to get some idea whether or not the wish to die was driven by a severe depression, 24 participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). The HADS was personally administered by the interviewer, immediately after the interview to avoid influencing the characteristic openness of a phenomenological interview. In Table 1, the outcomes are listed as participant characteristics.
Table 1–Characteristics of the selected participants (n = 25)

<table>
<thead>
<tr>
<th>Category</th>
<th>Participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
</tr>
<tr>
<td>Age (average 82 years)</td>
<td></td>
</tr>
<tr>
<td>65-70</td>
<td>1</td>
</tr>
<tr>
<td>70-80</td>
<td>11</td>
</tr>
<tr>
<td>80-90</td>
<td>8</td>
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<tr>
<td>90-99</td>
<td>5</td>
</tr>
<tr>
<td>Partner status</td>
<td></td>
</tr>
<tr>
<td>Partner (living together)</td>
<td>5</td>
</tr>
<tr>
<td>Partner (living in an elderly home)</td>
<td>1</td>
</tr>
<tr>
<td>LAT relationship (living apart together)</td>
<td>1</td>
</tr>
<tr>
<td>Widowed</td>
<td>14</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>No partner</td>
<td>2</td>
</tr>
<tr>
<td>Children</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>14</td>
</tr>
<tr>
<td>Children (but no contact at all)</td>
<td>2</td>
</tr>
<tr>
<td>Children (deceased)</td>
<td>2</td>
</tr>
<tr>
<td>Childlessness (both involuntary or by choice)</td>
<td>7</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Independent</td>
<td>19</td>
</tr>
<tr>
<td>Semi-dependent</td>
<td>4</td>
</tr>
<tr>
<td>Care home</td>
<td>2</td>
</tr>
<tr>
<td>Belief</td>
<td></td>
</tr>
<tr>
<td>Humanism</td>
<td>4</td>
</tr>
<tr>
<td>Christianity</td>
<td>6</td>
</tr>
<tr>
<td>Anthroposophy / Esoterism</td>
<td>3</td>
</tr>
<tr>
<td>Agnosticism</td>
<td>2</td>
</tr>
<tr>
<td>No belief</td>
<td>10</td>
</tr>
<tr>
<td>Most important former occupation</td>
<td></td>
</tr>
<tr>
<td>Supervisor, manager, director, entrepreneur</td>
<td>6</td>
</tr>
<tr>
<td>Psychotherapist / nurse / social worker</td>
<td>5</td>
</tr>
<tr>
<td>Technician, chemist</td>
<td>2</td>
</tr>
</tbody>
</table>
Politician 1
Teacher / lecturer 4
Accountant / secretary 2
Interior designer 1
Housewife / pastor’s wife 2
Several “unsuccessful” jobs 2

Relevant health-problems mentioned by participants

<table>
<thead>
<tr>
<th>Health Problem</th>
<th>Participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No serious illness</td>
<td>10</td>
</tr>
<tr>
<td>Sensory disorders: anosmia, hyperacusis, tinnitus, deafness, macular degeneration</td>
<td>7</td>
</tr>
<tr>
<td>Craniomandibular dysfunction, facial pain</td>
<td>2</td>
</tr>
<tr>
<td>Arthritis, rheumatism, fibromyalgia, hip replacement, rib and spinal injuries, osteoporosis</td>
<td>6</td>
</tr>
<tr>
<td>Chronic fatigue</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3</td>
</tr>
<tr>
<td>Intestinal disease</td>
<td>1</td>
</tr>
<tr>
<td>Valvular heart diseases: cardiac failure, transient ischemic attacks (TIAs), valve repair</td>
<td>6</td>
</tr>
<tr>
<td>Serious itchiness</td>
<td>2</td>
</tr>
</tbody>
</table>

Outcome of screening for depression (HADS)  

<table>
<thead>
<tr>
<th>Depression Score</th>
<th>Participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-7 (no indication)</td>
<td>15</td>
</tr>
<tr>
<td>8-10 (mild)</td>
<td>6</td>
</tr>
<tr>
<td>11-15 (moderate)</td>
<td>2</td>
</tr>
<tr>
<td>16 or above (severe)</td>
<td>1</td>
</tr>
</tbody>
</table>

Outcome of screening for anxiety (HADS)  

<table>
<thead>
<tr>
<th>Anxiety Score</th>
<th>Participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-7 (no indication)</td>
<td>21</td>
</tr>
<tr>
<td>8-10 (mild)</td>
<td>3</td>
</tr>
<tr>
<td>11-15 (moderate)</td>
<td>0</td>
</tr>
<tr>
<td>16 or above (severe)</td>
<td>0</td>
</tr>
</tbody>
</table>

2.4. Ethical considerations

The current study was evaluated by Medical Ethical Review Committee Utrecht, who confirmed that the Dutch Medical Research Involving Human Subject Act (WMO) did not apply, as participants were not patients but mentally competent citizens, and participants were not subjected to treatment.
or required to follow a certain behavioural strategy as referred to in the WMO (art.1b). Subsequently, official approval of this study by the Medical Ethical Review Committee was not required (protocol: 13-176/C).

All participants received an information letter outlining aim, procedure, the right to withdraw at any moment, privacy, contact details and the possibility of receiving aftercare (i.e. an extra conversation at their home or referral to professional help). They were also informed that additional information was available on the research website. Prior to the interview, the researcher contacted them by phone to make an appointment for an interview and to check whether the information was clear. They were asked to give written informed consent to participate in the study. Every participant received a narrative interview report of about two pages, on average two months after the interview. After they had received it, we contacted the participants. The majority of participants not only fully agreed with the report, but also explicitly underlined that participating had been a positive experience, because the interview had helped them to express their thoughts and feelings, which gave them a sense of relief and recognition. Also, most considered it an honour to have the opportunity to contribute to the scientific and public debate. In two cases, aftercare was provided.

2.5. Data analysis
The analysis was conducted by all authors based on the reflective lifeworld approach (Dahlberg et al, 2008). First, the researchers tried to get a sense of the whole dataset by thoroughly reading all transcripts. Keywords were marked. Notes were made in the margin. Based on subsequent readings a narrative report was written of every interview, which was sent to participants for member check, not only for validation but also for ethical reasons (Finlay, 2011). Then the analysis focused on the identification of meaningful parts. In order to obtain a deeper understanding of the data, the text was divided into smaller segments of meaning. For each separate interview significant statements were listed and then grouped into larger units of information: so called ‘meaning units’ (Dahlberg et al, 2008). These units were presented in 25 mindmaps – one per person – which helped to identify some meaning units that emerged in every story. When all meanings were identified, the researchers individually formed clusters of meaning by putting together meaningful units that seems to belong together. In this way, they separately tried to discover a temporary pattern of meanings. The results
found individually were then discussed together. Subsequently, all clusters were related to each other through synthesis, in order to discover the essential meaning of the phenomenon. The first author used Atlas.ti 7.5 as an additional tool for easy comparison of meaningful fragments and clusters, and to facilitate going back and forth between the whole and the parts.

During the whole process, the researchers adopted an open attitude to both the phenomenon and the process of understanding. After careful deliberation – consisting of several reflection sessions and exchanges of findings – agreement was considered satisfactory. Finally, to verify the findings, a peer audit was established in which the outcomes were discussed with 11 members of the ethics-of-care research group (Patton, 2002).

3. RESULTS
In this section, following the reflective lifeworld approach (Dahlberg et al, 2008), we first describe the essence which is the overarching characterization of the phenomenon. Next, we describe the constituents that further illuminate the different aspects of the phenomenon. Together the essence and the constituents provide a full and detailed description of what it means to feel that life is completed and no longer worth living.

The essential meaning of the phenomenon is understood as ‘a tangle of inability and unwillingness to connect to one’s actual life’. A permanently lived tension penetrates all participants’ stories: their daily experience seems to be diametrically opposed to and incompatible with their expectations of life and their idea of who they were. Living in the present is almost impossible, because the ‘here-and-now’ evokes significant feelings of disconnection, reflected in feelings of loneliness, not mattering, fear of dependence, self-estrangement and alienation. ‘Life is completed and no longer worth living’ is an expression of an – often quite desperate – desire that life-as-it-is should stop as soon as possible because of the unbearable burden it embodies. It is difficult to unravel the tangle of inability and unwillingness to connect to one’s actual life. Sometimes it appears to be an active resistance, at other times – even in the same lifestory – a passive inability. Sometimes it appears as an intertwining of being unwilling and unable, at other times it presents itself more like a continuum: unwillingness seems to shift gradually into inability.
The impossibility to connect to one’s actual life is strengthened by a personal life motto: most participants were outspoken, proactive people who highly value their independence and consequently fear dependence, who want to maintain control over their own life and to whom it feels unnatural to sit and wait for the end to come. They simply cannot surrender to life, suffering and dependence as it is/comes. Instead they feel ready to give up on life, actively ideating on ways to hasten death. The following description of five constituents – which should be seen as components of the essential meaning of the phenomenon – further explicate the meaning of the phenomenon: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; 5) a sense of aversion to feared dependence.

3.1. A sense of aching loneliness

All participants expressed feelings of loneliness: a sense of distance from others, a lack of valuable relations and companionship: ‘Deep inside, you are very much alone. Totally, totally alone’ (i–5). Some gradually withdrew into themselves more or less deliberately, for others losing connectedness was less intentional. Participants spoke of deep, heartfelt lonely feelings, regardless of whether there were others around (such as children, spouse, friends, caregivers). A 94-year-old man reported:

_I have two sons. My youngest son, who is quite close, keeping an eye on me, is very dear to me. (...) And I also have a partner with whom I have a very good LAT [living apart together] relationship. So those two bonds still exist. But for me, it’s no longer a reason to go on living. You only go on living, if you want to. (...) I feel like a sawed-off tree. Completely sawed-off. But a sawed-off tree still has roots. I have no roots anymore, no strong bonds anymore, and no close connection to life anymore. (...) Of course, I value those bonds, but hey, you fall in love, you get married, you have a LAT relationship. Well, that’s it, that’s as far as it goes. It’s a gilded edge, a nice dessert. But it’s not something to keep you alive (i–4)._ 

In several cases the contact with their children was quite good, but participants did not want to be ‘a hindrance’ to them.

_My children are all managing on their own. Nobody lives a shabby life, thank God. But you know, they don’t need me anymore. I know I’m not supposed to_
say it out loud, but if I visited my kids, I think they would say: ‘God damn, it’s the old man again.’ (...) I’m just getting in their way (i–10).

Other participants spoke of some remaining, worthwhile contacts with peers, but those contacts were becoming increasingly sporadic and did not compensate lonely feelings anymore. Despite people being around, they felt a lack of reciprocity and support.

In the last years, I have strengthened two social contacts. Nice outings, uh, with that friend. Uh, I mean going to concerts, cabaret, that kind of outing. But actually, I have come to the conclusion that this does not help enough. These things, it helps, it helps a lot, it’s great fun, but it’s not enough... These outings, they are only occasional, maybe once or twice a month (i–11).

3.2. The pain of not mattering
All the participants talked about gloomy feelings of not mattering. They viewed themselves as dispensable, redundant and not important to people or society. Some participants first described feelings of not mattering in quite neutral terms, like a fact of life one has to resign oneself to. They had accomplished their life-tasks – other people have taken over previous functions, children are independent and able to manage their own lives – and consequently they no longer felt they were engaged in nurturing and guiding younger people or contributing to society or the next generation.

However, at the same time there was sadness in every story. Despite the fact that some rationally considered detachment part of life, participants associated feelings of not mattering with intense sorrow and had difficulty living with this: they felt marginalized, thereby losing purpose and meaning. Many male and female participants related the meaning of life to their former occupation, which in most cases, they had left decades ago:

It’s just that, uh.... I cannot utilize my talents. I’m a techie, that’s what I like to do. (...) So yes, I feel that I have a lot of experience and knowledge in that area, but society doesn’t need me anymore. At the moment I strongly feel: my life is of no consequence anymore... (i–11).

Most participants used to be full and active members of society, they had a certain grip on the world, but slowly recognized they were becoming out-
siders and increasingly lost their sense of belonging: 'your influence is gone, nobody listens to you anymore, old axioms fall away, you are not able to keep up'. More and more they lost connection with the surrounding world. One participant compared his feelings with 'looking through the wrong end of a pair of binoculars': instead of things getting closer, everything is moving further and further away. Over the years, he felt more distance to the world around him. ‘It is like the end of a curve, a vacuum... Not my world anymore.’ (i–15) It evoked feelings of alienation and disconnectedness from life. Another man (92), a former superintendent in the shipping industry, talked about how his recent experiences on a cruise enhanced mournful feelings of exclusion and not mattering:

You have no effect on anything, you know. The ship sets sail and everyone has a job, but you just sail along. (...) I am cargo to them. That's not easy. Not easy. No, no, no. That's not me! No, no, no, no! (...) Yeah, it is difficult to fully express, huh, what I'm feeling. Humiliation is too strong a word, but it is bordering on it. Huh, I simply feel ignored, completely marginalized. You know, in the past, when I went aboard ship, I was the superintendent with full authority, carrying out important work. But now, I feel like a third wheel. Yeah, completely sidelined in all areas. I have no idea in which area someone my age is able to seriously participate. No. That is over (i–6).

In most stories, an intense longing to make a valuable contribution and to participate somehow emerged, but the respondents felt that their contribution was not taken seriously, not needed, they felt rejected, and this further intensified the pain of not mattering. A woman (84) told:

If only I could express myself! I could give lectures, I could do lots of things, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death. I do want to reincarnate to restart my school and then I will tell my story again. My story! (...) But now, I just sit here in my own silence, it's very quiet. Many days go by that I don't hear my own voice. And definitely, you have to go through this yourself to really understand, you know. This voice, my voice, which so strongly wants to talk... Well that's very difficult. I love people but I'm just sitting here all alone( i–9).
3.3. The inability to express oneself
The experience of no longer being able to carry out the activities one was committed to during life, clearly emerged in participants’ stories. Participants regarded these activities and capacities as central to life, not only as a reason to matter as described above, but also as a way to express one’s individuality. Therefore, the loss of these identifying activities meant a loss of self to them: ‘This is no longer me.’

Depending on what was important in their life, participants mentioned divergent losses, of which the most common was the loss of worthwhile projects that reflected one’s personality. Next, the lack of sharing and gaining new ideas to enrich one’s life and to cultivate one’s identity was often mentioned. Some participants explicitly regretted becoming unable to care for others, as this was most important in their lives. Four participants deeply grieved over the loss of their artistic abilities. One lady (87) who lives in a nursing home – whose room was full of expressive pictures she painted – talked about her deep sadness caused not only by her inability to paint any longer, but also because the ‘colourful world’ she loved so much completely lost its colour due to retinal degeneration:

You’re no longer human, I think. You cannot care for people anymore. (...) You lose so much that you are no longer human, I think. That’s how I feel about myself. I am treated as a person, that’s not my point, but for myself... (...) I see nothing, I see nothing but blackness. (...) When I was 58, I retired. Then they said: ‘What are you going to do?’ I said: ‘I am going to paint.’ Everyone laughed at me. But I used to draw when I was little. In a way, it has always been my talent. (...) In spring, it’s so beautiful out here. That little pond with those trees and the daffodils all in bloom, it’s such a rustic spot, so beautiful. The delicate green of the weeping willows... But now, it’s all black... (i–13).

3.4. Multidimensional feelings of tiredness
Most elderly people mentioned feelings of mental, physical, social and/or existential tiredness. In most cases, tiredness turned out to be a complex, multidimensional and overwhelming fatigue often accompanied by a gloomy and despondent mood. One participant felt extremely tired, just totally worn out, fed up with life-as-it-is: ‘...if I only have to lift an arm to get something done, I already feel completely overworked’ (i–4). Participants mentioned different (sometimes intertwined) reasons for tiredness:
- Struggling with serious but non-life-threatening diseases, physical deterioration and pain.
- Emotional grief or a (past) trauma that comes to the foreground in the silence of old age.
- Continuous fretting about a very tough life, missed opportunities and disappointments.

One participant (93), suffering from several vertebral fractures due to ageing, illustrated his tiredness metaphorically:

*It gives me a pain that can be compared with carrying a very heavy bag of cement on my shoulders, you know, a bag of Portland weighing 50 kilos, all day, anywhere and anytime. I wake up with it, I go to sleep with it. But I have learned to downplay it to a certain extent. (...) It is a deadly fatigue. A painful feeling of being dead tired. Very heavy fatigue. It is pain. Well, you cannot understand it, as you are not carrying a bag of cement in your hands... It’s so extremely heavy. But not only that, it’s extremely painful as well. (...) So that’s not very stimulating, that pain does not encourage you to stay alive.*

In other cases, this tiredness was experienced more as listlessness. Elderly people experienced a lack of serious interests and purposes in life as all meaningful life-tasks are accomplished. There was little energy or enthusiasm left. Old age just left them in ‘a mind-numbing monotony’, waiting in a void for death to come. Apparently, nothing was to be able to relieve the boredom. Simultaneously, participants felt unable to resign themselves to this state of listlessness, because to them it is irreconcilable with their idea of who they are, as they lived an active life. One participant – well into his nineties – still lived a very active life: responsible for a two-person-household; completely up to date on computers and the digital world; an active Twitter-user; engaged in various digital current and social affairs platforms. Despite this, he strongly felt that everything he did was nothing more than ‘worthless futility’. To him being busy seemed the only way to kill time, but life became utterly pointless to him. He strongly wanted to organize his own death as soon as his wife passed away.

3.5. A sense of aversion to feared dependence
The process of progressive, irreversible decline and subsequent dependence evoked strong, feelings of aversion, especially fear and shame. Participants
seemed to make constant comparisons between current and desired life, between themselves and others whose situation appears even more hopeless. Attaching great importance to their independence, they regarded involuntary dependence as an unacceptable, abhorrent condition devoid of dignity.

Most elderly persons clearly expressed feelings of intense fear as if overwhelmed by an impersonal, unpredictable external power, which played by its own rules and took away personal and bodily capabilities. Notwithstanding their inner resistance, they felt forced to capitulate. One participant (75) talked emotionally about his first experience of faecal incontinence as a crucial moment, when he strongly felt he was losing grip on his body, because things happened ‘beyond his control’:

*I went out with Anita, watching birds, and uh, I said: ‘Oh, I need to pee’, so I walked out of the bird hide, stood there and then I peed. But then, I’ll just say it, I suddenly pooped too. Then I deeply, deeply cried, standing there outside in nature. I became intensely sad. (...) I do not know, I burst into tears, I felt so sad about this happening to me. (...) Yes, it was, so I think, I had no control at all, it just happened without my involvement... I stood there and it just happened... (i–23).*

Less explicit but definitely present in participants’ stories were feelings of shame associated with lived or feared deterioration. More than half of the participants explicitly expressed disgust about the idea of ending up in a nursing home: ‘I don’t want to be reduced to an insane, idiotic zombie lying in his own dirt.’ They talked in terms of ‘not being human anymore’, ‘completely losing your dignity’, and ‘an on-going humiliation’. They viewed dependence as utterly incongruous with their idea of who they are. A man – living in a private apartment on the grounds of a nursing home – pointed outside his window and said:

*Look at the condition of those old ladies in the building opposite. Gaunt and half dead, pointlessly driven around in a wheelchair, it is simply horrible... In my eyes, it has nothing to do with being human anymore. They don’t even know it, they just go through the process, and then suddenly ‘the black car’ arrives again. It is a stage of life, I simply don’t want to go through (i–23).*
Several participants even talked about losing their ‘raison d’être’: they were distrustful and feared their lives would be taken over by others (like caregivers or family), deciding what is best for them, because they are no longer able to ‘guard their own individuality’. Some participants nearly panicked at the thought of being too late with ‘taking precautions’ to avert a state of total dependence. For most, there seemed to be only one desirable option to retain control: a so-called ‘flight-forward’ to stop this ‘humiliating process’ as quickly as possible by a self-chosen death.

4. DISCUSSION

4.1. Reflections on the findings
Using a reflective lifeworld approach, the purpose of this study was to deepen our understanding of the phenomenon of ‘life is completed and no longer worth living’ as it is lived and experienced by elderly people who do not suffer from a life-threatening disease or a psychiatric disorder. The current study found that this phenomenon can be understood as ‘a tangle of inability and unwillingness to connect to one’s actual life’, characterized by an on-going dialectic tension between the daily and desired situation, between is and ought, such as their desire to matter and the pain of feeling marginalized; their longing for connectedness and the pain of feeling disconnected; their desire for independence while facing increasing dependence and vulnerability. As they feel less and less involved in life, participants express a yearning desire to end this process, ideating on manners to escape from the uncomfortable feelings, and death seems the only possible way out.

Though there is much literature on suicide and the wish to die in older age, empirical research into the experiences of this specific population of elderly people who wish to die without having a serious medical condition is very limited; only a few studies pay partial attention to it, as we described in a literature review (van Wijngaarden et al., 2014). This study probably provides the first in-depth account of this little studied group. It contributes to the literature in several ways: it provides a preliminarily characterization of this population; it nuances the assumption that the wish to die in this population stems from an ethos of rationality; it illustrates that the wish to die is not only about individual experiences, but is also based on social grounds; and it questions the association between death wish and depression in this sample.
First, our study provides a preliminary, phenomenological characterization of the population under research. Disengagement in old age seems to be an inevitable, ubiquitous process of withdrawal of an individual from society, so this raises the question what essentially distinguishes the persons who, during this process, give up on life and those that do not? Our results reveal that the group of elderly people studied is characterized by an inability and/or unwillingness to undergo the process of deterioration. The elderly demonstrate a firm but vain attempt to resist an inevitably growing dependence and to preserve their remaining independence. Being proactive, independent people, their resistance is strengthened by a set of beliefs and by character. These findings support the idea of Freeman (2000), who frames this kind of experience as ‘narrative foreclosure’: the conviction that, even though one’s life as such continues, in one’s mind one’s lifestory has already ended. Life is not over, but one’s lifestory is considered so. One is unable or/and unwilling to identify with life-as-it-is: it is too alienated, too meaningless, too shameful or frightening, having no pleasant future expectations at all (Freeman, 2000). Being ready to give up on life is thus closely related to the subjective perception of the elderly involved and the way they ‘weight’ their life-problems.

Next, our findings qualify the common assumption that the wish to die because life is ‘completed’ mainly stems from an ethos of self-determination, autonomy and reasonability (van Rein, 2013). The results clearly show the ambiguity of participants’ everyday realities: their wish to die is indeed driven by the great value they attach to independence and autonomy, but it is also strongly influenced by fears, sadness and loneliness. While the population under research as much as possible wants to run their own affairs without interference from others, paradoxically the findings simultaneously indicate elderly to be highly dependent on others when it comes to their well-being. They are driven by a strong human desire to be visible, recognized, wanted, needed, valued, depended upon, or attended to by others. This illustrates the complex ambiguous tension in human life that, regardless of how independent a person might present himself, he is at the same time, a needy, vulnerable who depends heavily on others. To be of significance in the eyes of others and to experience mutual responsibility (by helping, sharing, supporting each other) is of vital importance for one’s quality of life and self-esteem.
Sayer (2011) has highlighted the importance of taking peoples’ concerns seriously, not merely to recognize them as private emotions, but to view them as illuminations of what is happening in our society. He argues that people’s concerns suggest an ethical dimension of the phenomenon that also needs to be acknowledged: What matters? What needs to be taken seriously? ‘Needs, desires, suffering and a lack of well-being indicate a state of the world and some aspects of that world that should be changed. They involve an impulse, a drive, a pressure’ (Sayer, 2011). Thus the expressed needs – e.g. experiences of marginalization and social exclusion – should not to be reduced to ‘an arbitrary, subjective experience’, but serve as an imperative for an on-going public debate on the place and role of elderly in society.

Our findings further raise intriguing questions regarding a close association between death wishes and depression in our sample and the nature of their wish to die. Depression is the factor most frequently studied in relation to death wishes in the elderly people. A Dutch study by Rurup et al. (2011) shows that 67% of older people with an actual death wish had depressive symptoms and 20% suffered from a depressive disorder. Remarkably, in this current study, only one ‘severe’ plus two ‘moderate’ indications of possible diagnoses of depression were found with the screening instrument used. This might suggest that participants’ expressions of deep sorrow probably are not, or only to a limited extent, indicative of a clinical depression but rather a profound understanding of personal reality. This suggestion is broadly consistent with an earlier published study of Kjølseth (2010) which states that having a wish to die does not necessarily mean that one suffers from a depression and stresses the importance of making a distinction between a clinically defined disorder and existential suffering. However, more research on this topic is required to increase our understanding of the association between death wish and depression in this population, as this knowledge is of crucial importance to align health care and policy with people’s concrete needs and concerns.

While our study does not directly inform policy makers, it certainly nuances and problematize the current debate, as it provides insight in the lived ambivalences and ambiguities of this particular population; the shortcomings in the prevailing conception of people as independent, autonomous and self-determining agents; and the inadequacy of considering this wish to die to be an individual problem. Perhaps a way to partly address the absences
of meaning experienced by these interviewees might be by changes to their (social) circumstances and relationships, rather then offering them a legal opportunity to die.

4.2. Reflections on limitations and strengths
Since it provides one of the first qualitative in-depths accounts on this topic, we presume that our study can be considered pioneering research into a largely unexplored phenomenon. However, at least two limitations need to be considered. First, as in all qualitative research, some intrusion of the researcher’s biases is inevitable. To reduce the effect of the researcher’s biases, we used various strategies to enhance credibility and confirmability, such as; 1) organizing member checks to verify whether the participants feel that the narrative report reflects what they actually intended to say; 2) keeping an on-going, reflective research journal to record the first author’s initial impressions; 3) organizing frequent briefing sessions between all authors in which developing insights were carefully and critically discussed; 4) and organizing peer scrutiny of our project, as described in the method section.

Secondly, due to the small sample size the generalizability of these results may be limited. Besides, our results reveal stories of Dutch elderly people who are part of a Dutch society in which the end-of-life debate continues progressively. This specific cultural situatedness certainly influences the outcomes, and the results may not be readily transferable to elderly people from other cultures or societies. For the Netherlands, however, the transferability of these findings to other similar groups of people seems justified given the broad variation within our sample. We thus presume that our interpretation can be seen as most likely, providing insight and thorough understanding of the phenomenon, well grounded in the lives of elderly people, addressing their concerns, while sensitive to the unique characteristics of human existence.
REFERENCES


Rurup ML, Pasman HR, Goedhart J, et al. (2011b) Understanding why older people de-
velop a wish to die: A qualitative interview study. *Crisis: Journal of Crisis Intervention & Suicide* 32: 204-216.


CHAPTER 4

Till death do us part:
The lived experience of an elderly couple who chose to end their lives by spousal self-euthanasia

ABSTRACT

Purpose: This paper provides the first qualitative account of spousal self-euthanasia in older people, a previously unexplored phenomenon. It investigates the lived experience of a Dutch elderly couple who strongly wished – and chose – 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.

Methods: The case study focuses on the particular experience of one elderly couple (70+) by presenting two personal accounts from an insider perspective. These were analysed using a thematic existential phenomenological method.

Results: Spousal self-euthanasia – which in the literature is associated with self-deliverance, self-determination and a reasonable wish to die – is presented here as related to alienation from one’s body and identity, the growing emptiness of life due to loss of activities, and an inability to reconcile oneself with one’s changed ‘being-in-the-world’. Their decision to end life is largely based on the anticipatory fear of further deterioration, further losing control, and not being able to control time and manner of death in the future. The couple’s agreement to end their lives together, however, held both in an impasse, as their concerns, sense of time and logic differed significantly. In this case, a close relation between having a death wish and severe depression is questioned.

Implications: This paper concludes by outlining the practical implications for professionals working in gerontology and recommends further research on the relation between self-euthanasia and depression in the elderly.
1. INTRODUCTION

In France, November 2013, Georgette and Bernard Caves, both aged 86 years, simultaneously ended their lives in a Parisian hotel suite. The next morning their bodies were found. They died hand in hand with a plastic bag over their head. After this self-directed death, their son confirmed to the press that both feared separation, dependency and physical decline more than death. ‘They wanted to abandon life in all serenity.’ (Willsher, 25-11-2013)

In the Netherlands, February 2014, David Postma (86) and his wife Willemke Postma-Kloosterman (84) committed auto-euthanasia. They were ‘on the threshold of a nursing home’, but by no means wanted to give up their independence. Before they took a lethal dose of medicine, they played some favourite music and danced their last dance. ‘A wonderful farewell.’ In the midst of their children, they died at a self-appointed moment. A short poem by David was printed in the obituary: ‘We leave this earthly life satisfied, it is our time, we’re going.’ (Meulen, 04-02-2014)

The two news reports above describe elderly couples involved in suicide pacts, also referred to as spousal suicide, joint suicide or double suicide. A suicide pact is ‘a mutual agreement between two people who resolve to die at the same time and, nearly always, at the same place’ (Cohen, 1961). Despite the fact that suicide pacts involving older people are rare, they attract extensive media attention, probably out of all proportion to their frequency (Brown et al., 1995). They are often framed as an expression of romantic attachment: as the thought of being separated – by the relocation or death of one of the two – seems unbearable, the couple choose to end life the way they lived it; together as partners in life and death.

Vink (2013) terms these pacts ‘double self-euthanasia’ (or double auto-euthanasia), to distinguish them from suicide or folie-a-deux, which are associated with depression or other psychiatric disorders, insanity and self-destruction. In contrast, ‘self-euthanasia’ refers to a person’s intentional act to end their life independently; based on a persistent wish to die; decided after careful consideration; implemented in a careful manner (Vink, 2013; Chabot and Goedhart, 2009); and associated with self-deliverance, self-determination, reasonability, rationality and dispassion.
The first systematic study on suicide pacts was published in 1961 by Cohen, who described 65 double suicides. Cohen suggests most pacts are an expression of the ‘romantic idea that two people who die together are not parted but travel together to a destination beyond the grave where they will remain eternally united’ (Cohen, 1961, p.149). A number of case reports have appeared since Cohen’s study, mostly from a clinical or psychiatric perspective. These give some insight into the characteristics of partners in suicide pacts. It appears that people who die in a suicide pact are more likely to be older, married, ill and from a higher social class (Brown and Barraclough, 1997; Young et al., 1984). In most cases, the nature of the spousal relationship is characterized as ‘exceptionally close and devoted’ and mutually dependent (Brown and Barraclough, 1997; Brown and Barraclough, 1999; Brown et al., 1995; Liem, 2008). Most couples seem to live an isolated life, ‘absorbed in their own small world’ (Cohen, 1961), which inhibits them from discussing their ideas with others (Liem, 2008). In most pacts, the initiator seems to have been the man (Liem, 2008). Some studies associate pacts with coercion or pressure on the part of the initiator (Young et al., 1984; Liem, 2008). The study of Brown and Barraclough (1999), however, challenges this claim as they found no evidence for coercion.

Previous studies have revealed the main grounds for spousal suicide pacts, which include relief from mental or medical disorders and reasons related to mental disorders (Brown et al., 1995; Cohen, 1961; Brown and Barraclough, 1999). One should note, though, that participants in suicide pacts suffer less frequently from mental disorders than those who commit suicide alone (Liem, 2008). Other motives include the negative impact of ageing, ill health, and constant mental suffering caused by grave illness. When an intimate bond is threatened, couples start balancing the pros and cons of a mutual suicide pact (Liem, 2008).

Most studies focus on examining characteristics and motives, based on data gathered from an outsider perspective, such as police files, coroners’ records, medical reports and interviews with friends and relatives. We found no research that addresses the experiences and motivations of participants to a suicide pact themselves, other than the suicide notes of the deceased (Cohen, 1961). Many scientific questions regarding this phenomenon thus remain unanswered, including: how do agreements to commit suicide develop? What is the background to and what are the considerations underly-
Taking an idiographic approach, this paper aims to provide a unique, in-depth insight into this rare and complex social phenomenon – spousal self-euthanasia on the grounds that life is no longer worth living – through a detailed exploration of first-hand accounts of two members of an elderly couple who strongly desired, and chose, to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression. This is the first study to investigate the process prior to a spousal self-euthanasia by describing the subjective, existential experiences and inner considerations of an elderly couple planning a spousal self-euthanasia. We show how spousal self-euthanasia became an option, and how the couple experienced their existence towards the end. As such, we offer an exploratory and tentative understanding of this complex phenomenon. In the literature, both the terms suicide pact and spousal self-euthanasia are used, however, for the aim of this phenomenological study, the term spousal self-euthanasia is preferred, because this term best expresses the self-understanding of the elderly couple involved.

2. METHODS

2.1. An existential phenomenological approach
Phenomenological methodology seeks to examine human experience as manifested in concrete situations, by asking: how is the phenomenon lived and experienced by people? For this case study, we focused on the particular experience of one elderly couple by presenting two personal accounts from an insider perspective. The two accounts were analysed using an existential phenomenological method (Ashworth, 2003; Finlay, 2011). This methodology was employed to develop in-depth understanding of the subjects’ lifeworld – understood as ‘the world that is subjectively lived’, rather than objectively explained (Finlay, 2011) – by describing the meanings that arise from those accounts.

In phenomenological research, every effort is made to limit presuppositions and theoretical assumptions, so as to approach the phenomenon with a sense of openness and wonder (van Manen, 2014). Phenomenologists acknowledge the impossibility of being truly open and negating one’s sub-
jectivity. However, they agree on the crucial need for ‘a phenomenological attitude’: maintaining as open as possible to enable ‘the process of entering into the experience itself’ (Finlay and Molano-Fisher, 2008). Through a careful, iterative reflective process, the researcher seeks to become aware of certain preconceptions and assumptions, and then manage their impact on the research.

2.2. Participants and sampling

This case study formed part of a larger research project on the lived experience of older people who consider their lives as ‘completed’ and no longer worth living, and who strongly wish to die while not being terminally or mentally ill (van Wijngaarden et al., 2015). Participants for this overall study were recruited between April and September 2013. Recruitment advertisements were placed in several magazines and websites all targeting elderly people, describing the context and aim of the research project. Twenty-five people over 70 years of age were selected by purposeful sampling. (For an in-depth account of the overall sample strategy, see Van Wijngaarden et al. 2015). The couple under research in this case study was part of our larger sample. We decided to analyse their case separately because of the uniqueness of their story. To obtain an indication of whether their wish to die was driven by severe depression, participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). With regard to this case, the husband scored ‘mild’ on the screening items for depression (8) and ‘no indication’ for anxiety (5). The wife scored ‘mild indications’ on the screening items for both anxiety (10) and depression (9). These outcomes suggested no indication for further diagnostic testing and little chance of serious depression.

2.3. Data collection

In October 2013, the first author visited the couple twice in their home. On the first occasion, the wife was singly interviewed in the living room. On the second occasion, the husband was singly interviewed in his study on the first floor. Both interviews lasted 1.5 hours. Before and after the interviews, the author and the couple met together in the living room. In sum, the interviewer spent about 4.25 hours with the couple.

Following the phenomenological approach, open in-depth interviews were conducted to explore the lived experience of this elderly couple who had
jointly chosen to end their lives because they felt that life was no longer worth living. The guiding interview questions were: ‘Tell me your story about what it means to feel that life is over’; ‘Can you describe what it means to have a strong desire to die together?’; and ‘Tell me about the process of how your agreements developed.’ Further leading questions were avoided, because it was intended that the direction of the interview be dictated by the interviewee. The interviewer tried to engage empathically with both participants and encouraged them to articulate their experiences in detail and offer concrete examples, posing questions such as: ‘Can you elaborate a bit more as concretely as possible?’; ‘What do you mean by...?’; and ‘What is it like...?’ (See Appendix 1 for the complete interview guide).

Both interviews were recorded and transcribed verbatim. To be able to understand the interview text in relation to its context, observational field notes were made during and immediately after the visits. They covered the contextual characteristics, the atmosphere and relevant non-verbal expressions. All written correspondence was added to the data: before the interview, the husband emailed six times about their personal situation and the developments in his wife’s rehabilitation. After the interviews, he emailed another four times. One of their children approached the first author by email, which led to an additional interview lasting 1.5 hours. The interview confirmed and strengthened our understanding of the case and provided insight into the children’s perspective. Shortly after they died, the children sent a notification of their deaths to the interviewer.

2.4. Ethical considerations
The research project was evaluated by an accredited ethical board, based on the following provided documents: a research protocol, the informative letter, a consent form, the interview guide and the HADS. The ethical board confirmed that the Medical Research Involving Human Subject Act (WMO) did not apply, as persons were not subjected to treatment or required to follow a certain behavioural strategy as referred to in the WMO (art.1b). All participants (the couple and the child) received an informative letter outlining the aim, procedure, the right to withdraw at any moment, privacy, contact details and aftercare if needed. They gave their written informed consent to participate in the study and for the use of their accounts in research and publications.
As this case contains a high degree of confidential information, the researcher asked the Central Committee on Research Involving Human Subjects for specific advice on how to strike a balance between protecting the privacy of both participants and providing sufficient detail to make this case study useful (Woodhouse, 2012; McCurdy and Fitchett, 2011). To ensure that the case study truly preserved confidentiality, non-essential information was disguised.

2.5. Data analysis
A thematic lifeworld analysis was undertaken by using eight existential lifeworld dimensions: self, embodiment, temporality, sociality, spatiality, project, discourse and mood-as-atmosphere. These interrelated dimensions, which have been developed in philosophical phenomenology, together form the ‘essential features’ of the lifeworld whilst ‘each one separately is helpful to emphasize particular nuances of the lived experience’ (Todres et al., 2007). They are applied to psychological and medical science by empirical phenomenologists, such as Ashworth (2003) among others. By means of an evocative description of these essential dimensions, a particular empirical lifeworld can be disclosed in a thorough and phenomenological manner (Ashworth, 2003). The lifeworld dimensions are described in Box 1.

The analysis was conducted in several stages. Every stage of the analysis was mutually discussed in the team. First, the researchers tried to engage deeply in the couple’s lifeworld by thoroughly re-reading the whole dataset (transcripts, correspondence, observational and reflective notes) and replaying the audiotapes. Keywords or key sentences were marked, notes were made. Based on this empathetic consideration, the first author wrote two narrative reports, supplemented with some initial, tentative conclusions regarding the lived experience of the elderly couple. Those were discussed in the team and then sent to the participants for a member check. Aside from some minor factual details, the couple could completely identify with the narratives and initial conclusions. Next, the first author used Atlas.ti 7.5.1 software to code all the data, to compare the themes that emerged and to relate them to the lifeworld dimensions.

Outcomes were mutually discussed in the team in several rounds. During the whole process, the authors adopt an open, slowed down attitude towards the phenomenon and the process of understanding.
BOX 1: Elucidation of the lifeworld dimensions

**Self:** *What does the situation mean for (social) identity?*
The self, considered a fraction of the lifeworld, includes the attributions of identity, such as ‘I am an artist’, as well as one’s experience of one’s own presence, agency and voice within a situation and how this is related to our interaction with others (Ashworth and Ashworth, 2003).

**Embodiment:** *How does the situation relate to feelings about one’s own body?*
Embodiment is about how a person relate to one’s own body, including their gender, disabilities and emotions. A body is not a thing or a possession, it is a being-in-the-world. In daily life, people tend not to be conscious of their bodies and take them for granted, but when serious bodily changes emerge, the body is no longer taken for granted and becomes an object, a thing-other-than-me. In phenomenological research this is called the distinction between ‘the subjective body’ and ‘the objective body’.

**Temporality:** *How is the meaning of time intrinsic to the situation?*
Everything has a time and duration, in a quantitative and qualitative sense. In lifeworld research, temporality refers to people’s sense of time and the way they experience continuities and discontinuities. It is about temporal meanings. The past and the future influence the present day as interconnected spheres: the past that is significant in people’s lifeworld is the past ‘as it appears now and the future is what comes, as it is coming towards us now’ (Van den Berg, 1972/2013), not as an objective, factual event, but as meaning.

**Sociality:** *How does the situation affect relations with others?*
Sociality refers to the way people’s lives are related to the surrounding social world. People do not just live on their own, but are part of an inter-subjective world. The way they relate to others – and others relate to them – may be central to understanding their sense of being. Thus the individual lifeworld cannot be fully understood without exploring this interpersonal dimension.

**Spatiality:** *How is the personal topography affected by the situation?*
Spatiality refers to the meaning of the surrounding world, things and the places in which one lives. What is the meaning of distance and closeness in the personal topography and how do changes in spatiality affect lived experience?
In lifeworld research, the focus is not merely on physical space, but more on the social and existential meaning of space. It is about how meaning is altered when circumstances change.

**Project:** How does the situation relate to the persons ability to carry out the activities they are committed to and which they regard as central to their life?

Projects in lifeworld descriptions refer to what people ‘care’ about, in the sense of having a personal concern for something. Since it is through the body that people are able to perform activities, physical changes and especially physical disabilities, have huge impact on how people relate to their projects/activities.

**Discourse:** What sorts of terms are employed to describe the situation and thus to live?

Discourse – in lifeworld research – is about the terms that people employ to describe their lived experience. In the words used, we can discover more deeply how people give meaning to their lives and how they modify and interpret their world, as language is the ‘house of being’ (Ashworth, 2006).

**Mood-as-atmosphere:** How does the situation affect ‘the state of mind’?

The lived experience is coloured by mood, as mood immerses all other dimensions of the lifeworld. It indicates the lived meaning of the situation, as Todres et al (2007) point out: ‘Mood has organising power is a great motivator or de-motivator (...) and affect people’s embodied, functional capacities.’

**References:** This description of lifeworld dimensions is based on a combination of the work of P. Ashworth (2003); P. Ashworth (2006); Todres, L., Galvin, K., & Dahlberg, K. (2007) and Van den Berg, 1972/2013).

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### 2.6. Brief description of the participants

Peter and Suzan, both in their seventies, were married for over forty years. They raised four children and both worked as university lecturers. In his spare time, Peter was an artist. They looked back on their lives ‘with satisfaction’ and evaluate their marriage as ‘happy and intimate’. In his forties, Peter went into therapy because he suffered from a childhood trauma and separation anxiety, which had quite an impact on their family life, as his problems
caused mental suffering to their children as well. Things went ‘all right after all’, but with one child personal contact remained rather difficult.

Short after retirement, both had to face physical problems. Suzan was diagnosed with severe, progressive arthritis, while Peter suffered from several transient ischemic attacks (TIAs), a sensory disorder and impotence. Because of decreased mobility, they had decided to move to a town nearby their children, but they were unable to take root in their new dwelling. The development of their wish to die was closely associated with deteriorated health and age-related losses. To their children, they spoke about their strong aversion towards ending up in a nursing home and their intention to terminate life before losing their independency.

With regard to their death wish, no mental health therapies were sought, as Peter and Suzan did not perceive themselves as being mentally ill and having a pathological wish to die. They rather perceived themselves as ‘normal’ citizens, with a ‘reasonable’ wish to die, in search for what they call ‘a dignified death’. For decades, they had been active members of two Dutch right-to-die organisations. Both organisations provide information on how to perform a self-chosen death. The couple planned to perform the self-euthanasia in their home, by taking a lethal doses of medicine. Within a few months after member check, they died together at a self-directed moment.

3. RESULTS
What follows is an in-depth lifeworld description of the lived experience of Peter and Suzan, following the lifeworld approach described above. Due to space limitations, we focus on the following lifeworld dimensions, as they were most prominent in participants’ stories: 1) self and project; 2) embodiment; 3) temporality; and 4) sociality.

3.1. Self and project: feeling alienated from oneself
Both Peter and Suzan strongly defined themselves in terms of their ability to engage in the activities they loved. Peter’s work as a lecturer in fine arts meant everything to him: it was his identity. He hoped that his lectures had ‘inspired students, stimulated them to look with new eyes and sparked a passion for arts in their lives’. He looked back on his working life with pride and satisfaction. When he had to retire, his world changed dramatically: ‘If your work is taken away from you, that’s just awful’.
His self-definition was based entirely on his past identity and was associated with former projects. In the first years of his retirement, he aimed to continue his former life through academic writing, painting and visiting art exhibitions. But when his health problems increased and his wife’s arthritis progressed, opportunities for ‘projects that animate life’ dwindled. Due to several TIAs he gradually lost his coordination, which meant he was no longer able to paint or sculpt adequately anymore. He talked about ‘a lousy, inept watercolour of his grandson’ and ‘a failed attempt to model a clay statue of his granddaughter’. The thought of being unable to create what he had in his mind was appalling. He dissociated his sense of self from his actual self:

*Not being able to draw and paint is the worst. (...) It feels as though my identity has been taken away. What do I have left? (...) Look, my identity is entirely in art. If you can no longer be active, if you cannot express yourself, then something quite substantial has been taken away.*

Suzan’s identity was associated less with specific activities than with the possibility of ‘being useful to others’: she regarded this as central to her life. ‘Life must make sense’. When she retired, she committed herself to ‘other projects on voluntary basis’ and her family. What mattered most was to continue making a valuable contribution to society. But after her health deteriorated rapidly, she felt limited to taking care of her own body. The fact that she could ‘not be productive’ anymore and do the things that made sense of her life, strengthened her feelings of uselessness: ‘I’m no longer needed’:

She felt hindered to attend art exhibitions, galleries and museums, which was a great loss, because she lived for art: ‘an indispensable, enriching part of life’ and ‘the most important thing in my relationship with Peter’. As she put it, ‘Now I have to miss the indispensable things’. Although she kept herself informed about new trends and expositions, this was not fulfilling, because she no longer felt fully engaged in the subject. Like Peter, she was an art-lover but she could not express her love anymore, something she experienced as a diminishing of her identity.

Despite the fact that Peter and Suzan went through different processes, they both felt distanced and estranged from their identities and were unable to reconcile themselves with their changed, actual selves. This caused deep existential uncertainty.
3.2. Embodiment: being threatened by one’s own body
Both Peter and Suzan felt threatened by their own bodies, as they no longer did what they expected them to do. Peter suffered from a sensory disorder. As he was fond of good food and cooking, he experienced diminishing smell and taste as a significant loss, spoiling his appetite. Life became utterly ‘tasteless’:

> When I’m going to make preparations for dinner, I often make a cheese course with Camembert, Brie and a piece of blue cheese. Look, of course I still know how it tastes (...) and I feel the substance in my mouth and then I try to imagine what the taste is like, but there is nothing. So, well, it’s not inspiring. Basically, it’s not fun...

As well as his drawing and painting, Peter was also struggling with feelings of incompetence relating to his scientific work, which he continued after retirement: ‘I am not sure whether my writings are still kosher’. He had been an intellectual – capable of ‘sharp and lucid’ thought – but now he had a growing sense of uncertainty about the quality of his research: ‘I can no longer fully assess whether my accounts are conclusive’. Whereas he had previously taken his ability for granted, his thoughts were now clouded by ‘lingering doubts popping up all day’. Peter went to hospital because he was worried about developing dementia. Despite the brain scans showing no evidence of this, he was not reassured. He ‘panicked’ at the thought that some day they would discover ‘plaque in his brains’. He feared ending up as ‘an insane idiot’, emphasizing: ‘You know, all my life I was in charge, able to write books and being addressed as a ‘highly learned and honourable gentleman’. I simply want to maintain my status until my final breath’.

His physical awareness was overshadowed by a sense of shame, exemplified by his struggle with impotence: ‘You lose something very important, especially in marriage. Sure, there’s acceptance, it’s just the way it is, though undeniably, it also causes severe embarrassment, because you’re no longer potent while the other might like you to be. That’s very difficult’. His body became such an embarrassment that he stopped expressing himself – no longer painting, sculpting or writing – to hide his dysfunctions. He judged his body to be incompetent and it greatly undermined his sense of dignity.
Suzan's embodied self was gravely threatened by pain and the increasing immobility caused by arthritis. Her body used to be her ‘being-useful-in-the-world’, but now she felt locked in by her body and trapped in the house. She also hated the fact that she had become overweight. Bodily changes caused profoundly alienating feelings; her body became an ‘it’. She dissociated her self from this ‘it’, expressed in her words: ‘It is a strange body. It’s not my body anymore, it doesn’t belong to me’. Every night, she said, she dreamed about her body functioning ‘normally’ again: ‘Jumping and endlessly walking, caring for the kids’. But in the same breath, she brushed her thoughts aside as ‘illusions’ and said: ‘I hide my head in the sand. Of course, I know that things are no longer possible, but I just don’t want to realize it. I simply cannot reconcile myself to reality’. Despite her undeniable deterioration, she joined a physical rehabilitation programme in an endeavour to make progress, hoping for physical recovery. However, she was simultaneously convinced that the physical change she desired would never happen, which even increased her feelings of estrangement: ‘You might call it ridiculous. And you’re right. At best, it will only bring a brief halt to the on-going decline. (...) It’s an idle hope, unreasonable, but still...’

3.3. Temporality: reaching an impasse
Lived temporality turned out to be a source of strong tension in the story of Peter and Suzan. Peter was obviously in a hurry, ideating on quitting life ‘sooner rather than later’. He was no longer able to engage in the ‘here-and-now’, as his existence was determined by fond memories of the past, as well as by his anxiety for the future facing him, appalling and inaccessible. He was seized by feelings of incompetence and fear of ‘that shameful humiliation’ of further deterioration and loss of control: ‘It’s the reason why I would rather take the short cut!’ Shame drove him to seek a way to counter these threats, and the only possible way out seemed a self-directed death. He felt compelled to take ‘precautions’ and organize his own death ‘before it is too late’.

Peter’s movements and way of communicating were endowed with a notable sense of urgency. This was strengthened not only by his bodily experiences, but also by negative memories of his parents living in a nursing home. Images of indignity, dependence and a lack of privacy were etched on Peter and Suzan’s minds and struck terror into their hearts. After Peter’s parents had died, Peter and Suzan had firmly promised each other that they
would end their lives before losing their independence, to avoid ending up in a nursing home.

Despite this promise, Suzan’s death wish was not as urgent as Peter’s. Like him, she had fond memories of her life before the physical problems, and she had no positive expectations of the future. Yet she was not as fearful of the near future as her husband seemed to be. Rather, she struggled with an on-going dilemma: on the one hand, she had a dormant wish to die and felt that she was no longer able to make a valuable contribution anymore. Moreover, she knew that her husband strongly wished to die and she certainly did not want to be left alone. Thus if he persisted in ending his life now, ‘it’s the best solution to go together’. On the other hand, she had a forlorn hope that she might be of some significance in the lives of their children and grandchildren, and might make some physical progress, as she reluctantly admitted: ‘There might be a possibility to still participate somehow... I still might be of some importance to others... who knows, a little physical recovery might be possible...’

While they found it difficult to discuss this dilemma together, they seemed to had reached an impasse: Peter felt ready to give up on life immediately, but he also felt obliged to postpone until Suzan also felt ready, as they had agreed to end their lives simultaneously. Suzan suffered from this pressure from her husband, who was emphatically waiting for her to decide. She still needed more time. During the interview, she cursed emotionally several times: ‘Damn, why can’t he wait a little longer for me. (...) Damn it, give me another year!’ At the same time, she realized that the longer she delayed, the longer he had to wait, while she knew that life had become an abomination to him. In a way, Suzan thought that she was being unreasonable by delaying the decision, that she was being unfaithful to their agreement: ‘Actually, we have not talked this through. It is just a bit difficult at the moment. I’m a little afraid that talking about it might unleash a torrent of arguments and emotions. (...) And of course, more than ten years ago, we captured our wishes in an advance directive. (...) So well, it is a bit unreasonable of me’. She tried to push away her ‘need for more time’ as a subordinate feeling, focusing on their agreement in the past.

In our contact prior to the interviews, their promise to end life together was presented as an expression of a close connection. During the interviews,
however, considerable tension emerged: on one hand, their promise indeed reflected a strong bond, but on the other hand, their promise let to an impasse and held them in a hold, as their sense of subjective time differed significantly and they were unable to really talk about it.

3.4. Sociality: living in an empty world

Due to Suzan’s physical problems and rapidly decreasing mobility, they ‘rationally decided’ to move to have more contact with their children and grandchildren, but the move turned out to be a disappointment. The fact that they were housebound made it very difficult to build new contacts and explore their new environment: ‘Actually, you have nothing to do with this town. (...) You don’t know the shops, it’s a totally different world’. Shortly after moving, their old friends still visited them, but that ended. ‘Our world has become much smaller, more empty’. They both felt uprooted and lost their sense of belonging: ‘Nothing binds you here. (...) If we hadn’t done it, we would probably have seen the kids much less, but for our own salvation it would have been better if we had stayed there. But going back is simply impossible’.

In relation to her children and grandchildren, Suzan felt reluctant and emotionally unable to talk about her hopes of being of some significance in their lives, which she associated with ‘an accusation’ her son had made after he went into therapy years ago. He accused her of ‘emotional neglect in childhood’, which left her scarred. Although they had ‘formally made amends’, she still talked about ‘feeling crushed’. She ‘buried this sadness deep inside’ and ‘tried to focus on other things’. Despite her attempts ‘to push it away’, these memories loomed large at certain moments and hindered her sense of being-mother-and-grandma.

In a way, Suzan still felt responsible for her children and grandchildren, and did not feel ready to leave them: ‘I would like to see that things go well with the kids’. Peter did not feel this sense of responsibility or connection anymore: ‘I simply don’t have that feeling, because I think: my life is over’. He informed his children about their plans:

*About half a year ago, we talked about it, more or less. (...) My oldest son understands, but doesn’t like it. But then I think: there are many things in life that are not fun. Death is not fun. But you cannot run away from it. (...) And they will get over it soon, in a manner of speaking.*
Their son reported how he had received the information about his parents’ plans, and how it had evoked feelings of powerlessness and detachment:

*I feel powerless, because we never really talk about it. (...) OK, we did talk about it, actually quite often. (...) But always very rationally and very abstractly. (...) But we never talked about the emotional side of things. (...) It’s just absurd, it’s absurd that they apparently believe that their life is over. Though we, as children, totally disagree with this idea. They have grandchildren who love having a grandma and grandpa. And they have children who love them (...) but apparently that plays no role in their decision. In my eyes, it’s a detached decision. (...) Sure, I feel forsaken, but that’s not new, that’s an old theme, so in that sense, it’s not strange.*

4. DISCUSSION

This paper presents the first in-depth account of an elderly couple who jointly wished and chose to die together at a self-directed moment, because they felt life was completed and no longer worth living, even though neither of them suffered from a life-threatening disease or severe depression. We present two individual but highly intertwined narratives about struggling with ageing, alienation from one's body and identity, the growing emptiness of life due to loss of activities and contacts, an inability to reconcile oneself with one's changed ‘being-in-the-world', and the deep existential uncertainty associated with this. This corroborates previous research on elderly people who feel ready to give up on life (Kjølseth et al., 2010; Rurup et al., 2011; van Wijngaarden et al., 2014; van Wijngaarden et al., 2015). Our study adds to former research by giving the first insider account of the subjective considerations and experiences of two members of an elderly couple planning spousal self-euthanasia.

For the husband, the performed self-euthanasia strongly appears as a way to ‘prevent’ and ‘safeguard’ himself. His wish to die was based largely on a deep sense of embarrassment caused by a loss of control and abilities. For him, life was completely over, as his self-identity was based on independence, status and excellence. As his competences decreased, he lost his ‘self’. The anticipatory fear of further deterioration and the fear of not being able to control time and manner of death in the future urged him ‘to take the short cut’. The wife also felt greatly hindered and threatened by her body.
Though, in contrast with her husband, she was caught in an appalling dilemma: on the one hand, she felt more and more disconnected from herself and from life, having a conscious wish to die, but simultaneously she had concerns about her children, which continued to connect her to life. While her husband's account is full of urge, her account is full of what she calls ‘idle hope’ to still be of any significance for her kids. For her, intending to end their lives by spousal self-euthanasia brought her in a considerable tension.

Although the couple talked about their agreement for years, they found themselves 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, sense of time and logic. It seemed difficult for each to keep pace with the other without a form of coercion, emotional or otherwise. The case ends in a paradox: on one hand, they died together at a self-appointed moment according to their mutual agreement; but on the other hand, their story indicates that this might not have been entirely what the wife wanted yet. The case thereby 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.

4.1. Some ethical thoughts
An important ethical question raised by this study is whether the researcher did have any obligation to intervene with regard to possible exercised pressure or coercion. As a matter of course, the researcher took into account all appropriate ethical rules to ensure safety of our participants, such as providing comprehensive information on beforehand; gaining informed consent prior to the interview; providing full contact information; debriefing afterwards; offering the possibility of an extra conversation at their home or referral to professional care. However, do these measures appropriately cover the researcher’s responsibility, when participants are preparing a spousal self-euthanasia? What about the duty to intervene? In this context, we believe there are several important considerations that must be taken into account:

Firstly, participants’ were no patients, but mentally competent citizens. They perceived themselves as normal, independent, autonomous and self-
determining citizens. This is not just their private opinion, as part of Dutch society confirms the legitimacy of such a wish to die (see Box 2). Secondly, both were fully aware of the emotional tensions. In the interviews, they told about each other’s emotional discomforts and the difficulty to communicate about these emotions. Afterwards, we debriefed them by sending them two narrative reports in which we explicitly mentioned the struggles and tensions that we had recognized. In their reaction, both endorsed these reports, but did not seek help or therapy for this. Thirdly, intervention would not be in accordance with our research approach and the appointments made prior to participation, as we told participants that we would take a phenomenological approach: free from pre-fixed theories about being-ill or not-ill; engaging with participants as they perceived themselves from an insider, non-judging, lifeworld perspective, giving them the opportunity to talk freely about their lived experience. Lastly, it is important to respect boundaries between research and therapy (Finlay, 2011). Prior to the interview, we explained that the researcher did not act according to the role of a counsellor but as a researcher.

Hence, being mentally competent, highly educated people, who were aware of the possibilities of therapy, consciously choosing not to seek (mental or relational) therapy, we felt intervening while not being asked was unjustified. Most likely, participants would have judged unasked intervention to be highly paternalistic. We did thus not try to change these people’s minds and their life view, but rather intended to understand them. Taking all this into consideration, we are of the view that, if extra support had been desired (which was not the case), a referral to external counselling would have been the only appropriate way.

4.2. Implications for practice and research
The case study provides insight into a rare, previously unexplored phenomenon. Although this case is a specific story, situated in a specific personal, social and cultural context, and while we acknowledge that elderly people within different contexts might have different stories, there are ways to learn from it, as it tentatively expands our understanding of the phenomenon of spousal self-euthanasia. First, professionals engaged in caring for older people should note that the identity of active, independent people, who strongly define themselves in terms of their life-projects, is at risk when these people have to deal with significant age-related losses. These elderly
people might try to reassert themselves and compensate for circumstances they cannot accept, but when they fail, they might feel alienated from their bodies. And perhaps they might perceive ending their lives at a self-appointed moment as a way of regaining control.

Second, it is noteworthy that this case questions the close relation between death wishes and depression, as depression is the most frequently studied factor in relation to death wishes in elderly people. These findings are consistent with other research that also indicates that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety (Corna et al., 2010) and suggest that depressive feelings might not be related to pathology but rather to normal aging (Ludvigsson et al., 2014). Further research on this topic is thus recommended. To what extent is (spousal) self-euthanasia in elderly people related to depression? Should this phenomenon be primarily assessed from a psychopathological perspective or more from an existential perspective? For professionals, this highlights the significance of careful assessment as to whether depression is the (primary) cause of a wish to die. Lastly, our study illustrates the complexity of a joint decision by a couple to end their lives together. Moving towards this ultimate choice is an ambivalent and ambiguous process, which initially has a great impact on an individual’s lifeworld. The situation becomes even tenser when it comes to a joint decision. For professionals, the difficult question is whether one should accept such an ultimate choice, rather than intervene. Probably, encouraging people to really talk about the emotional tensions about the different concerns and sense of time is most appropriate.
REFERENCES


CHAPTER 5

Caught between intending and doing:
Older people ideating on a self-chosen death

ABSTRACT

Objectives: The aim of this paper is to provide insight into what it means to live with the intention to end life at a self-chosen moment from an insider perspective.

Setting: Participants lived independent or semi-dependent throughout The Netherlands.

Participants: 25 Dutch older citizens (mean age of 82 years) participated. They were ideating on a self-chosen death because they considered their lives to be no longer worth living. Inclusion criteria were that they: 1) considered their lives to be ‘completed’; 2) suffered from the prospect of living on; 3) currently wished to die; 4) were 70 years of age or older; 5) were not terminally ill; 6) considered themselves to be mentally competent; 7) considered their death wish reasonable.

Design: In this qualitative study, in-depth interviews were carried out in participants’ everyday home environment (median lasting 1.56 hours). Verbatim transcripts were analysed based on the principles of phenomenological thematic analysis.

Results: The liminality or ‘in-betweenness’ of intending and actually performing self-directed death (or not) is characterized as a constant feeling of being torn 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.

Conclusions: Our findings show that the in-between period emerges as a considerable, existential challenge with both rational and non-rational concerns and thoughts, rather than a calculative, coherent sum of rational considerations. Our study highlights the need of due consideration of all ambiguities and ambivalences present after a putatively rational decision has been made in order to develop careful policy and support for this particular group of older people.
1. INTRODUCTION
The past decades have seen a rapid increase of life expectancy and longevity. Despite all the advances in healthcare and medical technology, old age is quite often accompanied by loneliness, age-related problems and disabilities. These problems have an influence on the perceived physical and mental health in older people, threatening their capacity to maintain meaning and purpose (Seale, 1996). This raises the question whether a longer life is associated with more years of life quality, or whether it is associated with increased feelings of dependence and prolonged disability. Indeed, it has been suggested in the Dutch debate on older people and a self-chosen death that 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. (van Rein, 2013).

In the Netherlands, one of the few countries in the world that have legalized euthanasia and assisted dying under strict criteria, there is considerable debate whether older people aged 70+ who consider their lives to be completed, should have legal options to ask for assisted dying (Buiting et al., 2012; Rajmakers et al., 2013). In 2010, the Right-to-Die-NL started a campaign ‘Out of Free Will’ and placed this discussion on social and political agendas. Based on a ‘rational and well-considered choice’ older people should have legal options for assistance with the termination of their life, they argue. Under current Dutch legislation, however, most of the concerned older people do not have a legal right to euthanasia, as they do not meet the criteria specified in the Dutch Termination of Life on Request and Assisted Suicide Act: the conviction that the quality of life has diminished so much that older people prefer death over life does not constitute legal grounds for assisted dying, as they do not suffer unbearably without the prospect of improvement from a medical perspective (van der Heide et al., 2014). Thus the Right-to-Die-NL advocates the further relaxation of the euthanasia criteria for the benefit of this group and aims to make ‘self-determination of life’s end a reality’ (van Rein, 2013).

The argument that older people should have the right to assisted dying based on a ‘rational and well-considered choice’ presupposes that ending one’s life can be considered a rational and autonomous choice, even if one is not terminally ill. In the literature this is termed ‘rational suicide’ (also referred to as ‘a self-chosen death’, ‘balance-sheet suicide’, ‘self-euthanasia’,
‘self-deliverance’ or ‘surcease’). There has been considerable debate between those in favour of ‘rational suicide’ (Battin, 1999; Lester, 2006; Hewitt, 2013; Werth Jr, 1996) and those opposing it (Moore, 1993; Moody, 1991; Kerkhof and De Leo, 1991; Richman, 1992; Yuill, 2015). While both sides in the debate argue their case based on ‘the good of humanity’, there are significant differences.

Authors who judge ‘rational suicide’ in old age as an honourable and sane choice underline 1) the individual’s moral right to self-determination; 2) the logical, understandable outcome of the balance sheet: as one ages, the negative points accumulate to such an extent that death becomes preferable to life; 3) the evil of needless suffering; and 4) the possibility of satisfaction and empowerment if one exerts control over one’s death. According to the proponents, criteria for assessing suicide as ‘rational suicide’ are that people have an unremitting hopeless condition; make a realistic assessment of their situation; are able to make a free, autonomous choice; are capable of sound reasoning (which implies the absence of severe psychological illness or emotional distress influencing the decision); have adequately considered possible alternatives; and act in consonance with their fundamental values.

Authors opposing ‘rational suicide’ in old age mainly use the following arguments: 1) the psychological argument; 2) the ageism argument; and 3) the slippery slope argument. Primarily, some authors fundamentally question whether deliberately ending one’s life can or should ever be seen as a rational decision: is it possible to distinguish ‘rational suicide’ from ‘pathological suicide’ or should suicide be considered prima facie evidence of mental instability? Next, the ageism argument argues that supporters of ‘rational suicide’ base their arguments on an ‘ageist bias’, which means that old age is wrongly associated with being a burden (on the personal, relational, societal and economic level), with unvalued status and great inconvenience. Death is offered as a solution for the problem of age-related suffering ‘that is perceived as insoluble’ (Richman, 1992), in fact, improving the conditions of these older people might lessen their wish to die. And lastly, by using the slippery slope argument, several authors point out the risk of the deteriorating respect for the value of human life and ageing, and the risk of societal values shifting from recognition of an individual’s right-to-die to a climate enforcing a societal obligatory duty to die (Moore, 1993).
Many studies on the topic of ‘rational suicide’ in old age focus on theoretical, ethical and legal argumentation. In fact, we found no empirical studies that explore the experiences and struggles of people ideating on a self-chosen death from an insider perspective. In order to develop conscious policy and good care for this group of older people, however, it is essential to understand how these older people experience their lives: what it means to live with the intention to end life at a self-chosen moment; how they make sense of their experiences; and to what extent their wish can be considered truly rational? This particular paper therefore aims to provide insight into what it means to live with the intention to end life at a self-chosen moment from an insider perspective.

2. METHODS

2.1. Sampling
This study is a qualitative in-depth interview study of twenty-five older people ideating on manners to end life at a self-chosen moment. It is part of a more extensive research project that aims to elucidate the experiences of older people who wish to die because they consider their lives to be completed and no longer worth living (van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015b). Between April and September 2013, research advertisements were placed in various magazines targeting distinct audiences of older people. Older people who wished to die because they felt their life was completed were invited to participate in an in-depth interview. The inclusion criteria were that participants: 1) considered their life ‘completed’; 2) suffered from the prospect of living on; 3) currently wished to die; 4) were 70 years of age or older; 5) were not terminally ill; 6) considered themselves to be mentally competent; 7) considered their death wish reasonable.

One hundred forty-four people responded by post, email and telephone. Participants were purposefully sampled in two sequences: the first selection was based on respondents’ initial description of their personal situation. Sample criteria were: a variety of cases; differences in (physical) health; various ideological and demographic backgrounds; and nationwide coverage. The interviewer then contacted potential participants. Upon closer inspection, some potential participants were excluded. They proved to be what we called ‘if-then respondents’: if their situation would continue to
decline, then they could imagine themselves favouring an assisted self-chosen death. Hence, at the moment of contact they had no active wish to die. Besides, some respondents were driven by strong motivations to advocate legalization of self-directed death, instead of giving an experiential account of their situation. In some cases, respondents withdrew from participating. One participant who was 67 years old, was included because of her unique ideological background. All participants were provided with detailed written information about aim and procedure of the study, the right to withdraw at any time and the possibility of aftercare if needed. All participants signed a consent form and were assured that their name and identity would not be disclosed. (For an overview of all background characteristics of the selected participants, see Chapter 4, Table 1).

2.2. Data collection
The interviews took place from April to December 2013 in participants' own home and lasted two hours on average. A phenomenological approach to interviewing was used to explore the lived experiences of older people who feel ‘life is completed and no longer worth living’ and wish to die at a self-chosen moment. The interviews had an open structure. Guiding questions were: ‘Can you describe what it means to have a strong desire to die?’; ‘In what kind of situations is your wish to die strong? ‘Can you describe that situation as fully as possible?’ The interviewer tried to empathically engage with the participants and encourage them to narrate their experiences in detail (See for the complete interview guide Appendix 1). The interviews were audio-taped and transcribed verbatim. During and immediately after the visits, observational notes were made about contextual characteristics, the atmosphere and relevant non-verbal expressions. Participants were asked to fill in a personal background information form. Next, participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). This was done to obtain a preliminary indication as to whether the wish to die was driven by a severe depression or not, as depression is the most frequently studied factor in relation to death wishes in older people. The HADS was administered by the interviewer immediately after the interview to avoid influencing the characteristic openness of a phenomenological interview. In Table 1, the outcomes of screening are included as participant characteristics.
In the year after the interviews, the interviewer received eight notices of older people who did engage in life-ending behaviour and died a self-chosen death. These death notices were sent at participants' own initiative.

2.3. Data analysis
The first analysis of all 25 interviews contributed to an earlier study which resulted in a phenomenological characterization of the phenomenon of ‘life is completed and no longer worth living’ (van Wijngaarden et al., 2015). For the purpose of this study all interviews were re-analysed, now focusing on the research question of what it means to live with the intention to end life at a self-chosen moment. A phenomenological thematic analysis (Finlay, 2011; Braun and Clarke, 2006; Patton, 2002) was used. The analysis followed a semantic, inductive approach (Braun and Clarke, 2006), which means that identified themes are experientially driven, and these are grounded in the data itself rather than being theory driven. The analysis consisted of different phases (as described below) in a recursive process, characterized by a constant forward-backward movement between the entire dataset, the coded extracts, and the descriptive analysis in progress. Atlas.ti 7.5 was used as a tool to compare themes and meaningful fragments.

First, the researchers tried to familiarize themselves with the data by repeated and active reading of the whole data set. Interpretation was discussed within the team. Afterwards, a narrative report was written of each interview and sent to the participants for a member check. Next, an inductive, bottom-up search was undertaken for themes related to the research question. Text elements were coded. Then codes were combined and summarized in main themes and subthemes. In the next phase, the themes were reviewed in search for a coherent and valid pattern: the themes should form an accurate representation of all meanings evident in the data set. Categories were judged by two criteria: internal homogeneity (i.e. the extent to which the data are internally consistent) and external heterogeneity (i.e. the extent to which the differences among the themes are bold and clear) (Braun and Clarke, 2006). When needed, a theme was refined and nuanced. Writing was not something that took place at the end, but an integral part of analysis, as the writing process itself deepened our understanding, clarified meanings and highlighted layers and polarities in the data (Braun and Clarke, 2006; van Manen, 2014). Findings were mutually discussed between all authors and revealed a high consensus. Some minor discrepancies led
to a more precise definition of the themes. Inter-subjective reliability was sought throughout the analysis process.

3. RESULTS
In this section we describe the themes found within the data. For all included older people, the in-between period between the firm intention to end life at a self-chosen moment on the one hand and the whether-or-not decision to actually terminate life on the other hand is characterized as a constant feeling of being torn, expressed in words like: ‘dilemma’, ‘tension’, ‘doubt’, ‘struggle’, ‘a difficult balancing act’, ‘a quandary’, ‘a splits position’, ‘an unsolvable problem’, ‘in two minds’ and ‘a contradictory process’. Below, this paradoxical position is explicated in the following polarities: 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.

3.1. Detachment and attachment
All participants felt ready to give up on life based on a strong sense of detachment; they felt disconnected from their actual life, and lived with constant anxiety about their future and further life-status deterioration. While maintaining control over their own life was a considerable concern among participants, in contrast, they sensed an inevitable loss of grip. This declining physical capacity threatened their independence and dignity. The interviews portray participants as deeply concerned to find a way that spares them further suffering: ‘I just want to keep myself safe, you know’ (i–20). For most, a self-chosen death seemed to be the most preferred option, to flee from life as-it-is or as-it-comes: ‘It’s a duality. That’s why I prefer to flee. And dying is the best method, as far as I’m concerned. I’m not afraid to die. I’ve never been afraid to die’ (i–10). One participant talked about her yearning to die: ‘Sooner rather than later! You know, I told my friend: keep in mind, when I am dead, you fly the flag!’ (i–17) Death was often associated with the end of suffering, a release of distress and humiliation, a state of rest and peace, an endless sleep, and in some cases reunification with beloved ones.

Simultaneously however, the tendency to postpone death – due to certain attachments to life – was also explicitly common in participants’ stories. They mentioned several attachments such as physical vitality, responsibili-
ties and duties towards themselves and others, and religious conscientious objections. Several participants told that they still sensed a physical drive to live on, regardless of their wish to die. They still enjoyed good food and drinks and wanted to feel comfortable in their body. One participant said:

*I feel like I’m holding a splits position. On the one hand, I definitely want to die. On the other hand though, there is still simply too much physical, intuitive life force. (...) So you just live on, you breathe, you eat and uh, take care of yourself. I mean, if you are really done, you would stop eating, wouldn’t you? (...) But that physical body of mine tells me: ‘I’m hungry for a sandwich.’ So, I have a sandwich. (...) That’s the dilemma I’m living in: you rationally want to die, but at the same time, there’s that unbreakable will to live, which makes me feel I’m being pulled in two directions (i–4).

Experiencing paradoxical physical attachment was not only about satisfying a healthy appetite. Several participants spoke about exercising once a day to keep fit and vital. One woman seriously considered a hip replacement operation to increase her mobility and independence, while also making plans to terminate her life. Another woman who desperately wished to die talked about her ‘inconsistent’ efforts to strengthen her physical health:

*All the time, I’m thinking: How to die? The only hope I have is that I am run over by a car. Or when I hear about an airplane accident, I think: Oh, I wish I was on that plane! It’s a dilemma, you know, because at the same time, I joined a gym to stay vital and independent as long as possible. But by strengthening my health, I prolong my life and postpone my death. So I am in two minds: I hate feeling washed-out, so I try to be as healthy and vital as possible (...) but on the other hand I think: How can I die when I feel so vital? (i–22).

Other participants felt disconnected from certain responsibilities towards themselves and/or others. A woman, who took all necessary precautions and had even fixed ‘a provisional date’ for her death together with her children, was still the initiator in the set up of so-called ‘villages-in-the-city** to strengthen social bonds in her neighbourhood, as she was concerned about

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**A village-in-the-city [in Dutch: stadsdorp] is a quite recent initiative by and for (older) residents in an urban city neighborhood to ensure modern neighborliness. Especially older people aim to organize themselves to ensure that they can continue living a independent, active, healthy and safe live as long as possible.
‘her own safety’. Two other participants were still looking for some ‘meaningful voluntary work’ (although they actually gave up any hope of finding it) and at the same time, they were preparing a self-directed death. Two men said that they needed to postpone their self-chosen death because of their ‘duty to care for their partner’ while both were fully prepared to organize their own death ‘as soon as possible’. A man, who was deeply concerned about the emotions of his children, expressed his doubts this way:

...If they all show the same emotions as my daughter, I don't think I can handle it. Then I'll probably give up my freedom to decide on my own life. Because then I will see so much sadness, I just can't handle that... (...) You hurt someone while it's not necessary, because I don't have to commit euthanasia. No one forces me. (...) It's voluntarily. So when I see their sorrow, then well, I actually think, I'm a bit of a coward. (...) I am choosing the path of least resistance. I'm going to solve my problems by taking a lethal dose of medicine. It's an escape from all my worries. (...) But in a way, I am abandoning them. (...) If I die from a cerebral haemorrhage or I get hurt crossing the street, I'll be dead too. But, you know, this is voluntarily... (i–10).

Three women explicitly expressed a dilemma associated with their spiritual beliefs. The idea of karma or God had so far stopped them from performing a self-chosen death, despite their yearning. Two of them were afraid that ‘a self-determined death goes against the stream of life’, is therefore ‘bad karma’, so consequently they expected that if they killed themselves, they would have to ‘pay’ for it in the next life. Another woman, who believed in a personal God, explained:

Yeah, it's a crisis of conscience, you know. My ego feels ready to give up on life, but I cannot reconcile it with my conscience, as my heart says: ‘No, don't do it, it's wrong, it's against God's will!’ (...) It's a dilemma. I live in it. Actually, I'm stuck in it. (...) I've read a lot of books about near-death experiences. People arrive in the other world but then they are often sent back, because their time hasn't come yet. So how can I decide it's my time? But on the other hand, I truly feel my life is completed. (...) It's quite ambiguous. (i–24).

This polarity between detachment from life and attachment to life recurred throughout participants’ accounts, and was described by them as ‘plainly discrepant’, ‘inconsistent’, ‘confusing’ and in some cases ‘annoying’.
3.2. Rational and non-rational considerations
In participants’ accounts, there was a recurrent sense that on the one side their wish to die was entirely their own and rational, but on the other side, they felt influenced by an inner and much more uncontrolled compulsion. All participants expressed feelings of strong determination and willingness to end their lives. They ‘reasonably’ considered their lives to be over and no longer worth living, based on a negative outcome of ‘rationally’ weighing the pros and cons of living on: ‘There’s nothing really that keeps me alive’ (i–4). ‘It is just so totally logical’ (i–5). ‘I just don’t know how to prop up my existence any longer’ (i–15). A lady, suffering from several physical discomforts, said: ‘You know, what kind of life is this? I don’t want to die, but my life is simply unliveable’ (i–1). She summed up all her physical sufferings: hearing problems, plus bad eyesight, plus the discomfort of diverticulosis, plus terrible itching, plus the intense pain from some vertebral fractures, and then she firmly concluded: ‘Death is just most preferable!’ (i–1). Another participant related his readiness in an almost calculative way:

There’s just no reasonable need to wittingly burden others with my misery, is there? My life is completed. (...) It’s about preventing myself and my family plunging into misery. It’s just unnecessary, so I try to prevent it (i–25).

When participants talked about this weighting and balancing, most people stressed the rationality of this process. Simultaneously, however, they all talked about being driven by bodily or emotional compulsions as well: ‘It’s just a mix of rationality and emotionality’ (i–15). The majority of participants explicitly said that the idea of living on much longer made them ‘panic’ and almost ‘drove them mad’. One woman questioned her rational choice and interpreted it more as an inner compulsion, as she said: ‘Choice is a difficult word. I’m also forced by myself’ (i–9). Another woman, living in a nursing home, decided to gradually stop taking medicine under a doctor’s supervision, because she felt that her life was no longer worth living. She illustrated the polarity between ‘rationally knowing’ on the one hand and an inner uncontrolled process on the other hand, with these words:

Now I’ve already reduced two daily pills: the blood thinners and stomach protectors. (...) They [the doctor and the nurses] all know, that if something happens to me, I don’t want them to drag me to the hospital. (...) In the morning, I’ll take my heart pills. Those will be the last to go. That will cause a lot of
pain, but then they’ll give me morphine of course. I know exactly what I want.
‘It’s a difficult but brave struggle,’ the nurses say. But I don’t think it’s brave.
It’s just woven into my brain. I can’t help it. The thoughts constantly come into
my mind (i–13).

3.3. Taking control and lingering uncertainty
With regard to the ‘organisation’ of the self-directed death, both feelings of
certainty and uncertainty emerge. The idea of maintaining and regaining
control by organizing a self-directed death is present in most accounts: par-
ticipants hoped to die before they lose more control, and organizing things
gives them a sense of certainty, control, rest and relief. They talked about
consulting a right-to-die organisation, to contact a counsellor for personal
advice, to gather information about methods for hastening death, self-eu-
thanasia and ways to order the right doses of medicine, or to check the au-
thenticity of online-ordered medication.

It feels very relaxed that I’m totally in control now. It’s just about putting the
liquid in a little bowl with some fruit custard and then eating it, and in about
half an hour, I’m gone... I ordered an extra large dosis [of lethal liquid], and
I’ve securely wrapped the bottle in plastic, so nothing can happen to it. Before
I got this, I first bought hundreds of pills online and I fooled my own doctor
into giving me sleeping pills as well. Then [after I managed to collect the right
medicine] all of a sudden there was another method with helium gas. So I also
purchased two bottles of gas, a plastic bag and a DVD with an introduction
on how-to-do-it. It’s all in the closet on the other side of the room. But then,
suddenly this liquid was promoted, somewhere in an article [in a right-to-die
magazine], so I ordered it and, you know, finally I feel safe. They even tested
it! You know, [with those other methods,] I was still afraid something might go
wrong. But this is so easy, you know, just a nice bowl of custard, that’s all! I’m
really relieved now (i–23).

Participants were pro-actively completing all kind of arrangements to put
their personal affairs in order ‘as well as possible’ before they died. Several
participants talked about organizing a complete house clean-up, throwing
away stuff that was no longer needed, tearing up photographs, letters and
official documents like diplomas. One man purchased a paper shredder to
shred all his papers. ‘It’s a way of making your place empty’. Most participants
already bequeathed a legacy to the people they leave behind. In addition,
some talked about giving away valuable things to meaningful others while they were still alive. One woman even bought and fully refurbished a new house for her children as a remembrance gift after she died.

The majority kept a record of (funeral) wishes, in some cases they compiled an extensive wish list regarding a ‘beautiful farewell’: from song choices, to self-written poems they wanted read at their funeral, and carefully thought out rituals. To ensure that their will would be respected in future situations, respondents signed all kinds of documents such as an advanced directive describing treatment preferences (and refusals), a do-not-resuscitate order, and in some cases a written euthanasia request defining the precise circumstances (such as suffering from dementia) in which they would wish euthanasia to be performed. Several participants appointed a proxy to manage their affairs should they become incompetent.

Despite all efforts to ensure the course of their end, the majority of participants still expressed feelings of worry and uncertainty about the dying process; especially about the extent to which they would be able to stay in charge up to the end, about whether they would succeed in avoiding a painful death, and about the ‘right method’ for self-euthanasia. A woman who had formerly suffered a heart attack and had taken all possible precautions to make her wishes for future treatment known, said:

Well anyway, it’s loneliness and fear, anxiety you might call it. Look, my mind is still sharp, but if I suffer a terrible stroke again, I’ll probably lose my mind... I want to avoid that! (...) Yes, it’s still in my mind, fear might be a bit exaggerated, but certain images frequently appear in my mind: it can happen to me again. And the big question is: who will help me? Really, who will help me then? So I just want to keep ahead of that (i–20).

Another woman who desperately longed for death and gathered lots of information about self-euthanasia, still took her ‘life-saving medication’ because she was afraid of the dying process itself:

I suffer from heart failure, (...) but still I take medication. That’s a bit contradictory. (...) I definitely do want to go to the other side where all my loved ones are, though I’m scared to death of the crossing. It mustn’t be too painful, oh dear, oh dear! (...) So, it’s just that fear. I’m so afraid to die of suffocation.
But still, it’s contradictory. Because if you truly wanted to die, you would say: ‘Well, it might be very nasty for a bit, but then it’s over’. But I so deeply want to die in a gentle way... (i–21).

Many participants also talked explicitly about their fear that self-euthanasia might go wrong. Several questions echoed through many stories: ‘How do I get the pills in the first place?’; ‘How can I be certain that I’ll get the right (amount of) pills?’; ‘Do I have reliable internet addresses?’; ‘How can I be sure that I don’t cause irreparable damage to my body or end up in a coma?’ and; ‘How can I be sure that I don’t burden others with deep grief or trauma’. For some participants, it became almost an obsession:

It’s a problem that is constantly in my mind. And there is no solution. It’s like, when you lose your keys, you keep searching them until you find them. At least, that’s the way it is with me. ‘Heavens, where did I put that key?’ Anyway, it lingers, it is constantly in your head as something insoluble. Well, it’s the same right now. It’s an on-going, underground search for possibilities: I might try this again, and give that another check... (i–4).

While he used all kinds of preparations and precautions to get a grip on his situation, this lingering uncertainty continuously played tricks on him.

3.4. Resisting interference and longing for support

For the majority of participants, self-determination, independence and autonomy were core-values and an essential prerequisite for a happy life. They placed great value on their individual freedom, on running their own affairs. ‘It’s about freedom. Total freedom. And now I want to keep that freedom, which I’ve always had, to die in my own way. (...) That’s, that’s, that’s the greatest value in life’ (i–10). Participants also consider it their own responsibility: ‘I just want to keep it under control. (...) And frankly, I think you shouldn’t burden someone else. It’s my decision, so I’m fully responsible’ (i–16).

However, this independent way of life also seemed to make them feel lonely in the preparation for this ultimate decision. One man, who strongly saw himself as an independent, autonomous person with full personal responsibility for everything he did, put it this way: ‘You know, it might sound tough, but it also means that you feel completely thrown back upon your own resources. You stand alone’ (i–4). And a woman – who had supported her husband who
had voluntarily stopped eating and drinking to hasten his death a year before the interview took place – showed one of her favourite postcards depicting a painting of someone lying on a rug, tenderly flown away by swans. She said:

_Sadly, it’s impossible for me to sail away like this. I’ll have to do it all by myself. (...) We were able to support my partner with making choices and with help. But I... I’ll have to do it by myself, at least for a large part... For I don’t want to get my kids in trouble anyway. Or the doctor (i–5)._ 

Despite the fact that most participants clearly stated that they regarded their choice to end life as their ‘own responsibility’ and ‘an autonomous, independent decision’, preferably made without any interference from others, the majority of participants at the same time paradoxically wanted interference with proper (medical) assistance to actually carry out the act to end life and they felt closely dependent on medical professionals for support and assistance. A lady almost cried:

_If anyone has a deep respect for life, it’s me! ... What the hell! Sure! Really! I mean, because I want it in a respectable way! I want someone... I want someone to help me. I want someone to make it easy for me to, so to say, place my soul in the hands of the Lord (i–1)._ 

Some years earlier, she had attempted suicide with an overdose of morphine, but she survived. Now, she desperately searched for a doctor who was willing to assist her, but her medical condition did not allow medical assistance within context of the Dutch Euthanasia law.

### 3.5. Legitimacy and illegitimacy

Participants’ accounts are full of what good death could be, namely: a self-chosen, self-directed, well-organized, dignified and legal death, preferably at home, surrounded by meaningful others, and with some medical assistance to ensure a smooth and successful attempt without the risk of mutilation.

In most accounts, there was tension between longing for legitimacy for their death wish so that it would be regarded as something ‘quite normal’, ‘understandable’ and ‘justified’ versus the experience of being judged as do-
ing something ‘unlawful’, ‘illegal’ and being part of ‘an underground movement’. This tension appears at the interpersonal and societal levels. On the interpersonal level, participants long for understanding and acceptance of their ideas and plans. All participants highly valued openness and a certain transparency with regard to their death wish: open communication – ‘in all sincerity’ – about their intention to terminate their own life with meaningful others was appreciated. They preferred an ‘honest’ death: ‘not slip away secretly on your own’, but ‘carefully and lovingly’ say farewell to others. In daily life, however, the majority of participants experienced that talking about their intention to terminate their own life was still a social taboo and was often ignored or received with denial and misunderstanding. One man said: ‘My son did simply not respond, not in words or in gesture’. A woman, who was met with defensive or angry reactions, told:

I chose very consciously to tell my children and my friends. (...) And they all had a go at me. And that wasn’t easy, that’s just not easy. I didn’t know it would be this hard. (...) It came as a huge blow to them. (...) In their eyes, death is a terrible thing and suicide is almost a sin. They [her children] were not raised religiously, but still it goes against their lust for life (i–12).

The idea of a self-chosen death was not only rejected by close family, but other older people like neighbours or occupants of the same nursing home also ‘got mad’ at them: ‘I cannot talk about it with people. They say: ‘Are you crazy!’ (...) I’d better keep it to myself’ (i–19).

On the societal level, they felt ‘let down’ and ‘abandoned’ by society and the government, and felt ‘inhibited’ in their freedom of choice. The majority of participants were of the opinion that they had ‘the right to a properly assisted death’ by a doctor. They advocate a more liberal interpretation of the Euthanasia Act. They claim to have a right to ask a physician to perform euthanasia or prescribe lethal medication, even if their only adverse condition is old age and the danger that they might lose control of their mind and body. As one man put it:

Some potentates in The Hague [city of government] are forbidding you to take your own life [in a dignified way]. You are deprived of your freedom. They make it impossible, at least to do it in a legal way, openly (i–4).
Others mainly attributed it to ‘the dictatorship of the church’ or ‘the unwillingness of physicians’. They felt forced to organize death in an ‘illegal’ way, for example because they had to tell lies to their general practitioner to get the required medication, or because they were afraid that people who helped them order medication over the internet might be prosecuted. Two women rejected the idea of claiming the right to dying assistance because of their lack of a serious medical condition. They emphasized it was ‘irresponsible to burden a physician with the act of terminating the life of someone like me’ [i.e. a person who is not suffering from an unbearable or terminal illness] as well as the fact that self-determination inherently means that one is also fully responsible for the final act oneself.

To underline the natural, understandable and legitimate character of the self-chosen death in older people, some participants made analogies with animal behavioural patterns: ‘To me, it mirrors a habit in the animal world (...) It’s often seen that animals who feel they have reached the end of life, withdraw and just wait until they die. So why can’t we?’ (i–10) Others drew an analogy between their death wish and ancient cultural habits:

*In former times, we also put grandma on an Artic ice floe with a bottle of gin. (...) If grandma was no longer useful to the clan, they said: ‘Well grandma, enough is enough. We have run out of food so the children come first. (...) Why should it be any different now? Yeah I mean it. (...) There is scarcity here too [energy and health care capacity] (i–5)."

Most participants were members or contributors of at least one Dutch right-to-die organization, in the hope that these organizations would ‘represent their interests’ and force a political breakthrough, namely the legalization of assisted self-chosen death in older people and the availability of a so-called ‘Drion pill’ [i.e. an end-of-life pill that would enable older people to end their own life if they wished to do so]. This pill was often mentioned by participants as ‘the most comfortable solution to their problem’ imaginable which would ‘surely make them feel at ease’. As one respondent put it: ‘It would be a great relief to have that pill on my nightstand’. (i–6). However, two participants also told that if they had had an end-of-life-pill, they probably would have taken it in a moment of despair. ‘Now I have to take an antiemetic three days in advance to prevent vomiting’, which stopped them from making a premature decision.
4. DISCUSSION
Our study characterizes the ‘in-betweenness’ (or liminality) of intending and performing self-directed death as living in a paradoxical position. Participants’ accounts are permeated with ambivalences and ambiguities. They felt both detached and attached; they felt both ready to give up on life and they tending to postpone hastening death; they sensed both their wish to die was sound and rational but they felt an inner and much more uncontrolled compulsion against doing it; and they tried to convince themselves to organise a ‘good death’ but were threatened by uncertainties and worries as they realised their impossibility to fully control death. Both sides coexist and are inextricably intertwined. Obviously, balances differ and shift from account to account, but a paradoxical tension is present in every included story, indicating that living in-between intending and actually performing a self-chosen death is an existential challenge, characterized by the complementarity between volition and compulsion as an inherent feature of this decision-making process.

Previous research has presented causal and risk factors associated with the wish to die, suicidal ideation and suicidal behaviour in older people (Rurup et al., 2011; Rodda et al., 2011; O’Connell et al., 2004). However, there is very little empirical research on the question of how people experience the ‘in-betweenness’ of intending and performing self-directed death. This study contributes to literature by presenting the first ‘real-life’ account of what it means to live this ‘in-betweenness’. It also sheds new light on a mainly theoretical debate about rational suicide by offering empirical insights into the tensions and ambivalences of living towards the ultimate decision to opt for a self-chosen death or not.

Our results question the conception of ‘rational suicide’ as an autonomous, free decision without pressure. The self-chosen death in the older people we studied appears to be neither decisively non-rational nor rational. On the one hand, participants were of the opinion that they made a ‘reasonable’ assessment of their situation. They perceived that they would be better off dead. They were assumed to have the ability make sound decisions, as there was no evidence of severe psychological disturbance. And generally, their considerations were in consonance with their fundamental interests and values. These characteristics are very similar to the characteristics mentioned in the literature on rational suicide (Lester, 2006; Hewitt, 2013;
Battin, 1999; Werth Jr, 1996). On the other hand, however, participants also talked about being forced by inner bodily and emotional compulsions and attachments.

The self-directed death wish emerges as an ultimate escape to safeguard oneself and a way to exert control over their current life. The older people involved—often strong-willed, autonomous and rationally oriented persons, who highly value an independent and self-determined life—failed to live according to their values and ideals. They felt threatened in their abilities, their performance and their identity, no longer able to live a perceived worthwhile life. Therefore, they preferred death over life, as they consider death to be the end of sorrow, pain and stress. These findings support the idea of Kerkhof and De Leo (Kerkhof and De Leo, 1991) that ‘rationality may be a very misleading concept for a proper explanation of suicidal behaviour’ and that true reasons—such as anxiety, fears or threats of losing core aspects of one’s identity—should not be obscured. Indeed, our study illustrates the inadequacy of considering this decision-making process as a matter of rational, deductive calculation, as these existential choices cannot be captured in logical constructions without taken into account the sense perception. Rather, the decision-making process is characterized as an embodied process influenced by all kinds of existential entanglements.

Participants commonly perceived a self-chosen death to be a blessing, a benefit, an improvement of their lot, because it would keep them from (further) harm, rather than causing it. It was often seen as a ‘good death’, which is consistent with other studies that have indicated voluntariness and being-in-control as constituents of a ‘good death’ in modern Western societies (Pool, 2004; Chabot and Goedhart, 2009; Seale, 2000; Kellehear, 2007; Clark, 2002). For most participants, human suffering had no positive moral significance, so why maintain life at all costs? To some extent the self-chosen death even appeared to be the consequence of participants’ commitment to personal, moral or aesthetic values, as for most participants self-development, self-determination, and independence were paramount. The termination of one’s life could be seen as a clear refusal and/or incapacity to reach a compromise with and adapt to life-as-it-is.
4.1. Further research

Our study describes the ‘in-betweenness’ of intending and performing self-directed death. It is, however, unpredictable whether these individuals will ultimately really opt for a self-chosen death. However, in hindsight the population under study turned out to be determined. In the year after the interviews, the interviewer received eight notices of older people who indeed engaged in life-ending behaviour and died via a self-chosen death. While our phenomenological approach does not aim to clarify causalities, but aims to describe lived experiences, it raises the intriguing question what essentially characterizes these people that makes them so determined to die at a self-appointed moment?

The Interpersonal Theory of Suicide (van Orden et al., 2010) indicates that people with a wish to die are most at risk when two interpersonal themes are simultaneously present namely: thwarted belongingness and perceived burdensomeness. Our study seems to confirm this association. In an earlier article, we already pointed at the sense of non-belonging and not mattering in this population (van Wijngaarden et al., 2015). This current paper shows that participants frequently talked about the fear of placing a burden on others by being old and dependent; they also, however, conveyed their concerns of burdening others with the impact of a self-chosen death (such as loved ones or the physician). However, more research on this topic needs to be undertaken to clarify why the population under study is highly determined on dying at a self-appointed moment.

We did not analyse the outcomes of the HADS in relation to the interview data. In the context of this research project our sole aim was to gain a preliminary indication as to whether the wish to die was driven by a severe depression or not. However, it is noteworthy that in the population under study, a close association between death wishes and depression is cautiously questioned, because there was an indication of a severe depression in only one case. This seems in consonance with other research that also indicates that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety (Corna et al., 2010), but much more research on this topic is needed to further explore this.
4.2. Practical implications
When faced with mentally competent older people who sincerely believe that their life is completed and no longer worth living, mental health professionals are highly challenged (McCue et al., 2015): What is the appropriate response? At least for this sample, the concept of ‘rational suicide’ as an autonomous, free decision without pressure is questioned. Rationality might contribute to the decision to terminate one’s life, but these data indicate that these people should not be approached merely as independent, autonomous and self-determining agents, but rather acknowledged as human beings struggling with life in all its ambiguity. It thus appears highly relevant to realize the possible disastrous impact of empowering people in their ‘rational, cognitive’ suicide wish (Werth Jr, 1996; Lester, 2014; Battin, 1991), as this study found that it probably is not a strictly rational consideration. The findings also indicate the need for sustained ethical engagement with these people and their wishes and desires, recognizing that they are highly determined to die at a self-appointed moment, although these wishes appear to be fluid and might shift or change.

4.3. Policy implications
Most participants were in favour of a more liberal interpretation of the Euthanasia Act and claimed to have a right to assisted dying, even if they did not suffer unbearably from a classified medical condition. Our study provides policy makers with in-depth insight into what it means to live with an age-related wish to die. In this way they may become more sensitized to the significant threats these people experience. It highlights the need for due consideration of all ambiguities and ambivalences present after a presumed rational decision has been made in order to develop conscious and careful policy for this particular group of older people.

4.4. Reflections on strengths and limitations
We took several steps to enhance validity and reliability: we worked in a research team of three researchers. The first author performed the data-collection, and all were involved in the analysis. We undertook member checks of the data collected, not only for ethical reasons but also to verify that the participants feel the narrative report reflects what they actually intended to say. Despite some minor factual remarks, participants confirmed that the narrative reports fully reflected their stories. By giving an in-depth methodological description we attempt to provide transparency and allow integ-
rity of results to be scrutinized. To reduce the effects of biases, beliefs and assumptions as much as possible, a reflective commentary was used and frequent debriefing sessions between all researchers’ were organized during data gathering and data analysis.

However, it should be noted that all participants were Dutch citizens living in the Dutch context where euthanasia has been legalized and an open and progressive public debate is going on. Besides, twenty-three participants were members of the Dutch right-to-die organization. This raises questions whether these outcomes can be generalized to different persons, settings, and times. Yet it is important to note that a growing awareness about death and dying, and the debate on how to determine time and manner of death has become more common, not only in the Netherlands but in the Western world as such (Chabot and Goedhart, 2009; Seale, 2000; Kellehear, 2007; Pool, 2004; Clark, 2002). Although cultural and societal differences may limit transferability of these results to other countries, the Dutch situation can certainly inform the debate on the legalization of assisted dying in other Western countries.

For the Netherlands, our findings are considered to be generalizable to other similar populations as we maximized variation within our sample. By providing thick description of the phenomenon, we have tried to facilitate readers to get a proper understanding of the scenario and enable them to compare the descriptions with those that they have seen emerge in other situations. Nevertheless, more research on this topic is recommended to compare empirical findings in different countries and cultures.
REFERENCES

Raijmakers NJH, van der Heide A, Kouwenhoven PSC, et al. (2013) Assistance in dying for older people without a serious medical condition who have a wish to die: A national cross-sectional survey. *Journal of Medical Ethics*.


CHAPTER 6

A captive, a wreck, a piece of dirt: Images and metaphors embedded in culture and anchored in the flesh of older people with a death wish

(in review)
ABSTRACT

Objectives: This article explores the use and meaning of metaphors about ageing in older people with a wish to die.

Method: 25 in-depth interviews with Dutch older people were re-analysed. We collected all metaphors with regard to the process of ageing. They were analysed by making use of a phenomenological-hermeneutical metaphor analysis approach.

Results: We found ten central metaphorical concepts: 1) struggle; 2) victimhood; 3) void; 4) stagnation; 5) captivity; 6) breakdown; 7) redundancy; 8) sub-humanisation; 9) burden; 10) childhood. It appears that the group under research does have profound negative impressions of old age and about themselves being and becoming old.

Discussion: This current study furthers our understanding of the experience of disconnection in older people with a wish to die. The discourse used reveals a strong sense of distance, disengagement and not belonging. The negative metaphorical representations found in the data seem to correspond with the negative deficit-oriented societal discourse on ageing. Our study indirectly demonstrates the potential negative power of commonly used social constructions of ageing. It empirically illustrates that widespread negative, stigmatized images not only might have played a role in the devaluation of old age in general, but also might have an effect on how older people see themselves.
1. INTRODUCTION

In the last decades, major changes have occurred in the Western experience of ageing and dying. Several authors have described these evolving developments (Kellehear, 2007; Seale, 2000). Due to the success of medical technology, improved public health and a significant rise in life expectancy, common death causes have changed. Most deaths are now related to organ failure, frailty and general deterioration, and an assortment of serious, disabling and chronic diseases (Kellehear, 2007; Seale, 2000). While on the one hand, a central focus in gerontology is on successful and healthy ageing, on the other hand ageing and dying are increasingly associated with the indignity of dependency, the prospect of a disappearing identity, and the rise of a so-called ‘shameful death’ (Kellehear, 2007). Authors have shown that cultural representations of old age are often quite negative: older people are marginalized and portrayed ‘as less than full citizens, or even less than adults’ (Kellehear, 2007; Behuniak, 2011; Hockey and James, 1993; Featherstone and Wernick, 1995). It is argued that there might be a correlation between older people feeling stigmatized with shame, disgrace, degeneracy and failure and the growing wish to anticipate and time our deaths (Kellehear, 2007).

Three authors of this current paper have performed a phenomenological interview study into this specific topic. They have explored the lived experiences of older people who considered their lives no longer worth living and wished to die at a self-appointed moment, while not suffering from a life-threatening disease (van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015b; van Wijngaarden et al., 2016b). This was done in order to gain in-depth comprehension of this specific wish to die: What do these older people mean when they consider their lives to be completed? What are underlying problems at stake? Why do these people prefer death over life? And what should be an appropriate and well-considered (societal) answer to their needs and concerns? It was found that the essential meaning of the phenomenon of ‘life is completed and no longer worth living’ is to be understood as disconnectedness to one’s actual life: daily experiences seem incompatible with people’s expectations of life and their idea of who they are, which strengthened a strong desire to end life at a self-chosen moment. This experience has been further explicated in the following themes: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion to feared dependence (van Wijngaarden et al., 2015a).
During the initial analysis of our empirical accounts, we also found a striking world of images and metaphors used by the older people to express their feelings, concerns and fears about their on-going deterioration. This is interesting because metaphors have the potential to give access to a different source of experiential knowledge, namely a preconceptional orientation with respect to thought and experience that is hardly accessible in rational discussion (Schmitt, 2005). Metaphors are thus a vital part of being able to gain a deep understanding of people’s lifeworld. This specific orientation is especially helpful when it comes to very sensitive and difficult topics such as people’s age-related wishes to die. While there are several studies that explore the cultural representations of ageing (Hockey and James, 1993; Featherstone and Wernick, 1995; Gilleard and Higgs, 2011; Cuddy et al., 2005) or dementia (Timmermann, 2010; Behuniak, 2011; Anderson et al., 2009; Kessler and Schwender, 2012), studies that explore the use of metaphors in older people’s narratives are very limited. Therefore, this current study specifically explores the use and meaning of metaphors in these accounts to further the deepening of our understanding of the issue at stake. Our central question for this study is: What metaphors and images do older people with a wish to die use to describe the process of ageing? And: What do these metaphors and images tell us about their self-understanding and imagined feared future? This study was done in order to further elucidate the lived experience of these older people and get a deeper sense of how they modify and interpret their world.

2. METHODS

2.1. Theoretical underpinnings of metaphor analysis
Metaphors are a form of figurative language; a word or phrase is to be understood beyond its literal meaning. In this paper, we follow the definition of Lakoff and Johnson (2008): Metaphors are understood as ‘a means of understanding one domain of experience in terms of the conceptual structure of another domain’. Metaphors and images used in talk show how people conceive and construct their world, mirroring people’s inner thoughts and meaning (Schmitt, 2005; Lakoff and Johnson, 2008; Quinn, 2005), but also illuminating the cultural and collective dimension of personal experiences. These thinking patterns are often unconscious, simply taken as ‘givens’. (Schmitt, 2005; Lakoff and Johnson, 2008). These largely tacit, taken-for-granted assumptions and understandings are often implicit, becoming (at
least partly) explicit in talk (Quinn, 2005). Metaphors can also be used as a rhetorical tool, assigning an ideological, political function (Schmitt, 2005). People then deliberately seem to make use of ‘culturally dominant metaphors’ with a certain ideological goal. And sometimes metaphors are used to verbalize difficult topics.

For this study, metaphor analysis (Schmitt, 2005; Lakoff and Johnson, 2008; Aubusson, 2002; Aita et al., 2003; Quinn, 2005) was used to identify metaphors and their meaning. The investigative understanding of the (shared) metaphors is not focused on the identification of linguistic patterns and models; rather, it is phenomenological-hermeneutical in its purpose. It seeks to bring the (often unconscious) use of metaphors to a conscious level to deepen our understanding of the lifeworld of older people, trying to elicit how these people give meaning to their lives and the world they live in by making use of (shared) metaphorical language. Finding the cultural meaning in talk ‘which organises the interpretation of individuals’ understandings of their lives, motives and identities’ (Quinn, 2005).

2. 2. Rationale behind combining of phenomenology and metaphor analysis
In our empirical work, we chose a phenomenological perspective. So we need to pose the question as to whether it is sound to combine a phenomenological approach (which is mainly viewed as essentialistic) with a metaphorical approach (which is mainly viewed as constructivistic). Phenomenology not simply aims to describe the world from a first-person perspective, but it rather ‘tries to extract from lived experience the essential meanings and structures of purpose, project, motive, wanting, trying, and so on’ (Ricoeur, 1993). To put it in different words: phenomenology attempts to systematically and conceptually explore meaning-structures of being-in-the-world (Svenaeus, 2000, 2011), revealing a common human understanding of the world. It views humans as being essentially embodied. Consequently, there is no thinking separate from the body. Instead, thought and language are interconnected to human bodily existence and bodily experiences. Following Merleau Ponty (1962/1945), phenomenologists conceive words to be ‘pointers’ to the things that are meant. Humans have an experience prior to thinking about things and then organize them according to the categories of language.

In their book Metaphors we live by, Lakoff and Johnson (2008) pose that their theory on metaphors accords with some central insights of the phenomen-
enological tradition (about epistemology, embodiment, truth and objectivity). Metaphors, they note, do have structuring, meaning-making qualities and form a structure ‘in which we live’. Metaphorical language reveals and produces interpretation and understanding of the world (Lakoff & Johnson, 2008). Phenomenological thinkers also view language as the articulation of the meaning-structures in the world. Svenaeus writes that metaphors can ‘reach the bottom ground’ of what human life essentially is (Svenaeus, 2011). And Ricoeur recognizes the fundamental power of language in constructing the world we perceive, and its power to create and recreate meaning through metaphor (Ricoeur, 1993).

Heelan (1993) – who also explores the relationship between phenomenology and Lakoff and Johnson’s theory of metaphors – quotes Lakoff and Johnson’s earlier work, when he claims that meaning functions by interpretation; the product of interpretation is meaning. He states: ‘Meaning is not private, but should be seen as a public domain where people share the products of human understanding, by common habits of action and by the use of language. Meaning is the public domain in which people understand one another, argue with one another, give reasons, establish goals and set up norms. Meaning is local and social, it is the product of active local interests and social communities and constitutive of their interests’ (Heelan, 1993). Hence, through the words and terms people employ, we can discover more deeply how people give meaning to their lives and how they modify and interpret their world. Language is the ‘house of being’ (Ashworth, 2006).

Following the arguments above, we take the position that the practice of meaning-making through metaphors overcomes the polarization between an essentialist and constructivistic view.

2.3. Data-collection

For this study, we have collected all metaphors with regard to the process of ageing from our empirical accounts. 25 Dutch older citizens (median 82 years) participated in this study. They were all ideating on a self-chosen death because they considered their lives to be no longer worth living. Inclusion criteria were that they: 1) considered their lives to be ‘completed’; 2) suffered from the prospect to live on; 3) currently wished to die; 4) were 70 years of age or older; 5) were not terminally ill; 6) considered themselves to be mentally competent; 7) considered their death wish as reasonable.
To provide insight into participants’ characteristics, we refer to Table 1 in chapter 3.

Between April and September 2013, research advertisements were placed in various magazines targeting older people. Older people who wished to die because they felt their life was completed were invited to participate in an in-depth interview. One hundred forty-four people responded by post, email and telephone. Participants were purposefully sampled. In line with our aim to gather and explore experientially rich descriptions, sample criteria were richness and uniqueness of experiences, and variations in ideological and demographic backgrounds.

Before the interviews, participants were provided with comprehensive information about research aim, the right to withdraw at any moment, their privacy and confidentiality rights, and full personal contact information of the interviewer (who was available for contact during the full term of the study). We gained informed consent prior to the interviews. The first author conducted all interviews in participants’ homes. She made use of an open and non-directive phenomenological approach. Participants were invited to elaborate on their experiences without restrictions (For the complete interview guide, see Appendix 1). These kind of open interviews permit the interviewees to reveal their own thoughts, insights and unique way of talking (Quinn, 2005). All interviews were audiotaped, median 1:56 hours in length. Interview data were transcribed. Field notes were made during and immediately after the visits, which contributed to contextual understanding and reflexivity. To obtain an indication of whether the wish to die was driven by severe depression, all participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

After every interview, a narrative report was written and sent to the participants, not only for validation but also for ethical reasons because it might enable participants to share in the meaning-making process (Finlay, 2011; Patton, 2002). After debriefing, a final phone call or correspondence was planned to share and evaluate. The response was mainly very positive. The majority of participants explicitly underlined that participating had been a positive experience, because the interview had helped them to express their thoughts and feelings in a non-judging environment, which gave them a sense of relief and recognition. To protect the safety of participants who dis-
closed a death wish, we communicated about the possibility of a follow-up conversation at their homes or reference to a counsellor if appropriate. Two participants made use of this possibility.

2.4 Data-analysis
As metaphors are the subject of this article, we will now focus on a description of how we selected the metaphors from our empirical accounts. To demarcate our search, first the topic was determined: only metaphors with regard to the process of ageing were selected. In line with Lakoff and Johnson (2003) and Schmitt (2005), the process of ageing was thus identified as the ‘target area’. Secondly, all relevant metaphors contained in the interview text were identified. A word or phrase was identified as a metaphor if: a) a word or phrase could be understood beyond the literal meaning in the context; b) the literal meaning stemmed from a sensoric or cultural experience (source area) and; c) the literal meaning was transferred to a second, often abstract, area (target area). Then, thirdly, clusters of metaphors were made and summarized in metaphorical concepts. This process of allocating metaphorical idioms to metaphorical concepts was continued until all metaphors were listed under a concept. For a schematic overview of the metaphorical concepts, some illustrating quotations and how they are grounded in the data, see Appendix 2. Some individual idioms were left out as they represented very personal, idiosyncratic formulations. Lastly, conclusions were drawn from the results.

2.5 Intersubjective credibility
To enlarge the intersubjective credibility, several steps were taken: A standardized procedure for metaphor analysis was used (Schmitt, 2005). The various stages and decisions along the way are well documented. According to Schmitt (2005), triangulation of metaphor analysis with other research methods is recommended; not only to validate, but also to understand differences in conclusions. Hence, there has been constant comparison with our previous, non-metaphorical findings, to assess consistence, differences and validity of the results of the metaphor analysis. And to verify the interpretation, the outcomes were thoroughly discussed with peers from the Long Term Care Partnership Amsterdam (a collaboration of academic researchers and care professionals) and with colleagues of the Amsterdam Centre on Ageing.
3. RESULTS
In this section, the results of the metaphor analysis are described. Participants – older people with a wish to die – spoke about the process of ageing in profoundly negative terms. The clustering of the metaphors led to ten central metaphorical concepts by which the older people under research described the process of ageing in terms of 1) struggle; 2) victimhood; 3) void; 4) stagnation; 5) captivity; 6) breakdown; 7) redundancy; 8) sub-humanization; 9) burden and 10) childhood. Below, we have described these metaphors illustrated with reference to common expressions and some evocative quotes.

1) Ageing as a struggle
Participants talked strongly about their own lives in terms and images of struggling, fighting and wrestling. Life is perceived as ultimately harsh, as a fight against their own bodies and the ongoing deterioration process, a struggle towards (feared or experienced) further decline and degradation. It is talked about as a hard and nasty thwack. ‘Mentally, it is a very heavy blow’. One participant – who in fact needed a zimmer frame to get around – strongly resisted the idea of herself needing a walker. She said: ‘It’s like fighting, you know, I definitely don’t want a walker’ (i–7). Another participant put it this way:

Yes, it is a fight to survive though. That’s what I have had to do for a long time now; struggling to survive yeh. Anyway. And not, indeed not, not letting them drag you... (i–16).

Participants told how they were trying to resist the progressing decay but failed to do so. Despite their (inner) resistance, they felt slowly broken down, losing strength and health. They felt they lost the fight. Some participants described themselves as being just totally worn out. One interviewee said: ‘You know, I’m weary to the marrow of my bones, but I have to continue. (...) It’s either pumping or drowning, so I pump!’ (i–4) In their experience, life had become a ‘battle of attrition’.

2) Ageing as victimhood
Participants also drew on a discourse of ‘victimization’. They frequently spoke of a referent-less ‘it’ which made them suffer unfairly by taking away their bodily capacities, their mobility, their privacy, their health, and even
their identity. ‘It’ got in their way, trying to take away something considered indispensable to them. Some participants explicitly spoke about these (actual or feared) loss-experiences in terms of a grim fate, feeling aggrieved but completely powerless to do anything about it and feeling forced to capitulate. They used the image of being a victim to emphasize their helplessness and unwanted dependency. ‘Everything has been taken away from me’ (i–18) and ‘I’m deprived of my identity’ (i–13). They were gripped by a strong sense of fatality.

Participants also considered themselves as a victim of ‘others’ (like close relatives or physicians) who might take over control over their lives ‘by deciding what is best’ for them ‘without taking into account’ their wishes. One participant talked about her fear of falling victim to family meddling in her life: ‘I’m afraid that they’ll take away my raison d’être.’ (i–12) Participants felt at the mercy of others deciding what’s best for them, fearing however that ‘others’ would not safeguard their interests. A physician will probably ‘force’ them to undergo (life-prolonging) treatment against their will: ‘The GP is just stringing me along’ (i–1). They felt left as a victim of someone else’s power.

3) Ageing as a void
Participants frequently talked about the ageing in terms of ‘a large empty space’, ‘an aching void that could not be filled anymore’. The ‘days are empty’, and the ‘world is empty’. They sometimes also talked about the world as if they were ‘no longer inhabitants anymore’, a world that was ‘no longer reachable’ (i–15) for them. One lady talked about herself spending the days sitting in her chair and staring ‘into the silent void’ (i–9). She had lost all hope that this emptiness could be filled again. She felt severely debilitated by the monotony and slowness of her days. In a few months, she would turn 100 years old. Reflecting on her upcoming anniversary, she said:

*I don’t even want to think about it. I lack everything. The only things I can still do are thinking and talking properly. But that’s all. There is nothing more. (…) My days are filled with a numbing emptiness. I’m simply waiting for the end to come. Every night I say, dear God, please take me. Every night! But it just doesn’t happen (i–19).*
4) Ageing as stagnation
Participants also used a discourse of movement, and more specifically a discourse of stagnation. The process of ageing was put into words by phrases such as ‘being blocked’, ‘being stopped’, and ‘reaching a boundary’, as if someone or something had deliberately stopped them. They not only felt stopped making any progress, they felt obstructed, prevented to do the things they preferred to do, unable to see or go beyond. They talked about their attempts to escape from this stagnation (and evade capture) in terms of movement such as ‘fleeing’ and ‘running away’. One lady who suffered from diabetes said:

Everything is getting arduous. Mainly because I’m physically disabled. Diabetes is blocking me. It really feels like a blockade. (...) Four times a day, I have to face this obstacle, whether I like it or not. But then, when I go to church and they treat me with a nice slice of cake – because that’s our habit, on Tuesday we’ll always have cake or other treats – then I have to give myself another injection, that’s five times a day! That doesn’t make me happy, but I just want to have the cupcake (i–13).

5) Ageing as a captivity
This fifth metaphorical concept closely relates to the fourth, but with images of captivity participants specifically referred to the process of ageing as being locked in: ‘It’s like you’re all alone in a tunnel and you cannot see the exit’ (i–6). They told how they felt trapped, taken captive by their own lives and the process of deterioration. To illustrate this captive feeling, they used images like a pit, an abyss, a tunnel, a whirl, a quagmire, a cage and a blockage. One lady said: ‘I’m constantly trying not to be dragged into that gaping abyss’ (i–2). Another interviewee said: ‘I feel like my life turned into a quagmire, a swamp full of misery’ (i–8). And a man – who had to move from a country house to a senior apartment – said: ‘You know, this building is called “La Château” but actually it’s a cage’ (i–3). He felt completely deprived of his freedom.

Participants perceived themselves as being completely powerless to change their situation. Some participants mentioned explicitly that they could not see ‘a way out’. One participant put it like this: ‘Life constantly puts the brakes on and I cannot release myself.’ Another lady made an evocative comparison between a youth-experience in which she was locked in and the way she experienced her current life:
I was in a class at school and we had to write an essay. But the teacher assessed my essay to be too short, not finished yet. (...) So he disciplined me and let me stay after school to finish my essay. (...). Mulishly, I started. In the meantime, the teacher was correcting. And then he was called away by someone. (...) After a while, it turned out that he had completely forgotten me and had left. He had closed the school and had gone home. So there I sat, with my over-completed essay. Locked in, I mean, I couldn't open the door! And really, right now, at this very moment, that's how I feel it. You know, my life story is finished, I think it's good, it's accomplished. But I am forced to continue it. They have closed the door. I simply cannot leave. I feel abandoned. They just close the door and leave (i–21).

6) Ageing as a breakdown
Participants spoke about themselves and their ageing bodies in very negative and dismissive terms such as ‘being a broken man’, ‘a creaky old one’, ‘a total wreck’, ‘feeling completely crushed’ and ‘worn out’. By using these images, they presented themselves as seriously damaged and malfunctioning. Current life was experienced as a breakdown of former, familiar life. One man – who formerly worked in the field of mechanical engineering – told: ‘I feel dismantled (...) I feel like sailing a rudderless ship with engine trouble’ (i–6). Another man pointed at an ugly semi-sawn-off pine tree in his overgrown garden when he talked about his life and said: ‘You know, I feel like that sawn-off tree. Completely sawn-off and uprooted’ (i–4).

While participants often referred to their present bodies, some also spoke about their feared future bodies in words such as: ‘I don't want to become a lonely, shrivelled human being’ (i–23). Another participant put it like this: ‘I don't want to end up in a rickety, dilapidated condition, having my breath coming in short pants, stumbling over a curb, and then being in need to be picked up by someone else’ (i–5). The fear of future decline deeply affected them, viewing dependence as utterly incongruous with their ideas of who they were.

7) Ageing as redundancy
The image of redundancy was also present in many accounts: participants talked about feeling ‘sidetracked’, ‘like a third wheel’, having ‘no function’ or ‘employment’ anymore. They used many images to illustrate their state of not being necessary or useful anymore. A former superintendent in the shipping industry put it like this:
You'll just sail along like a mast on a ship. You have no effect on anything, you know, just like that mast. The mast is just sailing along. It means that you are completely sidelined ... I feel completely sidelined in all areas (i–6).

Another man (aged 81 years old) put it like this: ‘Why am I still living? I really feel made redundant by society.’ He used to be a technical engineer. Engineering was not only his work, it was his passion. However, at the age of fifty-two, he was fired due to a reorganization. After dismissal, he did not succeed in finding another suitable job. Almost thirty years later, he still regrets it: ‘I’m a techie, but society has expelled me. That’s how I feel. I have a lot of experience and knowledge in the technical field, but no one ever asks for it at my age’ (i–11).

8) Ageing as sub-human
The process of ageing was also considered to be a process of reduction, objectification and dehumanisation. Participants no longer spoke about aged people as being human subjects, but rather as being objects: ‘a piece of dirt’, ‘a slice of meat’, ending up like ‘nothing’, losing (or deprived of) human qualities. Most participants made references to filth, dirt and defecation when they talked about old age. In some cases, they talked about themselves in terms of dirt. One woman who suffered from serious itching and severe constipation referred to the biblical Book of Job by saying: ‘I feel like Job living at a dung heap’ (i–1). Often participants used dirt images to explain their fear of what they thought to be their near future and to express their disgust about the idea of ending up in a nursing home: ‘Going to a nursing home means lying 24 hours in my own snuff’ (i–25). Or: ‘People are lying in their faeces and urine, as if no more than a piece of dirt’ (i–5).

Participants drew on a highly normative and persuasive discourse – by using words such as ‘inhuman’, ‘insane’, ‘unworthy’, ‘horrifying’ – to express their negative judgments about the state of being dependent and old. Participants also sounded disapproving as they used metaphors such as ‘an insane, idiotic zombie’, ‘vegetables’ and ‘carcasses’. In their eyes, the degradation process they witnessed simply is ‘not human’. ‘If you see the old crones walking around here, that has nothing to do with being human. (...) It’s like driving around a carcass in a wheelchair’ (i–23). Participants characterized the decline as ceasing to be a person before death, destroying the identity of the person: ‘You end up like being nothing, you’re not human anymore’ (i–13). These
metaphors were mainly used to express participants’ ideas about their own anticipated fears for the near future.

9) Ageing as being a burden
Participants also talked about the process of ageing in terms of being a burden to themselves, but even more to others and to society. They felt ‘foisting upon others’, ‘putting pressure’ on their children, and ‘costing too much’ (money and/or time). One lady who did not have children and struggled to keep up living all on her own, put it like this:

*Some people say to me: ‘Why don’t you go and live near your sister’s house? Wouldn’t that solve the problem?’ But you know, that’s not the reason why we live on this earth: to greatly complicate each other’s lives. (...) My youngest sister is 72. She has three daughters and seven grandchildren. For sure, it is much more enjoyable to care for them. And by the way, I don’t ask for her care, I don’t even want it! It would put me in an awkward position, I would feel very uncomfortable by putting too much pressure on her (i–1).*

10) Ageing as childhood
Lastly, participants also drew on a discourse of infantilization referring to ageing as (a second) childhood. They expressed their fear and disgust about old age in terms of being back in the state of a small child again. They feared both to be treated like a child and to behave like a child by using words like ‘being forced to defecate and urinate in close proximity to others’ (i–18), the shame of ‘wearing a doily’ (i–10), and the embarrassment of ‘only babbling and chatting all day’ (i–13).

4. DISCUSSION
The aim of this study was to collect and clarify the metaphors and images used by older people with a wish to die to get a deeper sense of how these older people interpret their lives. It appears that the group of older people under research do have profound negative images about old age and about themselves being old. Old age is considered to be distinctly negative, representing whatever is broken and inhumane. Metaphors like being a captive, a wreck, or a piece of dirt have become real for them, encompassing their whole lives. For them, old age is perceived as an unequal fight. The older person is conceived of as being powerless, being a victim of a referentless
‘it’ which takes away their personal worth, imprisoned in their own situation.

In a previous study, we have described that the group under research considered their lives to be no longer worth living, because they gradually sensed a loss of connection to their actual lives (van Wijngaarden et al., 2015). This current study furthers our understanding of this experience of disconnection. The discourse of victimhood, imprisonment, void, stagnation, redundancy, sub-humanisation and infantilization reveals a strong sense of distance, disengagement and not belonging. It elucidates what the situation means for their (social) identity: they strongly express themselves in terms of redundancy, thereby underlining their state of being unnecessary and useless. They feel they are no longer included, there are no meaningful projects available, no one seems to ask for their commitment. Not only do they talk in terms of feeling redundant but also of being a burden, which reinforces the sense of disconnection: they feel both unneeded and bothering, both sidetracked and getting in the way of others. The metaphorical accounts given in this study also provide insight into how these people relate their feelings to their own bodies by expressing themselves in terms of struggle, victimhood, stagnation and brokenness. They have to fight a fight with themselves, they feel a victim of their own deteriorating bodies: locked in and shut out at the same time. Powerless to change this situation or win the fight. This has a profound alienating effect. Besides, the negative metaphors used might also unconsciously function as a justification of their death wish by making it very clear that they indeed suffered unbearably and hopelessly.

It is widely supported that meaning is not private, rather it is local and social and functions by shared interpretations. Meaning can be seen as ‘a public domain where people share the products of human understanding, by common habits of action and by the use of language’ (Ricoeur, 1993; Taylor, 2004; Heelan, 1993). Hence, through the words and terms people employ, we can discover more deeply how people give meaning to their lives and how they modify and interpret their world. Language is the ‘house of being’ (Ashworth, 2006). It follows that metaphors not only illuminate personal perceptions, but also shared cultural beliefs (Schmitt, 2005; Quinn, 2005; Behuniak, 2011). Several authors have indicated that the study of metaphors can indeed give insights on cultural perceptions of ageing (Hockey and
James, 1993; Featherstone and Wernick, 1995). Other studies focus on images of dementia and show that living with dementia arouses a great deal of negative emotions and has become a collective feared disease (Timmermann, 2010; Behuniak, 2011; Anderson et al., 2009; Kessler and Schwender, 2012). Dementia is not only framed as an impending societal crisis. Moreover, it is also seen as an imminent personal crisis, strongly associated with the diminishing of human dignity and dehumanisation evoking feelings of disgust and anxiety. Behuniak's (2011) argues that negative social constructions can cause real harm, as they can command fear and encourage (cultural) disgust of certain phenomena, but also narrow people’s ideas about themselves (Behuniak, 2011).

Our study supports this idea of intertwinedness of public and private meanings in people’s experiences. It indirectly demonstrates that wide-spread negative, stigmatized images of old age not only might have played a role in the devaluation of old age in general, but also might have an effect on how older people see themselves. The negative metaphorical representations of old age used by our participants seem to correspond with the negative deficit-oriented societal discourse on ageing (Featherstone and Wernick, 1995; Hockey and James, 1993; Gillear and Higgs, 2011; Cuddy et al., 2005; de Lange, 2015). It seems that these shared cultural beliefs resonate in participants’ self-perception, thus becoming flesh: lived and perceived as true. Participants might have internalized the negative perceptions and understandings about age and seem to rely on these negative societal ideas to comprehend and organize their own lives. While there are many older people who still perceive the quality of their lives as acceptable or even good (being able to adjust and adapt to their decline), the use of cultural dominant metaphors seems to have a significant effect on at least a group of older people. It might strengthen the internalization of a feared future and a feared self and a negative evaluation of their lives ‘in the eyes of society’.

This raises important questions: What might be the effect on older people when old age is so often associated with being a burden (on the personal, relational, societal and economic level), an unvalued status and great inconvenience, senility and second childhood (Featherstone and Wernick, 1995; Hockey and James, 1993)? In our study, ageing anxiety (Lasher and Faulkender, 1993; Lynch, 2000) is strongly associated with the development of a wish to die. In line with Behuniak's argument, we pose that it is im-
portant to acknowledge the destructive power of these negative images and metaphors. It can delineate between those who are old and the rest of society and might strengthen competent older people in choosing a (what they call) dignified and humane death rather than being reduced to an undignified state of life at the end of their existence. She poses the importance of raising awareness and actively resisting the negative power of this negative discourse through an emphasis on connectedness, commonality and interdependency (Behuniak, 2011). As a society, she pleads, we should replace a minoritising view of old age and people with dementia with a universal view: as something that affects us all. We should not consider it solely as a private problem but as a social issue as well. While there is a widespread aversion towards ageing throughout human culture (Lange, 2015; Cuddy et al., 2005), it has been argued that ageing abjection has been intensified in recent years (Gilleard and Higgs, 2011). Appeals to universal ontology of human vulnerability might be a possible source to counteract these negative views on ageing (Gilleard and Higgs, 2011; van Wijngaarden et al., 2016).

4.1. Limitations
This study gives some important indications about how people use metaphors to modify their world, and how negative social representations resonate in people’s accounts and seem to have become lived and perceived as true. It is important, though, to bear in mind that these profound negative metaphors are used by older people with a wish to die, and not just an average group of older people. To develop a full picture of how the negative images of old age resonate in the lived experience of older people in general, additional studies will be needed focusing on a more diverse sample.
REFERENCES


van Wijngaarden EJ, Goossensen A and Leget CJW. (2016a) The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living. *in review*.


An approach that is grounded on the evidence of real experiences provides a kind of credibility that only human stories can give. Narrative truth is different from statistical truth in that it is not merely a numerical snapshot of averages and variations but a humanly textured scene that communicates meaning and significance, and therefore carries the presence of what has happened to someone.

(Todres et al., 2007)
CHAPTER 7

Disconnectedness from the here-and-now:
A phenomenological perspective as a counteract on the medicalisation of death wishes in elderly people

ABSTRACT
When elderly people are ideating on manners to end their lives, because they feel life is over and no longer worth living, it is important to understand their lived experiences, thoughts and behaviour in order to appropriately align care, support and policy to the needs of these people. 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 paper, we evaluate this dominant paradigm by considering three serious limitations, namely: 1) the risk of epistemic transformation; 2) the risk of reduction; and 3) the risk of obscuring the social and cultural embeddedness. Drawing on insights from our empirical-phenomenological research on the issue of elderly and the self-chosen death, this paper argues for a phenomenological perspective to counteract the medicalisation of death wishes in elderly people.
1. INTRODUCTION

In the Netherlands, there is a growing group of elderly people who want to die at a self-appointed moment, not because they suffer from a life threatening disease or severe depression, but because they consider their lives to be no longer worth living (Rurup et al., 2005a; Rurup et al., 2005b). In addition, several recent studies indicate that an increasing number of Dutch people can imagine appreciating having a physician assist them in the dying process, even if they do not suffer from a serious disease (Buiting et al., 2012; van Delden et al., 2011; van Rein, 2013). In order to develop deliberate policy and adequate support for these people, a deeper understanding of their lived experience is needed: What do they mean when they say that they consider their lives to be over? What are underlying motivations and experiences? And how do they make sense of these experiences? To find answers to these questions, we conducted the first in-depth interview study worldwide into this specific group of elderly people (van Wijngaarden et al., 2015; van Wijngaarden et al., 2016). One of our findings was that, while ideating on a self-chosen death, these elderly people definitely did not perceive themselves as being mentally ill. They strongly rejected the suggestion that their wish to die were pathologically driven, thinking of themselves as ‘normal’ citizens with a ‘reasonable’ wish to die, not in search for any help or treatment, but rather in search for what they call ‘a dignified death’.

However, as described in our literature review (van Wijngaarden et al., 2014), in most studies the wish to die in elderly people is understood from a medical, psychopathological paradigm, referred to as (or associated with) cognitive impairment, depressive disorder, pathological bereavement, and suicidality (Rurup et al., 2011; Forsell et al., 1997; Scocco et al., 2001; Raue et al., 2007). Besides a relation between death wishes and mental disorders, research has shown an association between several physical, demographic and social (risk) factors and the development of a wish to die, such as physical impairment, relocation, bereavement and lower perceived social support (Forsell et al., 1997; Harwood et al., 2006; Jorm et al., 1995; Raue et al., 2007; Rurup et al., 2011; Rurup et al., 2005b). Generally, the main focus of the studies found is on the need to identify these risk factors, and the necessity of prevention and treatment of suicidality.

Not only the wish to die is often medicalised, death itself is medicalised as well (Kellehear, 2007; Yuill, 2015). Due to the advances in medical technol-
ogy, people live significantly longer then before. However, living longer is not necessarily associated with living better. Indeed, together with longer life spans came the emergence of degenerative age-related diseases such as Alzheimer, stroke and arthritis; diseases that could not be cured. The idea came up that medical science has made it possible to sustain human existence beyond the point of desirability (Kellehear, 2007; Yuill, 2015). In many Western societies, Yuill argues, there is a growing anxiety – fuelled by the proponents of legalization of euthanasia and assisted dying – about the de-humanized medical technological life-prolonging machinery strengthened by a “pervasive feeling that medicine acts not in the interests of the patient but to further medicine’s own goals” (...) “The image of the runaway train of medical technology keeping people alive against their will simply became a modern nightmare” (Yuill, 2015).

The plea for quality of life rather than quantity became stronger (van Rein, 2013; Kellehear, 2007) and right-to-die movements claim that the advent of medical science requires “the corrective of the right-to-die” (Yuill, 2015). Euthanasia and assisted suicide were defined as active mercy killing and viewed as ways to retake control over one’s death and as personal freedom from unwanted interference and coercion in one’s own life and death. These developments can thus be seen as a reaction against the medicalisation (which refers to the process by which a wide range of ‘non-medical’ life problems become understood, explained and treated as ‘medical’ problem) of death. However, as Yuill argues, it is also an extension of medicalisation of death: assisted dying is perceived as a medical fix, a technological solution to the problem of the death and (feared) suffering in the shape of a very effective lethal injection. This medical solution is seen as a relief, not only for those close to death, but also for those for whom death is still far-away but who are more or less gripped by the societal fear and uncertainty associated with the end of life.

The death wish in elderly people is thus mainly understood as a problem of medicine, and suicidality is widely viewed as a treatable mental disease. Besides, dying itself became a medical act involving all kinds of life-prolonging and life-shortening medical decisions, which urge people to take their own responsibility for end-of-life decisions to not be completely dependent on the doctor, though paradoxically, they locate the solution of a self-chosen death also within the medical domain. This profound medicali-
sation of death, dying and death wishes has important impact on how we understand those issues (Yuill, 2015; Kellehear, 2007; Seale, 2000). Death is less and less seen as a spiritual, existential, philosophical or moral issue, as it was in the past (Seale, 2000). Rather than being a natural part of life, it is now surrounded by choice, decisions, regulation and legality; the so-called “bureaucratization of the last phase of life and death” (Yuill, 2015).

Whilst several authors have comprehensively surveyed the changes in societal attitudes and paradigms regarding death and dying (Kellehear, 2007; Seale, 2000; Seale and Geest, 2004; Seale, 1998), this paper will concentrate on the evaluation of the dominant medical, psychopathological paradigm regarding death wishes in elderly people. This paradigm has three serious limitations that should be considered, namely: 1) the risk of epistemic transformation; 2) the risk of reduction, and 3) the risk of obscuring the social and cultural embeddedness. Drawing on insights from our empirical-phenomenological research on this issue (van Wijngaarden et al., 2015), this paper argues for a phenomenological perspective as a counteract for the medicalisation of death wishes in elderly people.

Phenomenology is a very broad concept, including a wide range of philosophical phenomenological stands and traditions which are distinctively listed and described by Max van Manen (2014). Van Manen also describes that from the early 1950s, Dutch scholars in the field of pedagogy, medicine and psychiatry – belonging to the so-called Utrecht School – had begun to apply a phenomenological approach towards their professional practices. This application of phenomenological methodology to specific concrete investigations within the human and social sciences was called the “human science phenomenology”. In his own “phenomenology of practice” Van Manen builds upon this tradition of the Dutch School. His phenomenology of practice distinguishes itself from philosophical phenomenologies in that it does not deal with theoretical philosophical issues but aims to describe professional and everyday practices and experiences. These phenomenological inquiries are meant to enrich and guide these practices and experiences and “nurture a measure of thoughtfulness and tact in the practice of our professions and everyday life” (van Manen, 2014). When we use the word phenomenology in this paper, we refer to such a “human science phenomenology” in line with the tradition of the Dutch School.
This paper is built up in three main parts. It will begin by presenting two vignettes to illustrate the differences between the psychopathological and the phenomenological understanding of an age-related wish to die. Then, three limitations of the psychopathological paradigm are described. In the last part, we will conclude that the phenomenological approach can be seen as a helpful guide for in-depth understanding of the death wishes in elderly people, especially in elderly people without a life-threatening disease or evidence of severe depression. We explore how a phenomenological approach can counteract the medicalisation of the wish to die in this group of elderly people. And we show how the application of phenomenological insights can be useful not only for healthcare practices, but also for policy.

2. TWO DIFFERENT APPROACHES
To highlight the fundamental distinction between the medical-psychopathological and the phenomenological perspective, two composite vignettes are presented as characterizations of the population at stake. Both vignettes are closely based on our previous empirical research (van Wijngaarden et al., 2016; van Wijngaarden et al., 2015). They describe the situation of a man aged 79, who terminated his own life because he considered his life to be no longer worth living. Vignette 1 describes the clinical, psychological and social factors related to this man’s suicide, while Vignette 2 provides a phenomenological description. We will refer to these vignettes throughout this paper.

**VIGNETTE 1—From a medical-psychopathological perspective**

Mr A. was a 79-year-old white, middle-class, widowed man who committed suicide three years after his second wife died. When he was 43 years old, his first wife committed suicide. Afterwards, he experienced a mild, self-limited, reactive depressive episode. At 49 years of age, Mr A. married again. At 58 years of age, Mr A. retired. He perceived the loss of work as a breakdown in the structures relevant to his life and a loss of status and meaning. In the years after retirement, Mr A. developed a mild alcohol dependence. He had great difficulties in accepting the limitations of old age. At the age of 72 years, Mr A.’s wife developed a course of illness, which worsened quickly. Mr A. himself was still independent in his activities of daily living and took care of his wife. At the age of 76, she died. After her death, Mr A. had trouble with moving on and restruc-
Vignette 1 describes the experience of Mr. A. as an abstraction from the immediate experiencing in favour of a theoretical, scientific explanation of the causal structure of such experiencing (Toombs, 1993). Vignette 2 contrasts with Vignette 1 in that it provides a representation of a phenomenological understanding, namely an attempt to disclose the manner in which the individual constitutes the meaning of his or her experience. On this phenomenological level of being-in-the-world, meaning is not analysable in terms of causal relations and explanations, but depends on the lived experience and interpretation of the person involved (Svenaeus, 2000).

**VIGNETTE 2–From a phenomenological perspective**

Alex – a 79-year-old, widowed man – lived in a permanent tension; his daily life was diametrically opposed to what he considered to be important throughout his life. During his life, he found meaning in making a contribution to society. His work gave him a sense of status. But after retirement, he slowly recognized that he became an outsider, feeling sidetracked: “Society doesn’t need me anymore. My life is of no consequence anymore.” After his second wife died, he not only lost his working structure, but also his family structure. He experienced this as a total breakdown of all ordinary life. Nothing was expected from him anymore. Although he still organized some activities, he strongly felt that...
everything he did was nothing more than “worthless futility”. To him doing something seemed the only way to kill time, but life became “utterly pointless” to him. The here-and-now evoked pervasive and dominating feelings of non-belonging and disconnectedness from life: “It is like the end of a curve, a vacuum, it is not my world anymore.”

He also had great difficulties in identifying himself with his deteriorating body. He strongly felt he was losing grip on his body, because things happened “beyond my control”, which evoked considerable uncertainty about (and fear for) further decline. Physically nothing was taken-for-granted anymore. The flow of life had gone. Formerly, his body was his ‘being-useful-in-the-world’, but it increasingly felt like an opponent. The bodily threats were sensed so severely, that a vision for a (promising) future was completely lost. While life went on, he could not connect to his actual life any longer. For him, it was not his life anymore, unable or/and unwilling to identify with it, because it was too uncanny, too alienated, too meaningless. Life was fundamentally questioned as a foundation for meaning, rather it had become an enemy. Alcohol remained his only friend, as it gave him a sense of peace and helped time passed by a little easier. More and more, he felt ready to give up on life, actively ideating on ways to hasten death and escape from these uncomfortable feelings forever.

Having described some important differences, we will now elaborate on three limitations of the medical-psychopathological paradigm.

3. THREE LIMITATIONS OF A PSYCHOPATHOLOGICAL PARADIGM ON THE WISH TO DIE IN ELDERLY PEOPLE

3.1. The risk of epistemic transformation
Due to the widening scope of medical practice, more and more intimate and personal aspects of people’s lives, personality and behaviour are defined in medical terms: “the personal has become medical” (Fitzpatrick, 2001). Medicalisation processes – and the associated epistemic authority afforded to medical institutions – are not only the result of expansion of medical (and pharmaceutical) institutions itself, but of a changing culture as well. In contemporary culture, medicine is put in a position of power, as medicine is considered to be in the position to make human problems and human suf-
Suffering real and legitimate, and that should provide explanation, treatment and alleviation. Simon Wessely – a Professor in Psychological Medicine – states in BMJ’s special issue on medicalisation that “the acknowledgement by a medical profession that a patient’s condition has a name and is a legitimate illness is immensely reassuring and enabling” (Wessely, 2002).

While medicine definitely has positive effects on people’s lives by enhancing well-being (and in some cases even by illuminating people’s first-hand medicalized experiences as Wardrope (2014) rightly argues), there are also situations where medicine seems to overstep its proper limits (i.e. the medicalisation of mood, existential suffering, aging and death). These forms of medicalisation entail an epistemic risk, as conceptual, epistemic transformation not only redefines but also re-designates human life. Phenomena that were previously regarded as social, moral or existential phenomena are now considered to be medical, problematic, and in need for medical care. ‘Normal’ human conditions transform into treatable disorders (Conrad, 2007). It follows that it is important to analyse whether the changing forms of rationality are sufficiently equipped to deal with the nature of phenomena or whether the changing rationality should be considered as a category mistake, prohibiting people to understand the real nature of their experiences.

According to Illich (2003) medicine is not at all sufficiently equipped, as he states that “by transforming pain, illness, and death from a personal challenge into a medical-technical problem, medical practice expropriates the potential of people to deal with their human condition in an autonomous way and becomes the source of a new kind of un-health” (Illich, 2003). He states that medicalisation undermines the “cultural rules with which the individual could come to terms with pain, sickness, and death.” It deprives man from “ethical standards needed to deal with the fragility of life”, and from explanations regarding “the reason for pain, the dignity of the sick, and the role of dying or death” (Illich, 2003). He suggests that “cosmopolitan medical civilisation denies the need for man’s acceptance of these evils”, but rather focuses on the elimination and management of pain, sickness and death, thereby replacing “the culturally determined competence in suffering with a growing demand by each individual for the institutional management of his pain”. Man ends up unable to cope with fragility as an integral part of his life and pain has become treatable, and consequently unnecessary and meaningless. “The new suffering has lost its referential character” (Illich, 2003).
While Illich (2003) designates this harmful power of medicine to reshape our collective concepts and our individual experiences as “medical nemesis”, Fricker (2007) describes it as a form of “epistemic or hermeneutical injustice” (Fricker, 2007). She argues – largely in line with Illich’s arguments – that medicine prevents people from having suitable hermeneutical resources available to interpret and communicate significant areas of their experience. 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.

Applied to the medicalisation of the age-related wish to die, this could mean that this wish to die is probably not well understood in merely psychopathological terms. The struggles, the experienced contingencies, and the crisis in meaning probably should be approached as an existential challenge rather than be defined as a psychopathological disorder. Although suffering (also suffering that goes along with aging and accompanied dependence and deterioration) is often unpleasant, undesirable and difficult, in a way it can be conceived as a intrinsic – and perhaps even essential – part of human life.

3.2. The risk of reduction
Without trivializing the success of psychopathology, the need for good diagnostics, and the importance of an objectifying view in some cases, many phenomenologists address the profound downside of such a medical-psychopathological approach. Psychopathology is seen as a reducing attitude towards human nature: it is diagnostic, abstract, objectifying and theoretical in order to view and construct the world, providing explanations for disorders and diseases and developing effective and evidence-based therapies (Svenaeus, 2000; Svenaeus, 2011; Todres, 2008; Todres et al., 2014; Todres et al., 2007; van Manen, 1998; Finlay, 2011). Diagnostic classification schemes and symptom scales are ways to ‘frame’ the behaviour the patient. Phenomenology criticises the prevailing external view on the person and the tendency to consider man as a purely biological object, a living space of functions, with a primary interest in genetic, biological, psychological and social factors.

This objectifying, instrumental and problem-oriented view on people’s life and their worries and complaints, however, might undermine people’s own logic and subjective truth. The focus is not on the experience of life, but on
a reducing model of life. The wish to die, for example, might be reduced to a result of a potential mental disorder, tending to classify people into nomo-
thetic categories, defined by clusters of symptoms, prevalence, and risks. This focus on diagnostic language, however, strengthens a negation (or de-
nial) of the lived experiences and people’s subjective truth (Goossensen and Oude Egberink, 2013). Therefore, phenomenologists point at the impor-
tance to make an ontological shift from the main conceptions of medicine and psychopathology towards a phenomenological understanding. They argue that mental states are never abstractions, but reveal themselves in the reality of the surrounding world, of objects, and of personal relationships (Svenaeus, 2000; Svenaeus, 2011; Todres, 2008; Todres et al., 2014; Todres et al., 2007; Finlay, 2011; Toombs, 1993).

To analyse meaning and meaninglessness, and to describe how an individ-
ual constitutes meaning one needs knowledge about people’s lived experi-
ences, individual’s intentions and beliefs, and one’s social context.

It is the presence of the situation, projects, which gives meaning to sensory stim-
uli and causes them to acquire importance, value or existence for the organism. Perception cannot be divorced from a concrete situation. Every sensible qual-
ity not only exists within a specific milieu but is determined and defined with respect to the task at hand. Consequently, bodily acts must be understood in terms of their being acts which take place within a certain situation having a certain practical significance for the embodied subject (Toombs, 1993, 53).

Subsequently, phenomenology represents an attempt at the explication of meaning of the everyday, contextualized experience itself. It abstains from making any ontological claims about causality, but rather tries to study the way life is lived. It views the person as a human being rather than as an object of investigation and diagnostics, accordingly fostering “an embodied ontol-
ogy” (van Manen, 2014), a thick understanding from an insider perspective, an attuned sense of how things are for the person (Todres et al., 2014).

We can clearly see from Vignette 1 and 2 that the two approaches disclose a fundamental distinction. The clinical case report is an attempt to classify the wish to die through investigation based on objectified symptoms. It de-
picts what Martinsen calls ‘the recording eye’ (Martinsen, 2011) which puts the viewer in an outside position.
When we record, we systematize and differentiate, albeit within the frameworks of an already existing conceptual system. The recording eye is reductionistic and neutral; it may reduce living characteristics (Martinsen, 2011).

In contrast, the phenomenological description is rather an attempt to describe the inner perspective of the human being as a person trying to clarify ‘the sense-structure’ of the wish to die in order to gain an ‘attuned understanding’. It directs our attention towards Alex’s lived experience, by adding a more exploratory level that addresses questions of how the age-related wish to die is lived; what do the day-to-day struggles exist of? It elucidates the experiences underlying the age-related wish to die. This is what Martinsen calls ‘the perceiving eye’ which is characterized by openness towards the world by which “we are touched and emotionally involved before we understand the needs of the other” (Martinsen, 2011).

Thus, in order to understand what it means for Alex to live with a wish to die, it is not enough to know the facts and symptoms. Although this abstract knowledge is quite important, openness towards the very meaning and character of the acts he performs is crucial to become more sensitized towards underlying needs and reach deep understanding (Todres et al., 2014). Indeed, reduction might led to ‘mismatch’ between the conceived idea of the health professional about the problem at stake and the real perceived needs and concerns of the older person with an age-related wish to die. If we want to understand a person’s lived experience, we need a phenomenological understanding which is not primarily cognitive, intellectual and technical but rather pathic, which means situated, relational, embodied and enactive (van Manen, 2014).

By underestimating this pathic knowledge, the medical-psychopathological model might fail to sufficiently recognize and validate the existential concerns and suffering of these elderly people.

3.3. The risk of obscuring the social and cultural embeddedness
The psychopathological paradigm strongly tends to focus on the wish to die as being a merely individual problem, deriving from a dysfunctioning mental state. As mentioned before, the focus is mainly on the assessment of symptoms and evidence of disorders. This individualised interpretation, however, contains the risk of ignoring the social and cultural embedded-
ness of this wish. This is problematic because a phenomenon is never to be fully understood apart from its directedness to its world context, as social and positional aspects strongly influence the human existence. The focus on individual pathology might marginalize and obscure society’s dysfunctions. Only by taking the contextual situatedness into account – as the mode of being in the world – we can understand human existence more comprehensibly, illuminating what possible social and positional aspects might have an influence on the development of a wish to die.

Phenomenology instead is highly sensitive to the contextuality of situations, reciprocities, relationships, and involvements. No object or person is perceived as insulated, but rather comprehended as a being-in-a-context (Toombs, 1993). To be a person, to be an individual, a self, means to be someone with a certain history, related to history of other persons and social and cultural institutions (Svenaeus, 2000; Dahlberg, 2006). An individual cannot be separated from the social world in which he lives. There is no such thing as a “frozen existence” (Dahlberg, 2006). An object or person always appears within a social world and cannot be fully understood apart from its situatedness within – and its directedness towards – its world context. In its directedness towards the world an object or person exhibits a certain “intentionality”, which is explained by Toombs (1993) as: “intentional threads linking it to the surrounding world”. Lived experience is thus not only coloured by people’s biographical situation (manifesting itself in individual preferences, intentions, motives, desires, religious and ideological beliefs) but also by particular ethnic and social, and culturally specific meanings. How life is regarded and evaluated also depends heavily upon the shared understandings of a particular social group. Contextual situatedness is the mode of being in the world (Svenaeus, 2000; Toombs, 1993).

Applied to the death wish in elderly people, this means that we should take into account that the wish to die in elderly people has an effect on the social world, and the social world has an effect on (the development of) the wish to die. In order to more comprehensively understand ‘the real-life’ experience of wish to die, we should explore this reversibility of existence, and reflect on questions like: What possible social determinants might have an effect on elderly people’s well-being, which we create and maintain collectively? Questions like these might illuminate what possible social and positional aspects might have an influence on the development of a wish to die; and
help to get a sense of what ethical issues might be at stake and should be addressed within society. Looking from this perspective, the expressed needs – e.g. experiences of marginalization, social exclusion and indignity (van Wijngaarden et al., 2014) – might serve as a drive for debate within culture rethinking the place and role of elderly in society. The experience of ‘disconnectedness from life’ (see Vignette 2) probably is not merely an outcome of a private, subjective experience, but it might illuminate something that is happening within society. This might, for example, imply that the suffering which accompanies increasing deterioration and age-related problems is not solely related to the actual loss of function, but also affected by the person’s recognition of a devaluation in status reflected in cultural values (Toombs, 1993). Indeed, if we fail to take this contextual situatedness into account, there is a risk that the medical-psychopathological paradigm individualizes caution and (unintentionally) might social problems masquerade as individual problems.

3.4. An enriching counteract for the medicalisation of the wish to die

Based on the limitations described above, there appears to be ample reason to be alert to the negative effects of a merely medicalised view on the wish to die. Thus – again without meaning to disparage the need for good diagnostics of suicidality and depression – the authors argue that a phenomenological approach can counteract the medicalisation of the wish to die by providing an existential view of well-being that functions harmoniously with the human existence, due to its careful attention for the lived experiences of individuals, and their (social and cultural) situatedness. For people like Alex, it is even more important to look from a phenomenological perspective, as the psychological point of view provides no adequate explanation for his self-chosen death. While there were some indications for depressive feelings and coping problems with old age, there was no evidence of any psychopathological disorder (See Vignette 1). In fact, Alex himself strongly rejected the idea of being pathologically driven. He thought of himself as being a ‘normal’ citizen with a ‘sound’ wish to die, and not in need for any psychological treatment. Therefore, to explore appropriate ways of supporting people like Alex who are ideating on a self-chosen death, it is a prerequisite to stay in close connection with their lived experiences, trying to sensitively align support to their real needs. Their expressions of deep sorrow probably are not merely indicative of a clinical depression but rather of ‘non-pathological’ existential suffering.
4. PHENOMENOLOGY AS A GUIDE FOR PRACTICE AND POLICY

Many authors have discussed the applications of a phenomenological approach to medical and clinical training and practice. For example Carel (2011) underlines its usefulness for professionals in representing the reality of the patient's experience and perspective to them, in order to overcome the gap between the different forms of understandings and approaches between patient and professional (Carel, 2011). She also argues phenomenology could be used to monitor and enhance overall experiences of people with health care systems (Carel, 2011). And besides, she argues that phenomenology could prove useful for patients, giving them tools to reflect on and expand their understanding of their illness, helping them to philosophically examine their illness, its impact on their life, and its meaning (Carel, 2012). In line with Carel (2011), many phenomenological authors have showed how phenomenology can be fruitful in interpreting patient’s first-person perspectives, not only in research but also in practice (Todres et al., 2014; Ashworth, 2003; Svenaeus, 2000; Svenaeus, 2011; Slatman, 2014). Some specifically focus on its ability to enhance the communication between the professional and the patient (Toombs, 1990; Toombs, 1993) or its potential to humanize health care (Todres et al., 2009; Dahlberg et al., 2009; Todres et al., 2007).

However, there seems to be less literature on how phenomenology can inform policy and politics. We argue, though, that an appropriate policy response to the very real human problems requires a phenomenological perspective as well. There are some good reasons for this. Firstly, phenomenologically informed insights might help policy makers to become more sensitized to the multifacetedness of issue of the wish to die in older people. Phenomenology advocates the need for complexity rather than abstract knowledge. Politics which are mainly based on abstract, objective and measurable knowledge (such as statistics and figures) might lead to neglect of people’s lifeworld, limited understanding of the issue at stake, and poor alignment of policy to the concrete, real-life needs, concerns and struggles of people. This is illustrated by a phenomenological study of Van der Meide et al (2014) into the lived experience of older people in a Dutch hospital: According to policy makers, the client council was a suited tool to promote elderly participation, but Van der Meide’s research shows that in the hospital the lived experiences of elderly people aged 70+ are largely neglected (van der Meide et al., 2014a; van der Meide et al., 2014b). This also applies to the issue of elderly and the self-chosen death. In order to develop careful
and responsible policy for the specific group under study, and to ensure that these policies are aligned to real-life problems, it is an imperative to attempt to comprehend the way in which realities and problems are actually lived by these people.

Secondly, rich phenomenological descriptions also can perform proto-ethical work in forming thicker accounts of the ethical issues that are investigated and judged upon by normative ethics. Shlomo Cohen (2011) makes an argument about pre-requirements of moral thinking, which would lead us towards the object of our inquiry. “The general idea is that in order to function meaningfully, ethics needs a shared background of basic intuitions and dispositions regarding the human life form, or in other words, regarding our humanity” (Cohen, 2011). Cohen states that “in order to make sense moral reasoning must be preceded and supported by an acknowledgment of certain givens of human existence”. He also refers to Frederick Olafson who wrote a book about proto-ethics – Heidegger and the Ground of Ethics – in which he points at the proto-ethical character of phenomenology, arguing that an ontology of human relations “constitutes the ground of ethical authority” (Olafson, 1998). For a careful ethical debate (in politics and public), phenomenological descriptions of the wish to die in elderly people reflecting the lived reality and morality are thus an imperative.

And lastly, a phenomenological approach recognizes the contextual situatedness of a wish to die. When an increasing number of elderly people develops an age-related wish to die, this definitely affects the surrounding social world, but the social world also has an effect on the development of the wish to die. Policy makers should acknowledge this reversibility of existence and address the issue at stake at all levels.

So to conclude, from a phenomenological understanding of the wish to die, as presented in this article, arise several important political implications. Phenomenological insights might help to take up the complex real-life concerns and needs of these elderly people, to further the alignment of (new) policy with the existential and social dimension of human life, and form a basis to evaluate and further the humanisation of existing policy and practice.
REFERENCES


Rurup ML, Onwuteaka-Philipsen BD, Jansen-van der Weide MC, et al. (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: 157-166.


CHAPTER 8

The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living

(in review)
ABSTRACT
In the Netherlands, physician-assisted dying has been legalized since 2002. Currently, an increasing number of Dutch citizens is in favour of a more relaxed interpretation of the law. Based on an ethos of self-determination and autonomy, there is a strong political lobby for the legal right to assisted dying when life is considered to be completed and no longer worth living. Building on empirical research, this paper provides a critical ethical reflection upon this social issue. The descriptive part of this paper will discuss a question that is important for many Western countries, namely: What is the lived experience of older people who consider their lives to be completed and no longer worth living? Next, the normative part will analyse and clarify the question whether (physician) assisted dying can be seen as an appropriate societal response to the needs of this specific group by discussing the notions of autonomy, vulnerability, (in)dependence and dignity and rethink these notions from a care-ethical stance. This paper inductively points out some important social-political challenges behind the wish to die in older people. The authors 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, but on how to build an inclusive society where people might feel less unneeded, useless and marginalized.
1. INTRODUCTION
We are in the midst of some major demographical transitions. Declining fertility rates and increased life expectancy are important determinants for an ageing society. Life, ageing and dying have been prolonged. In order to attain successful ageing, emphasis is put on minimising physical and mental deterioration and disability, on life satisfaction, social participation and functioning, and on psychological resources (Bowling and Dieppe, 2005). Despite all efforts, old age is often increasingly accompanied by physical and mental age-related problems. These problems have an influence on the perceived well-being, threatening meaning and purpose (Kellehear, 2007). Older people may experience a shift from the benefit of living longer towards the suffering of living too long (van Rein, 2013). Being excluded from participation in mainstream social life, they may consider themselves to be ‘socially dead’ before they are biologically dead (Seale, 2000). It is argued that longevity and accompanied age-related problems – among other things – have constituted the awareness of determining time and manner of death and dying in the whole Western world (Chabot and Goedhart, 2009; Seale, 2000; Kellehear, 2007; Pool, 2004; van Rein, 2013). Indeed, in the Netherlands, an increasing number of citizens can imagine appreciating physician-assisted dying (PAD) in case they would suffer from old age, even if they lacked any classified medical condition (Ross, 2015; Buiting et al., 2012; Raijmakers et al., 2013).

Since 2002, PAD has been legalized in the Netherlands under strict requirements laid down in the Dutch Euthanasia Act. Notably, the Dutch law does not distinguish between physical and psychological suffering: the suffering does not need to have a diagnosable origin. Euthanasia is an option for people ‘who suffer unbearably and without any prospect of improvement’. However, in 2002, The Dutch Supreme Court ruled that a doctor who helped an older man ‘tired of living’ to die was found guilty of assisted suicide: this was called ‘The Brongersma-case’. This ruling is seen as upholding guidelines for PAD in the Netherlands: it is only permitted in cases of unbearable and hopeless suffering stemming from a medical condition (Huxtable and Möller, 2007; de Vries, 2004; Sheldon, 2003). In most cases of tiredness of life, it is very difficult to prove whether the suffering is irremediable and thus hopeless from a medical perspective (Raus and Sterckx, 2015; Rurup et al., 2005). It follows that under current legislation, most of the older people tired of living are not in the position to have a legal right to PAD. Indeed,
recent research has shown that most Dutch physicians find it inconceivable that they would grant a request for euthanasia from a patient who is tired of living (Bolt et al., 2015).

Currently, however, the Dutch end-of-life debate continues progressively and the public opinion is shifting. In 2010, the Dutch initiative group ‘Of Free Will’ started an influential campaign and placed the discussion about ‘older people and a self-directed death’ high on social and political agendas (van Rein, 2013). They argue that people aged 70+ who have come to the well-considered conclusion that the quality of their lives has deteriorated to such an extent that they prefer death over life, should have legal options for PAD or a non-medical assisted suicide, even if they do not suffer unbearably from a classified medical condition. They thus made a plea for further relaxation of the legal requirements, advocating that people’s personal judgment should be decisive, rather than the professional judgment of the physician. In 2014, in response to this civil initiative, a Committee of Wise People was established by the Dutch Government to explore the legal possibilities and the societal dilemmas with regard to PAD and non-medically assisted suicides in cases of ‘completed life in old age’ (Pike, 2010). In February 2016, this committee presented its report (Schnabel et al., 2016). Following this report, the Dutch government will thoroughly discuss this topic in Parliament in the course of 2016.

Ever since the Dutch have been embroiled in a heated debate as to whether or not to further extend the freedom of choice in end-of-life issues, remarkably very little empirical research has been done into this specific phenomenon of ‘completed life in old age’. In order to develop a careful and morally responsible policy for this specific group of older people, it is a prerequisite to first gain deeper understanding of this phenomenon. 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 (van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015d; van Wijngaarden et al., 2016).

Subsequent to our empirical work, this current paper provides an ethical analysis of the issue of older people and the self-directed death. With this ethical reflection, we aim to nuance and critically reflect on the current
social and political debate. This paper is divided into a descriptive and a normative part. Firstly, by using the Dutch situation as our case study, the descriptive part will discuss a question that is important for many Western countries, namely: What is the lived experience of older people who consider their lives to be completed and no longer worth living? This part draws heavily on our empirical research work (Cohen, 2011; Olafson, 1998) that is considered as constituting a ground for the ensuing normative reflection (Leget et al., 2009; Molewijk et al., 2004; Kon, 2009; Widdershoven et al., 2009). Secondly, the normative part will analyse and clarify the issue at stake. From a care-ethical stance, we will discuss the notions of autonomy, vulnerability, (in)dependence and dignity in relation to one other. We will conclude by critically examining the question as to whether the opted regulation of (medically or non-medically) assisted dying can be seen as a morally appropriate societal answer to the issue of ‘completed life in old age’.

2. DESCRIPTIVE ACCOUNT
This part of the paper concerns a description of the phenomenon and the people concerned. First, we will give some definitions of a so-called ‘completed life’. Next, we will provide a description of the lived experience of older people who consider their lives to be completed and no longer worth living based on our own empirical research. These descriptive empirical accounts serve to provide evidence and constitute a ground for the care-ethical considerations further on in this paper.

In 2001, during the Dutch parliamentary debate on the euthanasia legislation, the issue of ‘completed life’ was defined as:

_Without having an unmanageable disease or ailment paired with profound suffering from a medical point of view, the situation of these people of an advanced age makes them feel that the quality of life has diminished to such an extent that they prefer death over life._

In 2004, a committee on behalf of The Royal Dutch Medical Association performed research relating to the physician's role in cases of suffering from life. They came up with a revised description as they concluded that the level of suffering and despair in the lives of the people concerned was underestimated in the definition of 2001. Their definition is:
Suffering under the prospect of having to continue life at a profoundly diminished level of quality, which results in persistently recurring longing for death, without being able to determine a somatic or psychological reason (Dijkhuis et al., 2004).

In 2010, the initiative group Of Free Will defined ‘completed life’ as:

The position wherein an older person has come to the conclusion that the value and meaning of his life has diminished to such an extent that he has begun to prefer death over life, resulting in an explicit and lasting death wish (Beekman, 2011).

In addition, the Right-to-die NL made a list of age-related factors that constitute what they call a ‘completed life’:

- non-threatening ailments;
- bodily decline (poorer mobility, vision and/or hearing, tiredness, listlessness, incontinence) leading to loss of active life participation, loss of independence and personal dignity;
- dependency on care (one does not want dependency and becoming a burden to family, close friends or the community)
- loss of status and the direction of one’s own life;
- declining social network (caused by the death of a partner and/or children, friends and neighbours);
- loss of future and purpose;
- detachment from the community (the loss of the bond with people, the material aspect and the ‘world of now’);
- fear of the future;
- absence of prospects.

The Right-to-die NL has complemented this list of factors with the remark that – based on one or more factors – ‘one may come to the conclusion that life has been lived and, therefore, life should come to an end’. They further state that it is also conceivable that ‘people may want to avoid one or more of the above factors, such as bodily decline, becoming dependent on others and loss of direction, and conclude that their lives have been already completed’ (Peters, 2010).
Our own empirical research – which has already been published – has shown that the essential meaning of the phenomenon is understood as ‘a tangle of inability and unwillingness to connect to one’s actual life’. Daily experiences have become increasingly incompatible with people’s self-esteem. They attempt to resist an inevitably growing dependence and to preserve their remaining independence. Always having perceived themselves as proactive, independent people, their resistance is strengthened by beliefs and character. Even though everyday life continues, people feel as if their lifestory has already ended. Life is not over, but the lifestory is considered so. While feeling more and more disconnected to life, a yearning desire to end life is strengthened (van Wijngaarden et al., 2015a). The experience of disconnectedness is further explicated in five constituents: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion to feared dependence (van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015b).

Additionally, people’s self-evaluations proved to have a distinct social dimension: older people’s sense of indignity and unworthiness appears to be partly rooted in feelings of societal ignorance, marginalization and exclusion. Indeed, our empirical work has disclosed a profound sense of mistrust: the older people under study show a lack of trust in sufficient care arrangements. Concerns and anxieties are expressed about the adequacy of care resources in our society (van Wijngaarden et al., 2016). They also seem to lack the assurance that others would properly take care of them when they become utterly dependent; they prefer to safeguard themselves by performing a self-directed death (van Wijngaarden et al., 2016).

Further, our findings have nuanced the common assumption that the wish to die associated with a ‘completed life’ mainly stems from an ethos of self-determination, autonomy and reasonability (van Rein, 2013). Rather than being a calculative, coherent sum of rational consideration, these evaluations emerged as considerable existential challenges permeated with ambiguities and ambivalences: on the one hand, the wish to die was indeed driven by the great value that the older people concerned attach to independence and autonomy, but it was also strongly influenced by fears, sadness, loneliness and feelings of unworthiness (van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015b; van Wijngaarden et al., 2016).
3. NORMATIVE ANALYSIS

What follows now is an ethical analysis of the issue of a so-called ‘completed life’. As has already been described in above’s descriptive account, at first sight, ideating on a self-directed death in old age can be interpreted as a way to retain or regain control, and safeguard one’s so-called personal dignity: the older people concerned want to stop the declining process which is experienced as humiliating. At closer look though, the picture becomes far more complex. The wish for a self-directed death seems to arise from an ambivalent struggle with vulnerabilities and unmet needs which we define as ‘the things we cannot do without, things without which our life is seriously harmed or vitally impaired’ (Mackenzie et al., 2014; Reader, 2005; Wiggins, 2005). Below, we will first describe how autonomy, dignity and dependence play a role in the lives of the people under research. Next, we will rethink these concepts from a care-ethical stance.

3.1.a. Autonomy at risk

In general, people’s self-understanding is deeply influenced by what Taylor calls ‘modern social imaginaries’, defined as ‘the way people imagine their social existence, how they fit together with others, the expectations that are normally met, and deeper normative notions and images that underlie these expectations’ (Taylor, 2004). A powerful ‘social imaginary’ of most older people under research – like many Western citizens – is that they perceive the self-disciplined, independent, successful, entrepreneurial agent as the cornerstone of society, and economic productivity as the cornerstone of a new ethic. Independence and agency are not just seen as personal ideals. They are social ideals as well, contributing to national well-being and harmonious coexistence, hence something to strive for (Taylor, 2004). One of the main interests of the people under research is thus to maintain autonomy and independence. During their lives, most have attached great value to the ability to run their own affairs without interference from others as much as possible. They often highly valued work and personal projects: one’s public contribution to society is viewed as one of the most important goals in life. Consequently, ageing, the increasing deterioration of health and other age-related vulnerabilities threaten their sense of agency. They resist the idea of being vulnerable and fragile, as this is conceived to be incompatible with full autonomy. Vulnerability in old age is strongly associated with qualities such as weakness, helplessness, victimhood and humiliation (van
In their view, it puts their autonomy at risk.

### 3.1.b. Dignity at risk

Ageing, the increasing deterioration of health and other age-related losses not only threaten their sense of autonomy. For the majority of the people under research, their sense of dignity is also affronted. This stems from a life view in which dignity is closely related to one’s capacities, behaviour and ability to act competently (van Wijngaarden et al., 2015a). For them, dignity is – for a significant extent – about autonomy, independence and competence. In this view, only when you are able to govern your own actions and to behave reasonably, humanity is fully realized. A side effect of this self-understanding is that when people become increasingly dependent, needy, and economically unproductive, they feel judged by society and by themselves. They view – and may experience – dependency as a reprehensible, undignified, and character-destroying condition, a breach of humanity (van Wijngaarden et al., 2015a). It contradicts their values or commitments, their ideas of who they are, and who they ought to be. This has a profound impact on people’s identities. People might view themselves below their personal standard, or even as ‘less of a somebody than somebody else’ (Tronto, 2013; Tronto, 1993).

Regarding the people under research, the loss of dignity is thus closely associated with the loss of agency and competence. In addition, they also associate a sense of indignity with the loss of belonging and connection (Galvin and Todres, 2014) and recognition (van Heijst, 2011). Our empirical accounts are full of the strong human desire of being visible, recognized, wanted, needed, valued, missed, depended upon, or attended to by others (van Wijngaarden et al., 2015a). However, in everyday life, most older people under research completely lack the feeling of mattering within a community in a mutual way. Their concerns are reflected in experiences of marginalization and social exclusion, of loneliness, and the feeling of being disrespected (van Wijngaarden et al., 2015a). They consider their lives to be unworthy and undignified, not only in their own eyes, but also in the eyes of others, of society.

### 3.1.c. Independence versus interdependence

During our empirical research an interesting paradox emerged, namely that the older people concerned think of themselves as being autonomous, in-
dependent and self-determined agents who run their own affairs, and are capable of making rational choices (i.e. when and how to terminate life). Simultaneously though, they experience themselves as highly interdependent, vulnerable and needy as well (van Wijngaarden et al., 2015a). Faced with considerable existential challenges, their experiences reflect the ambiguity of everyday realities: On the one hand, the wish to die is driven by the great value they attach to independence and autonomy. On the other hand, it is also strongly influenced by anxieties, fears and unfulfilled needs. While they want to run their own affairs without interference from others as much as possible, paradoxically they simultaneously present themselves as being highly dependent on others when it comes to their well-being. However, they have difficulties accepting this ambiguity as part of life; rather, they strongly resist this.

The group of older people studied not only resists facing dependency upon others due to their life view. They also do not dare to face dependency upon others because they lack the assurance that others would take care of them properly, take care of their wishes, and respect their physical integrity (van Wijngaarden et al., 2016). They fear that others might take over control of their lives ‘by deciding what is best’ for them ‘without taking into account’ their wishes; there is ‘no absolute assurance’ that their family would safeguard their interests; a physician ‘might probably force’ them to undergo (life-prolonging) treatment against their will; their requests to terminate life ‘might not be respected’ (van Wijngaarden et al., 2016). There seems to be a certain absence of relations of trust, and a presence of negative perceptions and experiences.

These concerns of the older people are highly sensitive towards the fact that care is often not an activity between equal agents. Professional and informal caregivers might have their own ideas of what is necessary to meet the needs of those older people. The older people themselves sense (or expect) this care relation to be distinctly negative; compromising their agency, fearing to be paternalized or even infantilized. This concern shows that to be dependent on others, to accept others caring for you, requires a certain degree of trust that others will not impose their beliefs on you. If people do not trust other people, they do not want to be dependent. Most older people under research seem to lack trust that their autonomy can be fostered through (informal or professional) relationships of trust, respect and recognition.
The loss of control and the lack of confidence in tailored assistance and care strengthened the wish to safeguard themselves, trying to make themselves unapproachable to potential patronizing (van Wijngaarden et al., 2015d; van Wijngaarden et al., 2016).

### 3.2. A complicated issue

Acknowledging the tension between independency and dependency is crucial for a thorough understanding of the issue of older people and the self-directed death. It points at an apparent perceived discrepancy between cognitive thoughts and experience. On the one hand, the older people under research positioned themselves as autonomous rational beings, highly in favour of relaxation of the law, and being convinced of the persistence of their wish to die. On the other hand though, they also exposed themselves as vulnerable and dependent people, suffering from life and unmet needs. This raises a highly important question: How to deal with this discrepancy when making careful policy, as it seems to uncover that the wish for a self-directed death might be – at least partly – a desperate attempt to escape a perceived undignified life, driven by needs, anxieties and a sense of not mattering, loneliness and mistrust?

What makes the issue of ‘completed life in old age’ even more complicated is that our empirical research has clearly shown that it is not just an individual assessment of the quality of one’s life, it is also an assessment of the quality of one’s life through the eyes of others, of society. If we collectively think that autonomous agency is one of the defining characteristics of personhood, then what follows from this is that to be exceptionally vulnerable is to lack the traits of full personhood (Tronto, 1993; Tronto, 2013; Scully, 2014). It seems that the idea that life is no longer worth living is partly constituted by a societal idea that old-age dependencies seriously compromise one’s autonomy and dignity (van Wijngaarden et al., (in review); van Wijngaarden et al., 2015a; van Wijngaarden et al., 2015a). If we want to properly address the issue of completed life, it seems inevitable to address these societal influences and attitudes as well.

### 3.3. Rethinking ‘completed life’ from a care-ethical stance

Since care ethicists try to conceptually clarify what happens in everyday life from a bottom-up perspective, care ethics provides a fruitful framework to analyse the experienced ambivalence between independence and
dependence, between autonomy and vulnerabilities, and between cognitive thoughts and (much more fuzzy) experiences. Based on close empirical observation of how life is lived, care ethicists go beyond these perceived dichotomies. Rather than explaining away ambivalent tensions, they try to understand them as interwoven, entangled parts of reality, inextricably connected to life-as-it-is. Besides, care ethics points at the primacy of addressing human needs (rather than individual interests and rights) as needs that are a prerequisite of agency and a better foundation for responsible social thinking than human rights (Mackenzie et al., 2014; Reader, 2005; Wiggins, 2005; Tronto, 1993). To think from a perspective of needs is necessarily inter-subjective and cultural rather than individual. Needs are a matter of social concern (Tronto, 1993). Hence, being an evaluation of people’s experiences within society, a need points out the political-ethical dimension of a phenomenon that needs to be acknowledged and addressed (Sayer, 2011). This requires an investigation of what is happening in the lives of older people who consider their lives to be no longer worth living. What exactly matters to them? What are the underlying needs at stake? Attention to such contextual details and the (social and historical) particularity of practices can safeguard and promote the actual needs of those involved. Accordingly, we will now look at the issue of completed life in old age from a care-ethical stance in search of further clarification of the ambivalences and the (unmet) needs associated with this matter.

3.3.a. Dependence, vulnerability and autonomy
As mentioned before, becoming increasingly dependent on direct or indirect assistance from others gives the people under research a sense that they no longer belong to ‘the world of agency and choice’ (Lange, 2015). They are no longer able to fully determine the course of their lives. Autonomy is thus seen as the capacity of an individual to make and affect rational, self-determined choices; an ideal of the free, independent, and self-sufficient individual. In this perception, autonomy and dependence are opposites (Scully, 2014).

Care ethicists have criticised this specific explanation of autonomy and the representation of the human subject as a unified, autonomous self (Gilligan, 1982; Tronto, 1993; Tronto, 2011; Walker, 2007). Autonomy should not be thought of in terms of self-determination or self-management, but rather as a process of self-realization in which others play a crucial role (de Lange,
Indeed, they challenge the idea that vulnerabilities and dependencies are necessarily incompatible with autonomy (Mackenzie et al., 2014). In line with Ricoeur and Taylor (Ricoeur, 1994; Taylor, 1989) among others, care ethicists argue that humans are born in the condition of dependence and remain dependent upon others – varying from a smaller to a larger degree – throughout their lives. Clearly, care ethicists underline that autonomy should be recognized as an important normative idea for our social order, providing the necessary conditions for self-respect and self-agency and to protect people from paternalism (Tronto, 1993; Verkerk, 2001; Dodds, 2014). Yet they understand autonomy in a relational sense, acknowledging the networks of interdependencies within which people are embedded not as compromising choice and action, but as providing the conditions of the possibility for them. Thinking of humans as being interdependent is as integral to humanity as are the capacities of self-control, reflective and rational reasoning (Tronto, 1993; Walker, 2011; Walker, 2007). In this view, dependency is an indissoluble part of autonomy rather than a treat.

Notably, our empirical work confirms this care-ethical idea, and has demonstrated the inadequacy of the ideal of self-sufficiency based on the conception that a good life is a life in which we do not require the help or support from others in addressing our needs and carrying out our life plans (Verkerk, 2001). In their minds, the older people under research may have held the idea that they have been independent throughout their lives, however, at this stage of life, this ‘social imaginary’ lacks to provide them with a proper self-understanding, leaving them behind in a dichotomized tension, and questioning their full humanity. It seems that care ethics provides an understanding that is much more consistent with life-as-it-is-lived. These tensions are inherent to all human life. Indeed, the self can only be developed in interaction with others, being dependent on reciprocity and recognition, and constituted through and mediated by intersubjectivity (van Nistelrooij, 2014).

3.3.b. Shared vulnerability
Care ethicists also dispute the dichotomy between vulnerable groups and non-vulnerable groups. Rather than restricting vulnerability to some specific lives, certain contexts or circumstances, vulnerability is primarily seen as the capacity to suffer that is inherent to all human beings due to our embodied, social and affective nature (Dodds, 2014; Mackenzie et al., 2014;
Scully, 2014). Whilst it is not obscured that some people are more vulnerable than others, care ethics starts from the empirically substantiated notion of shared vulnerability. Furthermore, it points out the moral need to make a distinction between inherent and situational vulnerabilities (Mackenzie et al., 2014; Scully, 2014; Dodds, 2014). This means that some vulnerabilities are recognised as inherent to (i.e. old-age) impairment (such as degenerative processes, pain, fatigue and age-related losses), directly affecting health and well-being. Other vulnerabilities though are situational vulnerabilities, which means that they are context-specific (such as loneliness, marginalization, social exclusion, forced relocations). Among others, Scully (2014) argues that although the presence of impairments undeniably plays an important role, possibly the major impact on people’s lives is mediated through social, positional and institutional aspects that could be organised differently. Political, social, or attitudinal changes might at least decrease these (situational) vulnerabilities.

3.3.c. Normal and stigmatized dependence

As mentioned above, care ethicists recognise intrinsic dependence as crucial for human self-understanding (Dodds, 2014; Mackenzie et al., 2014; Scully, 2014; Kittay, 1999). Scully extends the idea of dependencies by making a distinction between what she calls ‘permitted dependencies’ (referring to the network of dependencies for food, light, heat, housing, communication, friendship, education, transport, rubbish disposal and health care, among innumerable other things) and ‘non-permitted dependencies’ (referring to stigmatized forms of dependence). She states that permitted dependencies refer to ‘needs that are so ubiquitous and so much a part of contemporary life, that they are not even seen as dependencies.’ These dependencies are ‘naturalised and normalised, met and supported without question, while the vocabulary of vulnerability is never used’ (Scully, 2014).

In order to enable people to live a good life, all need relationships of care to meet their (permitted) dependencies. While these ‘ecologies of interdependencies’ are not at all ‘a matter of rational contract or balanced exchange of services between equals’, but inevitably asymmetric, there is still a kind of mutual (and often voluntary) cooperation (Kittay, 1999). A core problem in the lives of the people under research is that they increasingly lack any sense of mutuality and reciprocity. Dependency has become a one-way dependency: they feel that they cannot do anything meaningful
in return, which is experienced as a humiliation but it also enhances feelings of senselessness. It is this one-way dependence that is strongly rejected and stigmatized, not only in the minds of these older people but also in the negative deficit-oriented societal discourse on ageing (Hockey and James, 1993; Featherstone and Wernick, 1995; van Wijngaarden et al., (in review); Behuniak, 2011).

In line with Scully, we think that it depends a great deal on societal responses to impairment whether these accompanied vulnerabilities and dependencies are experienced as profoundly negative or relatively trivial (Scully, 2014). Accordingly, there might be a risk that conceptualising the dependencies associated with old age as ‘undignified’ will lead to a vicious circle of negative stigmas. In the Netherlands, there is a growing societal approval that the suffering from age-related dependencies in some cases can be ‘best resolved’ by assisted dying if people prefer so (Schnabel et al., 2016; van Delden et al., 2011; van der Heide et al., 2014). It is not inconceivable that such an approval might enforce feelings of indignity and social marginalisation in old age.

Looking through a care-ethical lens shows the shortage of the prevailing one-sided focus on independency and individuality. Clearly, this ‘social imaginary’ falls short in appropriately recognizing the full humanity of every human being, leaving people in grave doubt as to whether others would agree that their life is (still) worthwhile. Care ethics questions whether it serves a ‘good life’ and ‘good ageing’ to think of vulnerability and dependency as a threat to human status and value, an inferior grade of humanity, a sub-human status (Tronto, 1993). We should probably counter these ideas rather actively and collectively rethink existing ‘social imaginaries’ on dependency and vulnerability within culture, and shift to a more sophisticated sense of human interdependence (Tronto, 1993). What if it were widely acknowledged that a shared inability to be in total control of our lives is common ground for people (van Heijst and Leget, 2011)? And what if we would be prepared to acknowledge that dependency does not automatically exclude autonomy, but can arise and be strengthened within a context of social relations capable of bringing about the feeling of one’s ability and legitimacy to act (Ferrarese, 2011)? How can we create new forms of (inter-generational) solidarity and community, rooted in the realization that each person should take responsibility for the other because all have an interest
3.4. A dignified old age

Above, we have already noted that there seems to be a relation between the experience of dependence and vulnerability and the experienced threat of one’s dignity. We will now try to further clarify this relation. In contemporary ethical discussions, mainly three versions of dignity play a role (Leget, 2013). Firstly, there is the notion of inherent dignity, which emphasises the fundamental human dignity of all persons, based on the unique fact that they are human. Dignity is an ontological given. While this abstract notion of dignity is independent of experience, it does uphold a fundamental equality of humans, making a moral claim on society to provide the basic freedoms and goods that are needed for the fulfilment of one’s dignity (Leget, 2013; Kirchhoffer, 2013). Secondly, there is the notion of subjective dignity, which refers to the experience of the one’s own dignity. In other words, it refers to a self-interpretation of one’s dignity, associated with self-worth and self-respect. In experiencing a sense of one’s own value, worth, ability and meaning, one ‘acquires’ this dignity (Leget, 2013; Kirchhoffer, 2013). Thirdly, the notion of social dignity refers to the experience that one feels respected by other persons and by socio-cultural practices and institutions. Attitudes, certain practices or institutions can both affirm and undermine the experience of the value of a human being (Leget, 2013; Kirchhoffer, 2013; van Heijst, 2011; Galvin and Todres, 2014).

None of these notions of dignity alone can provide a balanced moral view on dignity. A primary focus on intrinsic dignity might neglect a deep existential sense of indignity often associated with meaninglessness, hopelessness and a wish to die. Dignity as an abstract and objective phenomenon only has no meaningful application in the real world of people (Galvin and Todres, 2014). In contrast, a main focus on subjective dignity is too narrow to build one’s moral decision on as people’s ideas might be mistaken or distorted. Dignity is relative, not something we ‘have’, but something that can be acquired and forfeited as well (Kirchhoffer, 2013). A problem with a narrow focus on social dignity is that societal ideas are dependent on cultural practices that vary over time. As long as there are practices of stigmatization and marginalisation that – consciously or unconsciously – undermine the
dignity of minorities, social dignity is not sufficient for a balanced perception (Leget, 2013). Rather than affirming or disregarding people’s subjective ideas, in some cases, there might be a need for societal efforts to correct these ideas.

Care ethicists, among others, are sensitive to the need for an integrated view in which the various dimensions of dignity are intertwined and interrelated (Galvin and Todres, 2014; Leget, 2013). They are also sensitive in emphasizing that dignity is not only about agency and competence (to have), but also about belonging and connection (to be) and recognition (to be recognized). In other words, dignity is not only a dignity of ‘I can’, but at a deeper existential level, it is also a dignity of ‘I am’ (Galvin and Todres, 2014) and a dignity of ‘I am being seen’ (van Heijst, 2011; van Heijst and Leget, 2011).

If we now look at the issue at stake, we see that not only the subjective dignity of the older people is ruptured. The social dignity – which refers to the recognition by others and society – is threatened as well (Leget, 2013). Not only do they lack a sense of self-respect, but also a sense of reciprocity and mutual respect, which is of vital importance to the experience of life quality and self-esteem. Their dignity is thus painfully threatened at several levels. This raises the urgent question: What is a morally good societal response to this painful experience of indignity resulting in a wish to die?

Those who argue that older people should have the right to assisted dying base their argument on ‘the right to die with dignity’. Hereby, they make an association between dignity and the power to determine how and when to die. Living on while deeply suffering from old age is seen as an undignified route. The loss of dignity is seen as a ground for a dignified assisted death (Kirchhoffer, 2013; Beekman, 2011). People should have the right to such a dignified death, proponents claim. However, by putting an emphasis on dignity in terms of agency and competence, what remains underexposed – and maybe even disregarded – are the aspects of belonging, connection and recognition that are also essential for dignity. An overemphasis on the association between autonomy and dignity can obscure these social-relational needs.
4. CONCLUSION

To conclude, our purpose is to contribute to the moral deliberation on the issue of completed life in old age – and to the wider political discussion on ageing in modern societies – by capturing the complexity of the phenomenon. Our intention is not to judge this moral practice in a deductive, top-down way. Instead, we draw on our empirical work in order to reach some normative considerations with respect to the social practice at stake. Analysing the modern ‘social imaginaries’ on autonomy and dignity throws a light on our society, on how we deal with an ageing population, and society’s ‘new forms of malaise’, such as alienation, meaninglessness, feelings of social exclusion and existential loneliness (Taylor, 2004).

In sum, we think that the Dutch state should not regulate assisted dying in cases of completed life in old age in the absence of a serious mental or physical disease. First, it seems an individualized response to a partly societal problem, a neglect of the social embeddedness of the wish to die, and a crisis outside these people. The focus on assisted dying might be a neglect of other urgent needs. Secondly, as mentioned before, our research points at the concern that a societal approval that age-related dependencies are undignified and might be ‘best resolved’ by assisted dying may enforce feelings of indignity and social marginalisation in old age (Schnabel et al., 2016; Yuill, 2015).

The implications of care ethics are aiming at exerting influence on social and institutional changes by providing clues for humanization of society and policy. This current ethical reflection points out that the debate on completed life in old age should not aim primarily on the question of whether or not to legalise assisted dying (focusing on interests and rights), but on the question of how to build an inclusive society where people might not feel (or feel less) unneeded, useless and marginalized (focusing on needs and concerns). It should also be a debate on alternative moral views on ageing and society, the place and role of older people in society, highlighting the need of social responsibility and transformation to reduce the level of distrust in care, medicine and society. We think that societies and states have a moral responsibility to do whatever can be done reasonably to minimise the impact of inherent vulnerabilities and situational dependencies on the lives of older people (Dodds, 2014; Scully, 2014).
REFERENCES


Raijmakers NH, van der Heide A, Kouwenhoven PSC, et al. (2013) Assistance in dying for older people without a serious medical condition who have a wish to die: A national cross-sectional survey. *Journal of Medical Ethics*.


van Wijngaarden EJ, Goossensen A, Pool R, et al. (in review) A captive, a wreck, a piece of dirt: images and metaphors embedded in culture and anchored in the flesh of older people with a death wish.


CHAPTER 9

Ethical uneasiness and the need for open-ended reflexivity:
The case of research into older people with a wish to die

(in review)
ABSTRACT
This article focuses on research ethics in highly intimate research with a possible impact on life and death. We reflect on four complex ethical issues that came up during our research project into older people with a wish to die, in order to stimulate moresprudence. Drawing on our experiences, we discuss 1) the possibly establishing influence of our research on the wish to die (*moral experience of whether or not being guilty*); 2) the suggested duty to intervene (*moral experience of transgressing the person's autonomy*); 3) the dilemma of intimacy (*moral experience of disappointing trust*); 4) and the researcher’s authority and power over the data (*moral experience of presumed misrepresentation*). We suggest that being open about ethical uneasiness is highly important, 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.
1. MANY ETHICALLY UNEASY MOMENTS

During our research project on relatively healthy older citizens with a wish to die, we found ourselves pondering many times over ethically uneasy moments. We conducted highly intimate research with a possible impact on life and death, talking with people about their struggle with life and their wish to die. I [the first author and interviewer] entered participants’ homes, they opened up their very intimate, private lives. They told me their personal stories and then I ‘left’ them again. Despite the fact that all of the older people invited me themselves, gave their informed consent, knew the procedure and often explicitly expressed their relief to get the possibility to share their story, in many cases I still felt more or less uncomfortable leaving them. The fact that I knew that some of them were actively ideating on a self-directed death strengthened these feelings. What about our moral duty to intervene in order to prevent suicide, knowing that without exception, participants did not want any intervention? Participants perceived themselves as ‘normal’, independent, autonomous and self-determining citizens with a ‘reasonable’ wish to die, and truly did not perceive themselves as being mentally ill. Should we have compromised their autonomy, freedom and self-determination by insisting on treatment options, while they considered themselves as fully capable to handle their own lives?

These urgent questions, among many others, came up during our research meetings. They were also noted in the review reports we received after we submitted our papers for publication in high-quality journals. To quote two anonymous reviewers:

I have a concern about the ethical nature of the research (which may reflect my experiences in conducting research with vulnerable populations). I strongly believe that people who are vulnerable have a right to participate in research, if protected. However, I am not convinced that they were appropriately protected. This type of research requires extra caution, not just referrals to health care professionals.

It appears that no formal ethical breach is evident in that proper human subjects protections and approvals were in place, however [I still have an ethical concern]: Did you have any obligation to intervene?
The reviewers' concerns about the safety of participants who disclosed a death wish very much resembled our own reflections during our research meetings. Once again, we [all three authors who formed the research team] became keenly aware that conducting research into a highly intimate topic goes far beyond procedural research ethics. Conducting methodologically rigorous and procedural sound research is not evidently an equivalent of morally good research. Given that the exchanges with several reviewers were very fruitful, we felt encouraged to publish about our experiences.

The central thesis of this paper is that morally good research involves the importance of being honest and open about ethical uneasiness, doubts and uncertainties. In many borderline cases, there are only balanced and open-ended answers needing an enquiring mind, rather than clear and fixed ideas and solutions. We think researchers should more frequently share these vulnerable reflections with other colleagues in order to contribute to the moresprudence on research ethics. This paper proceeds as follows: First, we will briefly outline the academic debate about ethical research practices. Next, to provide some context information for our reflections, we will shortly describe our specific research project. Thereafter, we will come to the main part of our paper and discuss some of the most complex and ambivalent issues that came up during our research project. We thoroughly recap on how these issues were addressed during our research process and which open-ended questions remained. We conclude by posing that conscious awareness and acknowledgement of ethical uneasiness and open-ended reflexivity are indispensable to constitute a morally good research practice. Besides, we suggest that – just like methodological reflections on strengths and limitations – ethical reflections should be a regular part of research articles as well.

2. BEYOND THE BORDERS OF PROCEDURAL RESEARCH ETHICS

There are several guidelines and procedures for research ethics, which all emphasize important principles for the ethical conduct of research, such as the principle of informed consent, the right to decline at any moment, confidentiality, the absence of coercion, protection from harm and beneficence towards participants. The Nuremberg Code (1947) has served as an ethical foundation for human research since its publication. This code was developed in response to the terrors of human experiments done by Na-
zi physicians and investigators. It describes the human rights of research subjects and the obligations of physician-investigators towards research subjects. The Declaration of Helsinki (1964) restated similar principles and both codes still function as international reference points for research ethics. Based on these codes, most countries have now established national (and regional) committees on research involving human subjects that have to protect subjects taking part in (medical) research by reviewing and approving research proposals on the basis of their statutory provisions, codes and guidelines.

The main aims of these ethical committees are to maximize ethical and responsible conduct of research involving humans by taking into account their interests, and to protect them from possible harm and methodologically poor research. In practice, though, most research encounters bring up ethical uncertainties that go beyond the formal procedures. There are no definite rules or universal principles about (i.e.)

- possible power imbalances and instrumental and exploitative tendencies in research (Finlay, 2011; Schipper et al., 2010; Abma, 2000; Abma et al., 2010; Head, 2009).
- doing research into the lives of intimate others like family, students or clients (Ellis, 2007; Etherington, 2007).
- confidentiality in cases where one is confronted with very intimate disclosures about family secrets, abuse or traumas (Guillemin and Gillam, 2004).
- talking about a difficult and probably traumatic experience that might cause distress or even re-traumatize participants (Finlay, 2011; Guillemin and Gillam, 2004; Usher and Holmes, 1997; Labott et al., 2013; Buckle et al., 2010).

In all these borderline cases, among others, there is a moral tension that has already been acknowledged by many qualitative researchers. A lot has been written about how researchers can reflect and act in these grey areas. Guillemin and Gillam (2004) have made a distinction between what they call ‘big-issue’ ethics and acknowledgement of ‘ethically important moments’. Although they stress the importance of procedural ethics as ‘a valuable function in forcing us to consider and reflect on fundamental guiding principles that govern research integrity’, they also draw on the notion of
reflexivity as an essential way of dealing with what they call ‘ethically important moments’ that come up during every research project (Guillemin and Gillam, 2004). Being reflexive at these often subtle, unpredictable and difficult moments means that a researcher 1) acknowledges the ethical dimension of the everyday research practice; 2) is sensitive towards specific ethically important moments; and 3) is able to develop a means of addressing these ethical concerns (Guillemin and Gillam, 2004). In this paper, we want to elaborate upon this three-step approach and particularly highlight the need for honesty and openness about ethical uneasiness, doubts and uncertainties.

3. CONTEXT: RESEARCH INTO THE WISH TO DIE IN OLD AGE
To take the reader on our reflective journey, we will now first provide some context information about our research project. In the Netherlands, euthanasia and physician-assisted suicide can be performed under strict criteria laid down in the Euthanasia Law. Currently, the end-of-life debate is progressing. A growing group of Dutch citizens is now in favour of further relaxation of the law. They ask for the possibility of having a physician to assist them in the dying process, not only in cases when they suffer from a serious disease, but also when they suffer from being old and dependent. Besides, there is a growing level of support for the availability of a last-will-pill which should enable older people who are tired of living to organize their own deaths.

Notably, though, the issue of tiredness of life in older people really is a research area in its infancy. Only a small number of empirical studies have examined this phenomenon, and even fewer have analysed it in the absence of a mental disorder or a life-threatening condition (van Wijngaarden et al., 2014; van der Heide et al., 2014). To develop a careful and responsible policy on this issue, it is a prerequisite to first gain a deep understanding of this phenomenon, and find out what is really at stake in the lives of these older people. The aim of our empirical research project was therefore to provide in-depth insight into what it means to feel ‘life is completed and no longer worth living’ as lived and experienced by older people themselves (van Wijngaarden et al., 2015a). This was done using a phenomenological approach to explore this experience with an open, non-judging and wondering attitude.
After placing research advertisements in various magazines, we selected twenty-five people aged 70+ to participate in our study. All of them considered their lives to be ‘completed’ and strongly wished to die while not being terminally or mentally ill. Nor were there indications that any of the respondents suffered from a psychiatric disorder or clinical depression. Our empirical study has shown that participants essentially felt disconnected from their actual lives: daily experiences seemed incompatible with their expectations of life and their ideas of whom they were, which strengthened a strong desire to end life at a self-directed moment. This experience of disconnectedness was further explicated in the following themes: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the (growing) inability to express oneself; 4) a multidimensional tiredness; and 5) a sense of aversion towards (feared) dependence (van Wijngaarden et al., 2015a).

The in-depth interviews that were conducted were very intense and emotional. People shared their sadness, fears and shame. They talked about feeling unneeded, redundant, lonely and undignified. And for most of them, the only way to escape from these uncomfortable feelings seemed to be a self-directed death. While most had a strong preference for a physician-assisted suicide, this would often have been illegal because they did not meet the current criteria laid down in the Dutch Euthanasia Law. That was the reason why most of them were ideating on manners to end their lives by themselves.

4. UNEASY MORAL EXPERIENCES

During the research process, many sensitive ethical questions came up. In this paper, we want to reflect on the most striking ones and explicate to what specific moral experiences these questions refer. These are:

1. The 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 has unintentionally strengthened their intentions to end their lives at a self-directed moment? Did we take sufficient caring responsibility or could it be that we are partly guilty of confirming their plans?

2. The moral experience of transgressing the person’s autonomy: Should we have compromised their autonomy, freedom and self-determination and
insist 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?

3. The 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?

4. The moral experience of presumed misrepresentation: How do we relate to the fact that participants told their stories and that in many cases participants’ stories turned out to be much more ambivalent and vulnerable than they 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?

4.1. The uneasy moral experience of whether-or-not being guilty

We took all procedural precautions we could think of to ensure the (emotional) safety of participants. In the Dutch context, our research project was in full compliance with the law and the respected way of performing research into sensitive topics. Our study was evaluated by the Medical Ethics Review Committee UMC Utrecht (MERC), based on the following documents provided: a research protocol, the informative letter, a consent form and the interview guide. The MERC confirmed that the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply, as our potential participants were not patients but mentally competent citizens, and participants were not subjected to treatment or required to follow a certain behavioural strategy as referred to in the WMO (art.1b). Subsequently, official approval of this study by the MERC was not required (protocol: 13-176/C). Despite the fact that our research was not under the scope of the WMO, we applied all rights and obligations pertaining to a study under the scope of the WMO to our own research project (See Box 1).
BOX 1: Rights and obligations pertaining to a study under the scope of the WMO

- providing comprehensive information beforehand;
- gaining informed consent prior to the interview;
- communicating about the right to withdraw at any moment;
- respecting and protecting privacy and confidentiality rights;
- providing contact details of all researchers and full personal contact information of the interviewer (who is available for contact during the full term of the study);
- debriefing afterwards (narrative report and contact);
- protecting the safety of participants by communicating about the possibility of a follow-up conversation at their home or a reference to a counsellor if appropriate.

After every interview, a narrative report was written and sent to the participants, not primarily for participant validation but mainly for ethical reasons (Patton, 2002; Finlay, 2011). Rather than validating the correctness of our findings, it was about ‘empowering participants to share in the meaning-making process’ (Finlay, 2011). After they had received the narrative report, there was a final phone call or correspondence to share and evaluate. Also, most considered it a great honour to have the opportunity to contribute to the scientific research and more indirectly to the public debate. The response was mainly very positive. The majority of participants explicitly underlined that participating had been a positive experience, because the interview had helped them to express their thoughts and feelings in a non-judging environment, which gave them a sense of relief and recognition. Several participants expressed themselves in words like these: ‘This really is my story. I’m very grateful for it. I hope my family wants to read it.’ Although emotional relief and insight are not the primary purpose of an interview, it is nevertheless a positive side effect (Dahlberg et al., 2008). Our experiences confirm the suggestion of Buckle and colleagues (2010) that a research interview which explores complex, personal issues may be seen as beneficial to participants, rather than harmful.
Obviously, we continuously asked ourselves the question of what benefits and (even more importantly) what possible damage could be expected during and after the interviews: What were reasonably foreseeable risks and discomforts to participate? We always gave an interviewee explicit permission to withhold thoughts and to not go into details if they did not want to. And in line with Dahlberg et al. (2008), we think this is highly important, as this is ‘an acknowledgement of their sovereignty as human beings’. We felt the responsibility to provide support as long as needed, until the participants had ‘recovered composure’ before the interviewer left (Dahlberg et al., 2008). In practice, this meant that in a few cases, I [the interviewer] stayed for another hour. Besides, participants could always contact me and ask for an additional visit or a referral to a counsellor.

Despite the fact that we made all efforts to ensure protection from possible harm, some uncertainty remained about the question as to whether the interview could possibly have confirmed participants’ wishes to die. An uneasy comment of a research colleague went as follows:

*You should realize that, in an inconspicuous manner, an interference may take place under the influence of an in-depth interview. All precautions you took do not preclude what I mean. In my view, in-depth communication and its elusive influences have many layers and are very complex.*

Of course, one can jump to conclusions by presenting all sorts of reasonable arguments to rebut that the interview did not further confirm the wish to die, for example by raising the fact that participants had already been thinking about a self-directed death for years (which was very often the case); or by posing that the interviewer remained as non-judging as possible and never confirmed their plans; or that it is generally held that talking about suicidal thoughts and plans does not increase suicidal intent or hopelessness (Dumon and Portzky, 2013). However, research has given empirical evidence that qualitative research interviews do indeed impact participants’ views of their situations (Britten et al., 2012; Butterfield et al., 2009). We did ask for participants’ feedback after the interviews. They were very positive without exception: they felt recognised, relieved and understood. Possibly, the research encounter even strengthened their sense of dignity. But if an interview can empower participants in the meaning-making process (Finlay, 2011; Schipper et al., 2010), it is not inconceivable that it has (indirectly)
empowered them in their plans to end life. Did we take our responsibility sufficiently or could it be that we are partly guilty of confirming their plans?

Ellis (2007) has stated that ‘relational ethics requires researchers to act from their heart and their mind, and to fully acknowledge their interpersonal bonds to others, and take responsibility for actions and their consequences’, but what does this kind of responsibility actually mean in a concrete research practice? What exactly can we be held responsible for, and to what extent? In our view, morally good research requires full responsibility for foreseeable consequences of the research. However, to hold researchers responsible for so-called ‘underground influences’ that go beyond words might lead to a ‘hypertrophy of the responsibility’ (ten Have and Welie, 2005). This means that the attribution of responsibility to the researcher is not only confined to the foreseeable consequences of the research, but the researcher is also responsible for (and thus complicit with) the choices, lifestyle and life of the participant. We think that this would be inappropriate and goes too far in attributing responsibility.

Obviously, though, this is not a conclusive answer eliminating the need for reflection. Some uneasiness remains. We think it is highly important that researchers endure this kind of uneasy uncertainty, and dedicate themselves to ongoing and open-ended reflexivity, instead of hiding themselves behind ‘safe’ procedures or argumentations. Because enduring this uneasy uncertainty means that researchers remain aware of risks and are more careful in conducting their research.

4.2. The uneasy moral experience of transgressing the person’s autonomy

During our research, participants expressed their wishes to die and they sometimes spoke about the preparations they had already made to perform a self-directed death. Several times, we asked ourselves whether we had a responsibility to encourage participants to find treatment. Indeed, as mentioned before, some reviewers even suggested that we probably might have had a duty to intervene. The sense of uneasiness was even strengthened when we performed a case study into an elderly couple who strongly wished – and a few months after the interview actually chose – to die together at a self-directed moment (van Wijngaarden et al., 2015b). For years, the couple under study had talked about their agreement to end their lives when they would have reached the moment when they considered life to be no
longer worth living. However, this pact seemed to hold both in an impasse, because they differed in their assessments of life and the timing. The case study clearly shows a paradox: on the one hand, the couple died together according to their mutual agreement; but on the other hand, it gives an indication that it might have been a premature decision of the wife, and not what she wanted yet. Precisely because of the impression of urge or a form of coercion, one reviewer remarked:

_I was wondering why you did not encourage the wife to seek resources to support her in having a discussion with her husband about the timing of the planned deaths, because she was suffering from the impasse with her husband. I did not expect you to try and change their minds about dying. But with the hindsight you now have, would you recommend other researchers to ask the wife directly if she would like to get support?_

This is an intriguing question. We had chosen to not actively emphasize treatment options. But was that the right thing to do? There were more situations in which participants’ wishes to die seemed premature, at least from an outside position. Perhaps it would have been possible to counsel some of these older people to give up their plans. However, participants themselves were often very explicit in that they definitely did not want any intervention. Some participants did go to a hospital or to physical rehabilitation therapy for physical treatment, but deliberately no mental health therapies were sought. During the research process, we asked ourselves: Should we have compromised their autonomy and integrity by insisting on treatment fuelled by a desire to safeguard them, even though they did not want it? What is a humane and ethical approach in such situations? Did we have a duty to intervene knowing that participants were seriously ideating on a self-directed death? And would we have lost their trust if we had decided to insist on support without their consent?

The fact that our participants did not want any mental treatment might be partly explainable because of the Dutch cultural context. In 2010, the Right-to-Die-NL started the campaign ‘Of Free Will’ and put the discussion about ‘older people and a self-directed death’ on the social and political agendas. The most important issue of this continuing public debate is ‘making self-determination of life’s end a reality’. Based on a ‘rational and well-considered choice’ older people should have legal options for assisted dying, they
argue. This presupposes the idea that ending one’s life can be considered as a ‘rational and autonomous’ choice. This idea is supported by a considerable part of the Dutch general public. In the light of this cultural context, one might understand that the older people involved truly did not perceive themselves as being mentally ill and having a pathological wish to die. They perceived themselves as ‘normal’, independent, autonomous and self-determining citizens, with a ‘reasonable’ wish to die. They were not in search of any help or treatment (while being aware of the possibilities), but rather in search of what they call ‘a dignified death’. Often they had been active members of a Dutch right-to-die organisation for decades. These organisations confirmed the legitimacy of their wish to die and provided information on how to perform a self-directed death. Most likely, participants would have found further protection to be highly paternalistic and would probably withdrawn themselves from this study if we, for example, would have proposed treatment. So from a cultural perspective, one could argue that this wish to die – at least in a considerable part of Dutch society – is seen as acceptable and reasonable, not in need for intervention. We think we should take into account these contextual givens, but is this a decisive argument for not intervening?

We had an additional methodological argument that strengthened our decision to not intervene. Our research project aimed to give insight in the lived experiences of people from an insider perspective, not from an outsider, normative perspective. Therefore, we chose to engage with these people as they perceive themselves. A phenomenological approach, free from prefixed theories or frameworks about illness or no illness, seemed to be the best option to achieve this. Prior to the interview, we explained this open, non-judging interview approach to our participants. We assumed that our open, non-judging and non-committal approach – lacking a medical, psychological paradigm – gave room for people to tell their story freely. We indeed noticed that the fact that people felt not objected to and that their wish to die was not medicalized or psychologically ‘understood’, strengthened trust. Participants were very grateful to be able to openly share their experiences and struggles. In daily life, many of them experienced that most people (i.e. their family, friends or their GP) find it extremely difficult to just listen without judgement when it comes to disclosing a death wish. Several interviewees said they experienced the openness during our encounter as ‘a gift’. Should we then have made concessions to our own promises about an
open, non-judging and non-committal research approach? Or would that have been an act of untrustworthiness? We did adhere great importance to staying within the terms of our agreements.

We also believe that using our phenomenological approach actually made it possible to get as close as we came to the lived experiences of the people involved and obtain unique data full of lived ambivalences, ambiguities, complexities and polarities. Probably this would not have been the case, if we had been ‘protective’ in a way that participants themselves did not choose or prefer. But still the question remains: Do these arguments justify the fact that we did not intervene while people were ideating on a self-directed death?

In mainstream bio-ethics, this question would point out a conflict between the principle of non-maleficence and the principle of autonomy. The principle of autonomy entails respect for people’s self-determination. Patients may freely choose values, loyalties or systems of belief according to which they make far-reaching decisions. The principle of nonmaleficence requires avoiding harm and refraining from doing what damages the patient’s interest, taking all reasonable precautions to protect them from the causation of harm and promote wellbeing (Beauchamp and Childress, 2009). Yet an important factor to bear in mind is that our participants were not patients but citizens who perceived their wish to die as being in consonance with their life view and values. In their view, their wish to die was a result of an autonomous and realistic assessment of their life: the negative aspects had accumulated to such an extent that they preferred death over life.

We are of the opinion that intervention could not only lead to transgression of the boundaries between research and therapy (Finlay, 2011). Unbidden and unwanted interference with the choices, lifestyle and life of the participant might also result in what we earlier touched upon as a ‘hypertrophy of the responsibility’ (ten Have and Welie, 2005). This is especially the case because of the fact that participants considered themselves sane, healthy citizens living in a society where their wish to die is considered to be legitimate by at least a (large) part of the population, and capable of running their own affairs. We are of the view that prudently offering a free possibility of referral to external counselling was the only appropriate way to protect these people, without compromising their autonomy and freedom as citizens.
After scrutinizing our motivations and considerations, we felt that the most ethical approach was to respect the choices of our interviewees. But, for us as researchers, again some uneasiness remains, fuelled by a felt moral responsibility to nurture concern for participants' well-being. This uneasiness was enhanced by the fact that within the period of one year after the interviews, we received death notices of eight of the twenty-five participants (two of whom were the couple). What if these people indeed had had a hidden (and by us unnoticed) cry for help? Although it might increase feelings of uncertainty and vulnerability, the maintenance of on-going, open-ended reflection about these complex questions is needed to stay sensitive towards the moral aspects of research. We fully agree with Etherington (2007), who wrote that ‘researchers should come from behind their protective barriers of objectivity’ and impeccability, inviting others to join them in the learning process as this is the only way to build and sustain a transparent and reflective research practice.

4.3 The uneasy moral experience of disappointing trust

Our phenomenological research was characterized by a relational approach (Finlay, 2009; Finlay, 2011; Dahlberg et al., 2008), which means that we aimed for an open, embodied and empathic presence to participants. We hold the opinion that in-depth research requires an embodied encounter – in which both the participant and the researcher are actively involved, touched and impacted (Finlay, 2009). During the research encounter, an intersubjective space arises between the researcher and participant. Acknowledging these intersubjective dynamics helps the researcher to better understand the life-world of the other (Finlay, 2011; Finlay, 2009; Abma, 2000). Finlay makes a comparison with Martin Buber’s I-Thou relationship: it is a relation of mutual regard, free from judgment, demand, possessiveness and objectification (Finlay, 2009). The other is seen as a subject, not as an object. This, of course, is not an easily achievable task, yet these are the ‘underpinning foundations and the spirit of what we aim for’ in a phenomenological research approach (Finlay, 2009).

Following this relational approach, we conducted our research. The interviewer tried to be bodily and emotionally present, and engage as fully as possible with participants. This approach required not only ‘a true willingness to listen to the other’ (Dahlberg et al., 2008), but also an awareness of
her own bodily reactions and ‘a vulnerable engagement’ (Dahlberg et al., 2008). It will be recognisable to qualitative researchers that this way of doing research means that the interviewer is often deeply touched by participants’ life stories. The embodied approach enables researchers to better constitute the lived experiences of participants, but can also be accompanied with heaviness of heart.

In our research project, this heaviness of heart already became very noticeable during the sampling process. Due to the sensitive nature of this research project, this process involved much more than simply deciding sample numbers, characteristics and inclusion criteria. We placed research advertisements in magazines targeting older people. We mentioned that we could possibly not interview every respondent and that we might have to select people. However, the number of reactions was far beyond expectations. We received 144 reactions all giving a short description of people’s personal situations, which was sometimes quite intimate. While we conducted a very clear and transparent sample procedure and kept every respondent informed about this procedure, we still felt encumbered by not selecting people, because all these people seemed to be quite willing to participate and share their story. A few people mentioned that they had never talked explicitly about their own death wish before because they feared rejection. Regarding the safety of all those people who disclosed a death wish, it is important to underline that excluded respondents also had the possibility to contact the first author for referral to professional help at any time. From a procedural perspective, our approach was quite right, fair and clear, but still a dormant sense of uneasiness remained. In a way, all those people deserved to be visited.

During the interviews, participants’ disclosures were impacting on the researcher on an emotional and bodily level, which provided deep insight. Sometimes, the sense of aching loneliness became almost tangible. For the researcher, this opened up the ability to empathize with feelings of not mattering and disconnectedness. But this approach also had an uneasy side effect, which we will illustrate by an example: One participant cried almost constantly while he was telling his story. After two hours, he asked me [the first author and interviewer] to stay a little bit longer. And so I did. Later on, when I ended the intense interview, he wanted to hug me out of gratitude. He was extremely grateful for the opportunity to share his feelings, which he not only expressed during and after the interview, but also
the next morning. He sent me an email with some beautiful pictures of nature to say thanks again. After this research encounter, I felt deeply touched but also uncomfortable because his loneliness became so obviously clear. Despite the fact that he had some social contacts and lived in an apartment where he could join a daily communal meal, no one seemed to really listen to him.

Several other times, something quite similar occurred. Once, I was invited to stay for a while and go out for dinner. Several people asked me whether they could help me with my research, by typing the transcripts, recruiting other participants, or joining me at conferences, because they wanted to do something meaningful. To stay true to my role as a researcher (Finlay, 2011), and to the agreements we had made beforehand, but also to protect myself from getting too involved, I felt I had to draw a line. But it made me ask myself the uneasy question: How to feel about entering a life, trying to create an open, dialogical and reciprocal encounter for the time of the interview, and then ‘leaving’ these people again? Once more, I could quickly push away the felt discomfort and pose that I had had additional contact after the narrative report was sent. Besides, participants had the opportunity to get in contact at any moment and ask for an additional visit or a referral to a counsellor if preferred. But in some cases, it still felt a bit like emotional abandonment. Although this is not an unusual experience in qualitative research, in our view, it is very important to explicitly and openly acknowledge these uneasy feelings as it keeps researchers on their toes when it comes to their responsibility. It makes them more alert and careful, and in search of the most sensitive attitude achievable.

4.4. The uneasy moral experience of presumed misrepresentation

In qualitative research, it is fairly common that there turns out to be a gap between what participants think about themselves and how they present themselves in telling their experiences. In our research project, this was clearly the case. On the one hand, participants thought of themselves as independent, autonomous and self-determining ‘agents’. Based on an individual and ‘rational’ evaluation, they assessed their lives to be ‘no longer worth living’. They were in favour of further relaxation of the euthanasia law and several participants also expressed the hope that our research project might accelerate this process. On the other hand, they presented themselves as highly dependent on others when it came to their well-being. Their stories
were full of anxiety, sadness and loneliness and a strong human desire to be visible, recognized, wanted, needed, valued, depended upon, or attended to by others (van Wijngaarden et al., 2015a). The power of phenomenological research is precisely to illuminate these ambivalences and ambiguities, as it does not focus on perceptions and opinions, but focuses on contextualized lived experiences (Slatman, 2014). Therefore, the interviewer asks to elaborate on actions, situations, habits and events, for example: At what specific moments do you experience that your life is completed? Can you tell me what exactly happened, what you felt? Who else was involved and in what way? What kind of situations strengthen your wish to die? When do you feel confronted with these feelings?

Our way of interviewing thus invited participants to go beyond their cognitive considerations and conceived ethos and reflect on their lived experiences and lived morality. In most cases, a significant discrepancy between participants’ cognitive considerations and their lived (much more vulnerable) experiences came to the fore. Probably unconsciously, they exposed themselves as vulnerable and dependent people, the opposite of how most preferably positioned themselves: as independent and self-sufficient people. It turned out that their initially presented self functioned (at least partly) as a cognitive masquerade. Let me illustrate this by describing the paradoxical reactions of two participants: One lady wrote me a lengthy letter after receiving the narrative report. She completely agreed with the ‘careful and beautiful narrative’, which fully corresponded to her experiences. Simultaneously, though, she regretted that she had presented ‘such a one-sided, vulnerable picture of herself’ and she argued that she was much stronger and more opinionated than she had portrayed herself. Another interviewee sent me an email about a year after the interview. She had read a news item about the outcomes of our research and she was disappointed. She wrote to me:

I have such fond memories of the interview and the narrative report had been so recognizable, but this characterization in the newspaper is so vulnerable. Maybe this concerns the other twenty-four people you have interviewed more. But when I read it, it feels like we are in need of help and I don’t like that at all.

What do these paradoxical reactions of both ladies illustrate? Could it be that the inability and the unwillingness to deal with dependency, deterioration and vulnerability – which turned out to be the essence of the lived
experience of these older people (van Wijngaarden et al., 2015a) – also play a role here? Finlay (2011) describes that there are all kinds of complex conscious and unconscious dimensions that resonate in the participant validation. Participants see their experiences from their own perspective, they will never be able to see the research in the same way as the researcher does. She quotes Giorgi by posing that ‘participants are experts in what they have experienced, they are less clear and categorical about the meanings of their experiences’ (Finlay, 2011). Participants have their own motives, ethos, needs and interests, she argues. ‘It may be in their interest to protect their socially presented selves’ (Finlay, 2011). But even if they indeed protect their ‘socially presented selves’, the fact remains that this also relates to the principle of power. The researcher has the authority over the outcomes and decides what picture is presented. Ellis (2007) quotes Josselson who argued: ‘Language can never contain a whole person, so every act of writing a person’s life is inevitably a violation.’ And she asks herself: ‘If this is true, how do we research and write ethically?’ (Ellis, 2007). How to expose people in a true and ethical way, especially when there is a considerable discrepancy between participants’ lived experiences and conceived ethos? And how should a researcher relate to the (conceived) ethos and the interests of participants?

Driven by the outcomes of our research, we tend to favour restraint and qualify the public debate: The results have given insight into the lived ambivalences and ambiguities of the population at stake; the shortcomings in the prevailing conception of people as independent, autonomous and self-determining agents; and the inadequacy of considering this wish to die to be an individual problem. Besides, we have argued that addressing the social and positional aspects of the wish to die might be a more appropriate response to the concerns of these people than offering them a legal opportunity to die. Most participants, though, hoped for quite the opposite: they were in favour of a more liberal euthanasia policy. Despite the fact that we have always been very open and clear about our neutral position (not being proponents of a further relaxation of the law) and research aim, participants can still experience our conclusions as a misrepresentation, which is an uneasy feeling. In our opinion, this sense of misrepresentation is not caused by a lack of truthfulness or a wrong interpretation. Indeed, it was much more a matter of revealed discrepancy in participants’ lives. While we think it is not justified to consider our research outcomes as a threat to trust or as misrepresentation, enduring the uneasy feeling once again makes the
researcher aware of the position of power. It not only urges truthfulness to the data, but also to the identity of the participants. In our case, I contacted both ladies and tried to be as transparent as possible about our choices and approach. This has restored the mutual understanding this time, but naturally this is no guaranteed outcome.

5. UNEASINESS AS A CONSTITUENT OF A MORALLY GOOD RESEARCH PRACTICE

In this article, we have presented some self-disclosures about ethically uneasy moments that we have faced during our research into older people with a wish to die. Scrutinizing these ethical challenges made us realize once again that conducting methodologically rigorous and procedurally sound research is no assurance for morally good research. In practice, ethics goes far beyond procedures and needs constant open-minded and open-ended reflection. Earlier on in this article, we referred to the three-step approach of Guillemin and Gillam (2004), who describe that practicing ethical reflexivity requires the acknowledgement of the ethical dimension and the ability to address these ethical concerns. We have elaborated on this idea by explicitly qualifying that addressing an ethical concern is not the same as ‘solving’ ethical challenges and concerns. We particularly highlight the need for open-ended reflection by emphasizing the complexity and diversity of the ethical possibilities in borderline cases of great responsibility. Indeed, we argue that ethical uneasiness can be seen as an important research tool in these situations. An open-ended reflective stance – with room for complexity and plural understanding – rather elucidates moral complexities and enlarges moral sensitivity than ‘solves' problems.

There are many forms of qualitative empirical research that raise specific moral questions, due to its sensitive nature. These moral questions are not resolved by the legal, moral and methodological rules. To assess the moral rigour of a research project, the researcher’s ethical competence is far more decisive than whether an approval of the ethical committee has been obtained. Thereto we would encourage researchers to explicitly reflect on their efforts made to enhance a morally good research practice. Just like methodological reflections on strengths and limitations, we argue that detailed ethical reflections should be a basic part of research articles.
By discussing ethical issues and thoroughly recapping on how these issues were addressed (rather than solved), researchers contribute to the more-sprudence on research ethics. Sharing these reflections with other researchers – and thus contributing to the moresprudence in research ethics – is helpful in that it might: 1) increase the researcher's awareness of risks and cautions during the whole process; 2) build a learning dialogue between researchers, providing guidance for other colleagues in dealing with complex ethical issues; and 3) contribute to the on-going, collective task of re-thinking the research practice to nurture an ethical research climate which is committed to trust and accountability.

To conclude, when practicing open-ended reflexivity, researchers might become ‘vulnerable researchers’ as Etherington (2007) has stated, but only by means of transparency can we invite others to join us in our ongoing learning process of becoming an ethically competent researcher (Etherington, 2007). To become thoughtful and thoroughly reflective researchers, Hansen (2011, 2015) has noted, we have to put ourselves ‘at risk’ and acknowledge the unknown and uncertain. Only by ‘living the questions’ we get into a true relation with the world (Hansen, 2011; Hansen, 2015). Room for lasting ethical uneasiness and open-ended reflexivity seems indispensable to constitute an accountable and morally good research practice.


Labott SM, Johnson TP, Fendrich M, et al. (2013) Emotional Risks to Respondents in Sur-


van Wijngaarden EJ, Leget CJW and Goossensen A. (2015a) 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*.

CHAPTER 10

GENERAL DISCUSSION
GENERAL DISCUSSION

In this final chapter, we will explain how we have achieved the main objectives of our study outlined in the Introduction, which are: 1) To describe from a lifeworld perspective the phenomenon of ‘life is completed and no longer worth living’. 2) To explore what it means to live in-between intending to end one’s life at a self-directed moment and actually performing a self-directed death (or not). 3) To connect our empirical insights with the ethical debate on ‘completed life in old age’ and provide a care-ethical understanding of emerging social-political challenges behind this phenomenon. In addition, we will also reflect on our research methodology and discuss some of the strengths and limitations of this study. We will conclude with some suggestions for future research.

1. MAIN FINDINGS AND INTERPRETATIONS OF THE FINDINGS

We will start by describing the results related to the first and the second objective. Given the fact that these empirical findings are already described and discussed in the former chapters of this thesis, we have chosen to rearrange and interpret the data in this section by using a theoretical lens. Thereto, we will reflect on these empirical outcomes using five experiential lifeworld dimensions, namely self, embodiment, intersubjectivity, temporality and spatiality (Ashworth and Ashworth, 2003; Ashworth, 2003; van den Berg, 1972/2013; Todres et al., 2007; Galvin and Todres, 2013). These dimensions are helpful in highlighting particular nuances of the lived experience that is described in this thesis.

1.a. A tangle of inability and unwillingness to connect to one’s actual life

Our first research question was: How can the phenomenon of ‘life is completed and no longer worth living’ be described from a lifeworld perspective? In chapters 3, 4 and 6, the lived experience of the older people under study is presented. The results of chapters 3 and 4 show that it should essentially be understood as ‘a tangle of inability and unwillingness to connect to one’s actual life’, characterized by a permanently lived tension: participants’ daily experiences seem incompatible with their expectations of life and their idea of who they are. This experience is further explicated in its five constituents: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion to feared dependence. In chapter 6, the metaphors used
by participants further our understanding of this experience of disconnection and the aversion to dependence. The discourses of victimhood, captivity, a void, stagnation, redundancy, sub-humanisation and infantilization reveal a strong sense of distance, disengagement and not belonging. While participants feel more and more disconnected to life, a desire to end life is strengthened in their lives. Our research shows that the sense of disconnection is completely intertwined with the way people experience their identities, their bodies, their social relations and their sense of time and space, which we will now depict in further detail.

Disconnectedness from the self: What does the experience of ‘life is completed and no longer worth living’ mean for the identity of the older people involved? Our phenomenological study shows that the identity of the participants is severely ruptured. They feel unable and unwilling to integrate this new phase of life into their life stories. They sense that they have lost essentials that constituted their lives: identifying activities, capacities by which they expressed themselves, worthwhile projects that reflected their personality. They do not truly matter anymore, not in their own eyes, and (at least in their perception) not in the eyes of others. Meaning patterns are disturbed, provoking ‘an attunement of unhomelike being-in-the-world’ (Svenaeus, 2011; Svenaeus, 2000). Especially in chapter 4, but also in chapters 3 and 6, the reader can sense the experience of shame and indignity, which is evoked by failure of the older people to live according to their own values and commitments (Sayer, 2011). They gradually lose their self-respect, feel inadequate and sense an increasing lack of worth and integrity. At an existential level, they feel disconnected from themselves.

In chapter 3, we described that in the narratives, there turned out to be an ongoing tension between is and ought; between how life actually is and how it should be. The older people at stake primarily define themselves in terms of self-regimentation, being in control and being independent. Hence, for these people it seems very difficult to recognize their growing dependence, because it contradicts the image of themselves on which their self-esteem depends. They feel like less than their personal standard. In this context, De Lange has introduced the notion of ‘immunization of the self’ by which he means that people refuse to adjust to the changed situation (Lange, 2010). For their self-definition, they lean entirely on their identity in the past. This notion might, however, suggest too strongly that this refusal is character-
ized as being an active, conscious and chosen resistance. The results of our current study strengthen this idea by showing more ambiguity and ambivalence. In our study, resistance has appeared as an intertwined relation between unwillingness and inability: sometimes it appears as an actively refusing resistance, sometimes more like an exhausted resignation, and at other times it seems to be an external force that paralyzes, although these experiences appear interrelated as well.

In chapter 3, we have also posed that our findings show a resemblance with the notion of Freeman, who has referred to the experience of disconnectedness in terms of ‘narrative foreclosure’ (Freeman, 2000). This is the conviction that even though one’s life as such continues, in one’s mind, one’s life story has already ended. Regardless of whether one continues to get up every morning, no new chapters or characters are apt to be added to one’s story: life is not over, but the life story is. People feel unable to identify with their current life stories: life seems to be too alienated, too meaningless, too shameful or frightening, too incoherent, too pessimistic or tragic, too constrained and dominated by others. While having no future expectations worth living for, they are afraid of a new narrative opening, afraid of a further diminishing of the self.

This notion of narrative foreclosure not only shows similarities with the outcomes of our own study, but also with the description in the advisory report of the Committee of Wise People on assisted suicide in older people who consider their lives complete (Schnabel et al., 2016), where it is stated that the older people concerned have the unpleasant experience that biologically their lives continue, while biographically their lives have stopped already. On closer inspection, our findings also nuance this idea of narrative foreclosure. Again, the experience of people appears to be more ambiguous. It turns out that the separation between the biological and the biographical is not so clear. Surely, people may want to foreclose any continuation of their biographical narratives, strongly resisting the idea of a continuation of their biographies. In practice though, just like their biological life, their biographical life has not stopped yet. Actually, they ‘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 which has not come to an end yet. To make it even more complex, 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 projected biographical end in which people fear to lose their identities. On many levels, completed life in old age appears to be an ambiguous phenomenon. Facing this ambivalence is crucial for a good understanding of the issue at stake.

Disconnectedness from one’s body: How does the experience of ‘life is completed and no longer worth living’ impact the way people relate to their own body and how do the bodily experiences impact the experience that life is completed? Our research shows that the older people under research experience age-related losses and the accompanied deterioration as a breakdown of all ordinary life. The here-and-now evokes a sense of not belonging and disconnectedness. Formerly, their body was their way of being-in-the-world. They took their bodies for granted. But now, nothing is taken for granted anymore. As serious bodily changes emerge, they feel more and more that they have lost control over their capacities and bodily functions. The body is no longer experienced as a unified potential or capacity for being and doing. Rather it is experienced as non-potential and as an incapacity. It progressively becomes an enemy, an opponent. Participants increasingly sense that it is not their ‘own’ body anymore. It has become an object, a thing-other-than-me. Some explicitly talked about feelings of estrangement when it came to their bodies, unable or unwilling to relate anew to this changing, strange body. It seems that they cannot acknowledge this strangeness as part of themselves, a part of their identities (Slatman, 2014b).

In chapter 8, we have shown that having control over one’s body and being independent is an illusion; we cannot control our bodies. Indeed, dependency and vulnerability are inherent to human life. However, it is very clear that the people under research suffer from the idea of losing control and becoming more and more dependent (in a stigmatized way). A sense of disconnectedness is evoked. This experience of disconnectedness from one’s own body can be elucidated by reflecting on Frank’s concept of the ‘disciplined body-self’ (Frank, 1995/2013). In his book, he describes four types of bodies (Frank, 1995/2013). These ideal types can be seen as theoretical
constructions designed to describe some empirical tendencies in the way people relate to illness or ageing. The concept of the ‘disciplined body-self’ shows a close resemblance to our empirical findings and our phenomenological characterization of the older people under study, and is fruitful in interpreting the impact of the embodied dissociation more deeply. Frank states that the ‘disciplined body-self’ primarily defines itself in terms of self-regimentation, being in control and independency. Consequently, one of the gravest crises for the ‘disciplined body-self’ is the experience of losing control. The body-self ‘strives to compensate for the contingencies it cannot accept, endeavours to reassert predictability and uphold its identity’ (Frank, 1995/2013), trying to protect itself from further dependence.

It has already been mentioned in the Introduction that embodiment is an existential condition concerning the physical aspects of human subjectivity. Embodiment is about how a person relates to his own body, including its decline, disabilities or illness. It follows that bodily changes and losses in the narratives should not be basically understood in a functional or behavioural way. The older people under study truly embody the contingencies in their bodily being-in-the-world, which has serious implications for who they are. They not only have that incapable body. In their experience, their body is incapacity. Indeed, they sense that they themselves are that incapable body, while simultaneously they do not want to connect to that incapable body anymore. The loss of control over their body thus has a huge impact on them: on the one hand, they associate themselves with their bodily incapacity on an existential level, though on the other hand, they simultaneously feel dissociated from their body as well.

**Disconnectedness from others:** People do not just live on their own, but are part of an intersubjective world. The way they relate to others – and others relate to them – is central to understanding their sense of being. Thus, in order to properly understand the phenomenon under research an important question was: How does the experience of ‘life is completed and no longer worth living’ affect the older people’s intersubjectivity? And how do their social relations impact their experience? Our research has shown that this subjective experience that life is completed – with underlying feelings of indignity and unworthiness –was not only based on an evaluation of the self by the self. It is not only about the shame of losing autonomy, capability and control. It also had a profound relational dimension. Participants lost
the sense that other people agreed that their lives were indeed worthwhile. While most participants had formerly lived an engaged, busy life, they now felt left without meaningful roles. The experience of not being listened to, not being taken seriously anymore and/or the lack of expressions of respect and appreciation did affront their sense of personal worthiness. They lost the sense of their dignity being respected. In most narratives, a strong sense of disconnectedness from the others and the world was present. Participants used a discourse of not belonging, of being an outsider, and of distance.

This experience of loneliness, of not being recognized anymore, and the increasingly restricted social interactions (due to e.g. decreasing mobility or the death of loved ones) was clearly present in the participants’ stories, as described in chapters 3, 4 and 6. Although this experience is often mainly classified as an ‘interpersonal deficiency’, as we have described in chapters 2 and 7, it can be better understood as existential loneliness (Goossens, 2012; Jorna, 2012; Jorna and Voois, 2014). Rather than suffering from a complete absence of interpersonal relationships, participants suffered from the experience that their remaining contacts did not compensate their lonely feelings anymore. Despite people being around, they felt a lack of reciprocity causing a deep inner existential ache, a sense of emptiness and a void. The sense of existential loneliness was not only constituted by a separation from others, but also by a growing unfamiliarity with themselves and the surrounding world.

A disrupted sense of time: Our study also shows that the sense of temporality of the people under research is disrupted. In chapters 3 and 6, we have described that many participants used a discourse of delay, stagnation and boredom. They felt like they were living in ‘a mind-numbing monotony’, ‘waiting in vacuity for death to come’ and suffering from a feeling of inertia. While their biological time had not stopped yet, in their experience, their biographical time had already ended.

In phenomenological research, temporality refers to people’s sense of time and the way they experience continuities and discontinuities and how this gives meaning to them. Besides, a phenomenological understanding of time is always temporally extended. Temporality is not understood as a collection of isolated now-points along a chronological timeline, but rather
as a continuum. This continuum ‘incorporates not only the present now-points, but also those now-points which are just-past, as well as the anticipations of future now-points’ (Toombs, 1990). Time should not be understood as successive but rather as concentric (Merleau-Ponty, 1962/1945); the past, the present and the future are interconnected spheres. This implies that ‘the past becomes meaningful in people’s lifeworld as it appears in the present, and the future becomes meaningful as it appears towards us now’ (van den Berg, 1972/2013).

Applied to our research, participants’ narratives not only show a strong sense of disconnectedness from the here-and-now, but the future is also often portrayed as really frightening. Indeed, in most stories future fears are anticipated as part of the here-and-now. Especially in the metaphor study in chapter 6, it is shown that participants have internalized profoundly negative expectations of the future, which influence the actual meaning of life. In Frank’s words: ‘The story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable’ (Frank, 1995/2013). It seems that these anticipated fears are often experienced as a disruption or discontinuity of personhood and life. Both current discomfort and future discomfort which is thought to come, are presently lived as an inseparable, intertwined unity.

**Spatial disconnectedness:** Lastly, the social and existential meaning of the places where participants had lived had often changed considerably. An important question is thus: How did changes in spatiality affect lived experience? In particular, the metaphor study in chapter 6 reveals a strong sense of spatial limitation and estrangement. Some participants mentioned that they felt disconnected from the place where they lived because of retirement or relocation. They lost a place they formerly belonged to. Others focused more on the loss of mobility by using images of stagnation, victimhood and captivity to illustrate that they felt blocked, stopped and obstructed. They sensed that their world was getting smaller. On the other hand, there were also older people who talked about a growing distance, a large space, a void between them and the surrounding world. They felt that they led a more and more secluded life. Some even spoke about the world as if they were no longer inhabitants of it anymore.
Contribution to the literature

In sum, based on our research the phenomenon of ‘life is completed and no longer worth living’ can be described as ‘a tangle of inability and unwillingness to connect to one’s actual life’ influencing all dimensions of the lifeworld. The present study makes several noteworthy contributions to the literature. First, our current findings add to the limited body of literature on the wish to die in older people who aren’t diagnosed with a severe mental or physical illness. Indeed, to our knowledge, our study is the first qualitative in-depth study focusing specifically on this topic. Secondly, in our review of the literature in chapter 2, we found several influencing factors playing an important role in developing a wish to die, namely: age-related losses, personal characteristics, biographical factors, social context, personal perceptions and values. Our study fully supports these findings and shows many thematic similarities. Main topics – such as the loss of connectedness, the loss of control, the loss of meaning and the loss of self – are in accord with our study. However, a key strength of our phenomenological study is that it not only presents fragmented results such as ‘themes’ or ‘categories’ without clarifying they are parts of what. Rather, we tried to present ‘a general structure of meaning’ of the phenomenon under research (Dahlberg et al., 2008; Dahlberg, 2006a). Such a structure of meaning contains both essential, general meanings and meaning nuances, such as quotes from interviews. It is this full structure which presumably says something new and enhances our understanding of this phenomenon.

Thirdly, another strength is that our study has given a phenomenological characterization of the people with a wish to end life at a self-appointed moment, but not from an outsider perspective as other studies have done (Kjølseth et al., 2009; Harwood et al., 2006), qualifying those people in a rather negative way as ‘stubborn’, ‘inflexible’, ‘obstinate’, and ‘emotionally closed’, as described in chapter 2. Rather, we have provided a characterization from an insider perspective in line with the way people view themselves, which was described in chapter 3. And lastly, by providing a complementary phenomenological understanding of the wish to die in older people – instead of focusing on a (psychopathological) behavioural explanation or the identification risk factors – our study complements a mainly medical understanding of the wish to die. By taking a phenomenological approach, we have attempted to make explicit the meaning of the everyday life and give a broad understanding of the experienced contingencies from an insider perspec-
tive, an attuned sense of what things are like for the people under research, without compromising people’s subjective truth. Besides, the wish to die is not perceived as a merely individual problem, deriving from a mental illness. Rather, it includes the social and cultural embeddedness of this wish by being highly sensitive to the contextuality of situations, reciprocities, relationships, and involvements. The strengths and benefits of such a phenomenological perspective, in comparison with a medical perspective, are described in more detail in chapter 7.

1.b. A constant feeling of being torn
Our second research question was: 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)? In chapter 5 (and more indirectly in chapter 4) the experiences of living in this in-between period are presented. The results of chapter 5 show that the liminality or ‘in-betweenness’ of intending and actually performing a self-directed death (or not) is characterized as ‘a constant feeling of being torn’. This feeling of being torn 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; and 5) legitimacy and illegitimacy. Below, we will describe the experience of ideating on a self-directed death by using the lens of the experiential dimensions, in the same way as we did above.

The bodily dimension of the wish to die: The wish to die of the older people under research is closely associated with bodily decline. They felt threatened by their own bodies. The unintentional and unwanted bodily changes often caused profoundly alienating feelings and strengthened a wish to die. On the other hand, though, that same body still gave most of them a sense of energy and vitality as well. The body often seemed to exercise restraint on the wish to die by emitting a kind of physical life force; i.e. the joy of good food and a healthy appetite. It thus gave several paradoxical signals. They often felt torn between bodily listlessness and some remaining bodily vitality as well; and between bodily readiness to give up on life and simultaneously a little bodily love for life. This tension was often experienced as deeply confusing, as described in chapters 4 and 5.

The intersubjective dimension of the wish to die: Chapter 5 discusses the intersubjective tension that is associated with living in-between intending
and actually performing a self-directed death. On the one hand, there is a strong desire to make an autonomous choice to end life without any interference of others. On the other hand, the participants felt an aching loneliness due to the absence of support and the impossibility to share their struggle with the ultimate decision. Both sides of this existential paradox were lived simultaneously. While they consciously sought independency, at the same time they suffered from the experience of living alone towards the end of life. In our care-ethical reflection in chapter 8, we have analysed this ambivalent tension in more detail. Our analysis shows that the favoured independence can become vulnerability as well: in some cases, participants felt lonely while at the same time they kept other people at a distance more or less deliberately. Their independence seemed to strengthen their loneliness. Besides, another interpersonal dilemma appeared: although the wish to die was strengthened by feelings of loneliness, invisibility, and not mattering, it was also reduced or postponed by the felt responsibilities towards and concerns for others, as described in chapters 4 and 5.

The temporal dimension of the wish to die: As described in chapters 4 and 5, the wish to die has a distinct temporal dimension. Participants felt torn between urgency and postponement. On the one hand, the older people felt locked in in life. Their future was a dead end. It seemed as if they were ‘frozen in time without meaningful invitations for the future’ (Galvin and Todres, 2013). They missed ‘the call from the future that motivates them in a way that constitutes a sense of purpose’ (Galvin and Todres, 2013). This sense of hopelessness shows close similarities to what Todres and Galvin describe as ‘a time of no respite’: an intolerable present and a repulsive future might give people the feeling of ‘an eternity of suffering’. For most, it was very difficult to be present in the here-and-now. Rather, it aroused a tendency of running away, fleeing forward. Many participants were obviously in a kind of hurry, urgently driven to seek a way out before it was too late. On the other hand, though, the tendency to postpone hastening death – due to certain attachments to life – was also explicitly common in participants’ stories. Despite the fact that life had lost its attractiveness, there were still responsibilities and duties towards themselves and others, and a forlorn hope that maybe things would be better in the near future.

The spatial dimension of the wish to die: The wish to die also appears to have a spatial dimension, as the thought of death seemed to create new space.
While the narratives demonstrated a pervasive fear and disgust of living on (and in some cases of the dying process itself), the fear of being dead seems largely absent. By contrast, all stories show a deep desire to escape from the paradoxes and uncomfortable feelings, and death seems the only possible way out. In some stories, death was perceived as the plain end of all things; some participants did not have any post mortem expectations. For others, death was associated with positive things, such as a state of rest and peace, an endless sleep, and in some cases reunification with loved ones. Despite these differences, in all cases death was associated with the end of suffering, a release of distress and humiliation, a liberation and deliverance of being locked in in life. The way participants talked about their death wishes resonates with what Galvin and Todres call ‘abiding expanse’. By ‘abiding expanse’ they mean that a person is tuned into spatial possibilities, offering an exit for literal and metaphorical adventures or journeys (Galvin and Todres, 2013). Certainly, a self-directed death might be a highly paradoxical way of abiding expanse, but this is indeed the way participants talked about it. The self-directed death appears as a way to regain autonomy. It emerges as the best solution thinkable. While participants have no future expectations except terrifying ones, death provides a so-called dignified exit. In some cases, ideating on death seems to create a liminal space that gives a sense of relief regardless of whether one actually terminates one’s own life or not.

Contribution to the literature
In our study, living between intending and performing a self-chosen death (or not) shows itself as an embodied dilemma, characterized as ‘a constant feeling of being torn’. It appears as a tangle of 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. Our research has several implications.

Firstly, it introduces empirical evidence into the largely theoretical debate on a so-called ‘rational suicide’. Indeed, it provides an empirical argument for the inadequacy of the dichotomy between a rational or non-rational wish to die, which we have discussed in chapter 5. Our findings correspond to the phenomenological and care-ethical acknowledgment of humans’ fundamental embodied connection with the world we live in (Mackenzie et al.,
In real life, there is no dichotomy between the individual and the world, subject and object, mind and body, cognition and emotion (Merleau-Ponty, 1962/1945; Slatman, 2014a). In real life, there is no dichotomy between the individual and the world, subject and object, mind and body, cognition and emotion (Merleau-Ponty, 1962/1945; Slatman and Widdershoven, 2015; Dahlberg, 2006b). It follows that rationality should not be merely reduced to reasoning, logic and argumentation and the power to make your own decisions entirely of your own volition (Solomon, 2002; Weerman, 2016). In line with these acknowledgments, our empirical results show that terms like a ‘self-chosen death’, a ‘self-directed death’, or a ‘self-determined death’ fall short to describe the phenomenon under research, and disguise the fact that the ‘choice’ to end life at a self-appointed moment is often experienced as an ambivalent and ambiguous existential struggle. Rather than an outcome of cognitively weighing the pros and cons, it shows itself as a tangle of complex (and often paradoxical) internal and external processes. Our study also demonstrates that an ultimate choice such as whether or not to end life is never made in a vacuum. Instead of a detached choice, it appears to be an intentional choice (in a phenomenological sense); it cannot be understood apart from its situatedness in – and its directedness towards – its world context (Dahlberg, 2006b; Merleau-Ponty, 1962/1945).

Secondly, our findings seem to confirm the idea developed in the Interpersonal Theory of Suicide of Van Orden et al. (2010) that people with a wish to die are most at risk when two interpersonal themes are simultaneously present, namely: thwarted belongingness and perceived burdensomeness (van Orden et al., 2010). This apparent similarity is interesting because our participants did not have evidence of a severe mental disease. It raises the question of to what extent there might be differences in a suicidal ideation in mentally ill people and death ideation in older people with a completed life.

1.c. The social-political challenges behind ‘completed life in old age’

In chapter 8 of this thesis, we dealt with the third research question, which was: How can the gained empirical insights (from research questions 1 and 2) be connected with the ethical debate on completed life in old age and what considerations can be provided for a care-ethical understanding of emerging social dilemmas? While in the Netherlands there is a strong lobby to legalize (medically or non-medically) assisted dying in cases of completed life in old age, our study strongly questions whether this can be seen as a morally appropriate societal answer to the issue at stake. A number of important
social-political challenges emerge from our findings. Firstly, as described above, rather than being 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. This raises the intriguing question of whether we should lobby for possibilities to hasten death and eliminate these ambiguities, or whether we should prioritize to address these ambiguities.

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. To adequately address the issue of older people and the self-directed death, we have suggested in chapter 8 that we need to rethink this one-sided focus on independency and individuality within our culture, because this imagery falls short in appropriately recognizing the full humanity of every human being, leaving people in doubt as to whether others would agree that their lives are (still) worthwhile. This is in line with the recommendations of the recent advisory report of the Committee of Wise People (Schnabel et al., 2016). Legalizing assisted dying for older people seems to be an individualized response to a partly societal problem, a neglect of the social embeddedness of the wish to die, insensitive to a crisis outside of these people. The focus on assisted dying might be a neglect of other urgent needs. Our research confirms the concern that a societal approval of age-related dependencies being undignified and ‘best resolved’ by assisted dying may even enforce feelings of indignity and social marginalisation in old age (Schnabel et al., 2016; Yuill, 2015).

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. Concerns and anxieties are expressed about the adequacy of care resources in our society (14). The participants also seem to lack the assurance that others will take care of them properly when they become utterly dependent. As described in chapters 5 and 8, most people under research seem to lack trust that their autonomy can be fostered through (informal or professional) relationships of trust, respect and recognition. This mistrust seems to fuel their death wishes. Indeed, a self-directed death seems a way to safeguard themselves (14). Again, this shows that legalizing an assisted
self-directed death for these people might be a solution for a problem that partially has societal (and even economic) roots. Perhaps improving the conditions of those older people might lessen the wish to die and be a more inclusive and solidary solution. 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, to (re)establish trust, and minimise the impact of inherent vulnerabilities and situational dependencies on the lives of older people (Dodds, 2014; Scully, 2014).

Contribution to the literature
Quite some ethical literature has been written on the topic of (assisted dying in cases of) tiredness of life (Raus and Sterckx, 2015; Huxtable and Möller, 2007; de Vries, 2004; Sheldon, 2003; Pike, 2010). However, these analyses were mostly performed from a theoretical stance. Our study has contributed to the ongoing ethical debate by pointing out some important social-political challenges behind the wish to die in older people from a life-world perspective. Besides, we see care ethics as empirically informed ethics. The interaction between empirical research and theoretical reflection is the foundation for normative views. Our empirical study has provided new evidence to strengthen central care-ethical concepts like vulnerability and dependence.

2. EXISTENTIAL SUFFERING FROM DISCONNECTEDNESS IN OLD AGE
Having discussed our findings, we now want to evaluate the terminology used in the Dutch debate. Earlier in this discussion we have already criticized the terminology of self-directed death and self-chosen death. In this section, we will focus on the terminology of ‘completed life’, ‘tiredness of life’ and ‘suffering from life’.

While empirical research into this phenomenon is very limited, completed life or tiredness of life in old age is an acknowledged problem for the general public, clinicians, researchers, and policymakers. It is widely discussed in the media and journals, and addressed through policy and practice initiatives. However, as outlined in the Introduction, there is no formal, agreed conceptualization, not to mention an agreed definition. The
enigmatic character of a so-called completed life seems to be embodied in the diversity of concepts and accompanied definitions. This diversity might not only point out differences in the (theoretical) interpretation but also in the underlying ideology. This lack of precision and consistency is problematic because it makes it difficult to compare research; not only in the area of theory and integration of research findings, but also on more practical levels, such as policy making and (clinical) care. Clearly, this variety of the terminology does not serve a better understanding as to what the needs and the concerns of the older people involved are. Thus, one of the challenges in this field of research is to make an effort towards a (provisional) definition describing an observable constitution of the phenomenon based on our empirical research. But before we make a first attempt, we will now review the existing terminology.

**Completed life:** In the Dutch debate, the expression ‘completed life’ is most commonly used. However, our research supports the conclusion that ‘completed life’ is an inappropriate expression to describe the phenomenon at stake, for the following reasons:

1. Our study has shown that a so-called ‘completed life’ is not at all about ‘fulfilment’, ‘completeness’ or ‘wholeness’; instead, it is about existential suffering. Indeed, on an experiential level, completed life refers to a negative conditional determination of the current quality of life, an ambivalent attempt to foreclose life.

2. The term ‘completed life’ suggests a firm and well-established decision 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.

3. Closely related to the former point, though important to distinguish, completed life suggests that it refers to a moment clearly marked in time, a fact. However, in the lives of the people involved it appears much more as a highly complicated process, an existential struggle with varying intensity.

4. The term simply ignores the fact that someone is still living on. At least at a biological level, life is not completed yet. We have described above that it is actually the body that often seemed to exercise restraint on the wish to die by emitting a kind of physical life force. While there is a strong feeling that life is no longer worth living, often there is also an ambivalent,
embodied longing to live on. The term ‘completed life’ might strengthen the idea of dualism between the body and the mind, which is not helpful in understanding this phenomenon.

All in all, we thus 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 this term and the meaning of the experience it refers to. The term can be seen as a frame, an image or a 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.

**Tiredness of life:** In the literature, the term ‘tiredness of life’ is most frequently used. This term concerns the idea that ‘life is not worth living, or that you’d be better off dead’ (Barnow and Linden, 1997; Dennis et al., 2007). While in our opinion this term is less complicated than the term ‘completed life’, it is still not an accurate representation of the phenomenon under study for the following reasons:

1. Our research shows that ‘tiredness of life’ should be seen as a constituent of the experience that life is no longer worth living. It does not refer to the experience as a whole, but to a part of it.
2. The term tiredness suggests a close association with physical tiredness while our research has pointed out the significance of recognizing existential tiredness as well. The tiredness in the people under research was clearly multi-dimensional.
3. Another complication of this term is that it suggests too strongly that tiredness of life is an individual issue: the person’s body is old and worn out. However, as described before, our research has shown that the experience has a distinct social dimension. The term tiredness of life gives too little account of this dimension.
4. In the literature, tiredness of life is associated with a clinical depression (Barnow and Linden, 1997; Barnow and Linden, 2001) and used in the context of terminal illness. It is important, though, to distinguish between the experience that life is no longer worth living in the context of severe mental or physical illness, and the experience that life is no longer worth living without evidence of a severe mental or physical illness.
**Suffering from life:** Overall, the results of this study indicate that both concepts, completed life and tiredness (or weariness) of life, are non-representative and unclear. The term ‘suffering from life’, introduced by The Committee Dijkhuis (2004) – and afterwards adopted by The Royal Dutch Medical Association – seems to be most in line with our empirical data. To begin with, the term ‘suffering from life’ goes beyond the mind-body dichotomy. It refers to the personally experienced threat, not excluding physical, emotional, existential or even social suffering. Next, suffering refers to the impending destruction of the person; to a threat of the continuation of one’s existence, not merely to one’s life but to the integrity of a person (Cassell, 1994; Cassell, 1998). In this sense, suffering from life does not underestimate the level of despair in the lives of the people concerned.

Although the terminology of suffering encompasses important aspects that are underscored or even neglected in the other terms, the term ‘suffering from life’ does not cover the phenomenon under research for at least two reasons:

1. Our research shows that the people under research not only suffered from life. They suffered from the threats of all kinds of age-related losses, i.e.: loss of autonomy, loss of meaning and connection, and loss of future. In particular, the older people suffered from the sense of disconnectedness from life, others and themselves, strongly associated with a sense of existential loneliness.

2. Suffering from life is not age-related. Although many characteristics of the investigated phenomenon show similarities with characteristics in people tired of life from other age groups, this specific phenomenon is age-related. We presume it is desirable that this should be reflected in the terminology.

Thus the term suffering from life falls short as well. To indicate that the phenomenon should primarily be understood from an existential paradigm (and not from a medical psychopathological paradigm) we propose that the description ‘existential suffering from disconnectedness in old age’ might most closely resemble the phenomenon under research. With some reservation, we propose a provisional definition in need of complementing in Box 1.
BOX 1: A provisional definition of ‘existential suffering from disconnectedness in old age’

*Older people who got into a tangle of inability and unwillingness to connect to life (to themselves, others and the world) resulting in the experience that life is no longer worth living and death is preferred over life, while there is no evidence of a severe physical or mental disease. This sense of disconnectedness is constituted by:*

- a profound sense of existential loneliness; older people feel separated from others.
- the pain of not mattering; they view themselves as dispensable, redundant and not important to people or society.
- the growing inability to express themselves; they are no longer able to carry out the activities they were committed to in life.
- existential and physical fatigue.
- a sense of aversion to feared dependence, referring to the fear of losing control and the uncertainty as to whether others will guard their interests if they are dependent on these people.

3. METHODOLOGICAL CONSIDERATIONS

In the last pages of this thesis, we will discuss the main methodological strengths and limitations of this study. First, we will evaluate the quality of this study. Subsequently, we will discuss some epistemological aspects of phenomenological research and share some considerations about the kind of evidence this study provides.

3.a. Evaluation of the quality of the study

Due to the nature of phenomenological research, commonly used qualitative research measures – such as sampling, member check, and saturation – are not generally compatible with phenomenological research. These predetermined procedures cannot properly validate a phenomenological study, because a phenomenological study does not describe the factual or causal empirical (van Manen, 2014). Rather, it describes the existential empirical meaning structures of a phenomenon. Thus the validity of this phenomenological study should not be sought in the validation of the quality of the accounts, but instead in the evaluation of to what extent the study prop-
erly displays what this phenomenon is like (van Manen, 2014; Halling, 2010). The key question is thus whether the phenomenological descriptions of the underlying meaning structures are valid. We will use four criteria that phenomenological researchers commonly use for the evaluation of the quality of this kind of study, namely rigour, relevance, resonance and reflectivity (Finlay, 2011).

**Rigour** refers to the coherence between the underlying phenomenological paradigm and the actual conduct of the study. Rigour also concerns the soundness of the interpretative process demonstrated in the study, and the inner logic of the findings. All method sections of the chapters in Part 2 of this thesis partly evaluate the rigour of the interpretive process. In phenomenological research, the question of variation and the information richness of cases is more important than the questions of sample size and saturation (Dahlberg et al., 2008; Patton, 2002). This can be explained from the ontological and epistemological idea that ‘meanings are infinite, always expanding and extending themselves. Consequently, no meaning saturation can exist’ (Dahlberg et al., 2008). Although being aware of the fact that some authors argue that the practice of sampling is not coherent with phenomenological research (van Manen, 2014) as it might presuppose that one aims at empirical generalization from a sample to a population, we have used the notion of purposive sampling in a manner that is consistent with our phenomenological assumptions. Likewise, our study aimed to provide an essential understanding – and thus an existential generalization – we needed to gather and explore the experientially rich descriptions. Respondents were thus purposefully sampled, based on the richness of their experiences and variations in demographic backgrounds. Next, by performing a member check, we did not ascertain the factual empirical. Rather, we aimed to ascertain whether the anecdotes derived from the accounts resonated with participant’s original experiences. Furthermore, the knowledge claims were validated in dialogues among the research team, and with other research peers and health professionals at many discussions during national and international meetings. Additionally, the use of different perspectives and methods in the four studies in chapters 2, 3, 4, and 5 will hopefully convince the reader that all together they provide a coherent description of the lived experience.

**Relevance** is about the scientific and practical value of the study in terms of its applicability and contribution. While the issue of completed life and the
self-directed death in older people is a highly debated topic in the Netherlands, scientific knowledge is still seriously limited. This research project has thus provided a much-needed initial insight into this phenomenon. Firstly, it has given a rich and accurate description of the phenomenon of suffering from life in older people. This description is an indispensable step towards common conceptualizations of the phenomenon. Secondly, this project has clearly indicated the inadequacy of considering suffering from life to be a solely individual problem. In fact, the study has pointed out the benefit of a social understanding. Thirdly, the study has shown that the wish to die in older people who consider their lives to be ‘completed’ should not be understood as fixed and rational. All kinds of ambiguities are present after a putatively rational decision has been made. In many cases, the wish to die appeared to be an anticipated and ambivalent desire driven by strong emotions such as loneliness, a feeling of not mattering, fear of dependence, anxiety and shame. This research has played a policy-supporting role in nuancing and qualifying the Dutch debate on the self-directed death in older people suffering from life (Schnabel et al., 2016).

Resonance concerns the question as to whether the accounts provide vivid and profound insights into lived experiences and meaning by using evocative language. Van Manen uses the term ‘inceptual epiphany’ (van Manen, 2014), meaning that a high-quality phenomenological study should offer ‘the possibility of deeper and original insight, and perhaps, an intuitive grasp of the ethos of life commitments and practices’ of the people under study. In order to reach resonance, we based our analysis on experiential, descriptive accounts and we constantly tried to avoid empirical material that consists of opinions, beliefs and views. Even though many participants were also highly opinionated about the issue at stake – especially about the question of whether assisted dying in cases of completed life should be legalized – we tried to stay focused on the lived experience of the older people involved, not only during the data gathering and data analysis, but also in the presentation of the data. We presume that this has led to a descriptive richness that has the quality of being resonant and can enable the reader to engage with the phenomenon under research.

Reflectivity refers to the researcher’s openness about the research process, to self-scrutiny and to ethical integrity. These issues were thoroughly discussed in chapter 9, and also more shortly in several other places in Part
of this thesis. We have striven for an attitude of openness, susceptibility and sensitivity to the participants and to the phenomenon during the whole research process. Dahlberg et al. (2008) poses that phenomenological research requires ‘objectivity in research’, which she distinguishes from ‘objectivism’. She acknowledges that pre-understanding-free, history-free, tradition-free, or in any other way context-free research does not exist. However, researchers should strive for ‘objectivity’, which (in phenomenological research) is characterized by being as open as possible and allowing the phenomenon to appear to us as it is lived. Practising this reflective attitude is called ‘bridling’ (Dahlberg et al., 2008). By means of a reflective research journal and an ongoing dialogue with co-authors and peers during the whole research process, we put all efforts into slowing down the process of understanding, and trying to prevent our personal ideas and scientific assumptions from having an uncontrolled effect on evolving understandings. While we presume that these efforts have improved the validity and rigour of our study, we do recognize that these efforts always fall short. During our research project, there was a vigorous debate about completed life in old age. We as researchers were part of that debate and being involved made it difficult to stay open, ‘not making definite what is indefinite’ (Dahlberg et al., 2008), or to take a position too early. We do acknowledge that openness is not so much a standard of achievement; it should rather be seen as a ‘reductive-reflective dance’ (Finlay, 2011). It is a process in which the researcher is constantly challenged with old and new ideas, stepping away from initial assumptions, moving on to new insights and interpretative revisions (Finlay, 2011).

3.b. Meaning-based evidence

An important epistemological question is: What kind of knowledge have we gained during this project? Phenomenological truths should not be understood as ‘final and law-like absolutes’ and ‘conclusive distinctions between the true and the false’ (Todres et al., 2007; Halling, 2010; van Manen, 2014). Phenomenological truths should rather be understood as ‘possibilities around which unique variations and actualities can occur’. Truth is considered to be ‘an ongoing conversation which is never finished and depends on questions and context’ (Todres et al., 2007). To explain this specific conception of truth, Van Manen describes the Heideggerian distinction between veritas and aletheia (van Manen, 2014). Veritas is a notion of truth that refers to pragmatic, technical and bureaucratic knowledge that relies
on controlled and controllable methods and instrumental procedures. In contrast, phenomenological truth should be understood as *aletheia* which is a notion of truth that refers to disclosure, unconcealment and openness. Truth as *aletheia* is about the elucidation of how the world is disclosed or opened up. It thus involves a ‘heedful attunement to how things appear in the world’ and present themselves to us. It is ‘not an all-or-nothing affair but rather a complex and constant interplay between showing and hiding’ (van Manen, 2014).

Given these considerations, it follows that our phenomenological inquiry did not aim at logically valid deductive conclusions. Rather, it aimed at providing plausible and inceptive insights into the primal meaning structures of lived experiences (Halling, 2010). It also follows that phenomenological truth, and thus phenomenological evidence, is ambiguous and never complete (van Manen, 2014). It has been argued that generalization and theory development do not belong to phenomenological research at all. However, we follow the position of Dahlberg et al. (2008) among others, who pose that a phenomenological inquiry wants to reach knowledge that goes beyond the concrete individuals. We aimed for the formulation of an essence, a general structure of meaning. However, it has been mentioned before that phenomenological research results are always contextual and meanings are always infinite. In chapters 3 and 5, we have explained we presume that our interpretation can be seen as most likely, providing insight and a thorough understanding of the phenomenon under research. This transferability claim should not be understood as a universal, factual and/or quantitative generalisation. Rather, it should be understood as an ‘existential generalization’, providing a meaning-based, essential understanding of the phenomenon that should help to ‘make contact with life as it is lived’ (van Manen, 2014; Halling, 2010).

Because we have already reflected on the question of the transferability of our findings in chapters 3, 4, 5 and 6, it suffices to say here that we are aware that our results are influenced by the cultural and political context in which our research took place. While the idea that life can be considered as no longer worth living is more common in old age, the strong wish to end life at a self-appointed moment might be strengthened by the Dutch cultural and legal context of our study.
3.c. Future research
Whilst our study has made a considerable contribution to the literature, it has also provided many questions in need of further investigation. Firstly, an important question is to what extent the outcomes of this research project – with its specific Dutch cultural embeddedness – are transferable to other countries. Secondly, no theory is yet available to explain the phenomenon. Further research should examine questions like: How does the wish to die come about and evolve over time? What is the role of a person’s character and biography? And how do significant relationships influence the experience of suffering from life? What are cultural and social influences on the development of a wish to die? What is the role of cultural representations of ageing and death and how are these reflected in the narratives of people?

Thirdly, while we made a first attempt in chapter 8 to connect our empirical insights with the ethical debate on completed life in old age, an ongoing ethical understanding grounded in the lives of the people involved is needed to align careful and ethically sound policy and support for these people. And lastly, our phenomenological understanding of the lived experience of the people involved can be enriched by rethinking our empirical outcomes in the light of the phenomenological concepts of temporality, finitude, thrownness, and being-towards-death. According to Heidegger among others, these notions are essential for the understanding of being and can elucidate our understanding of human existence and the way we live towards death.

A final note
This thesis has come to an end. The main purpose was to enter people’s lifeworld and to gain insight into living meaning. I sincerely hope that the results of our study have revealed an embodied truth of the older people’s lives. And that they have indeed enlarged the understanding of the lifeworld of these people. My ambition is that our results might benefit the development of a careful policy and due care for older people who suffer from life. And hopefully we will keep wondering with an open mind about life in general and this phenomenon in particular, as truth is always open-ended and transcending our perceptions of the world.
REFERENCES


Frank AW. (1993/2013) *The wounded storyteller: Body, illness, and ethics*.


SUMMARY

SAMENVATTING
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 actu-
ally 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 explained 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 phe-
nomenon 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.
SAMENVATTING

Als de ouderdom mijn geest in verwarring gaat brengen en bepaalde delen daarvan gaat ondermijnen, als hij mij geen leven meer overlaat, maar alleen een levensbeginsel, dan zal ik uit dat verweerde en bouwvallige huis springen (Seneca, 1980).

Het lijkt me aan geen twijfel onderhevig dat veel oude mensen er een grote rust in zouden vinden als zij over een middel konden beschikken om op aanvaardbare wijze uit het leven te stappen op het moment dat hen dat – gezien wat hen daarvan nog te verwachten staat – passend voorkomt (Drion, 1991).

Ouderen die hun leven ‘voltooid’ vinden, die lijden onder het vooruitzicht verder te moeten leven en daarom een zelfgekozen levensinde verkiezen; het is geen nieuw onderwerp. Wat wel relatief nieuw is, is dat momenteel in Nederland een maatschappelijke discussie gevoerd wordt over de vraag of we hulp bij deze zelfgekozen dood moeten legaliseren, faciliteren en dus institutionaliseren. Hebben ouderen die na zogenoemd ‘ampel beraad’ tot een weloverwogen beslissing komen dat zij klaar zijn met leven zijn, recht op hulp bij zelfdoding? Alvorens te komen tot zorgvuldige politiek-beleidsmatige keuzes is het noodzakelijk om inzicht te hebben in de aard en de existentiële grondslag van deze stervenswens. Het gaat dan om wezenlijke vragen als: Wat bedoelt iemand eigenlijk als hij aangeeft zijn leven als ‘voltooid’ te beschouwen? Wat zijn onderliggende motieven en ervaringen die tot deze stervenswens leiden? Voor zover wij weten is er tot op heden nog geen wetenschappelijk kwalitatief empirisch onderzoek gedaan naar de ervaring van ouderen die zeggen een ‘voltooid leven’ te hebben. Dit proefschrift wil in deze leemte voorzien. De volgende onderzoeksvragen stonden centraal:

1. Wat is de essentie van de geleefde ervaring van ouderen die hun leven als voltooid beschouwen en de wens hebben om hun levensinde zelf te regisseren (zonder dat zij lijden aan een levensbedreigende ziekte of een psychiatrische stoornis)?

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2. Wat betekent het om te leven met de intentie van een zelfgekozen levenseinde (in de periode tussen het voornemen en het al dan niet daadwerkelijk beëindigen van het leven)?

3. Wat zijn de morele vraagstukken rond het fenomeen van voltooid leven die in het wetenschappelijke, publieke en klinische debat moeten worden geadresseerd? Hoe kan de thematiek geduid en geëvalueerd worden vanuit (zorg)ethisch perspectief?


DEEL 1: STATE OF THE ART

Hoofdstuk 2 is een weerslag van een literatuurreview naar de vraag welke ervaringen en motivaties ten grondslag liggen aan de stervenswens van mensen die levensmoe zijn zonder dat zij lijden aan een ernstige depressie of een levensbedreigende ziekte. Wetenschappelijke databases werden doorzocht op publicaties tussen 1991–2011. Studies die specifiek ingaan op een stervenswens zonder een directe medische en/of pathologische oorzaak bleken zeldzaam. Er werden uiteindelijk 9 studies gevonden die voldeden aan de inclusiecriteria. De gevonden studies geven inzicht in de existentiële impact van de vele verlieservaringen waarmee het ouder worden gepaard gaat; het verlies van controle, verbondenheid, betekenisgeving en identiteit. Deze verlieservaringen spelen een belangrijke rol bij de ontwikkeling
van een stervenswens. Daarnaast spelen de volgende factoren ook een rol: persoonlijkheidskenmerken, biografische factoren (zoals trauma’s en andere heftige gebeurtenissen), de sociale context en persoonlijke opvattingen en waarden. De duiding van de stervenswens verschilt sterk per studie. Sommige studies beschrijven de stervenswens vooral in termen van pathologie, terwijl anderen de stervenswens beschouwen als een ‘natuurlijk’ fenomeen; de stervenswens als een resultaat van een rationele en navolg bare beoordeling van de kwaliteit van de huidige levenss staat. Ook vonden we één studie waarin gepleit wordt om het pathologische paradigma te vervangen door een existentieel paradigma en de stervenswens te verklaren in termen van existentiële rouw.

DEEL 2: DE GELEEFD ERVARING BESCHREVEN

Hoofdstuk 3 beschrijft het eerste deel van de resultaten van een fenomenologische interviewstudie naar de geleefde ervaring van ouderen met een voltooid leven. Deelnemers aan het onderzoek waren 25 Nederlandse wilsbe kwame ouderen (met een gemiddelde leeftijd van 82 jaar) zonder terminale ziekte of (gediagnostiseerde) psychische aandoening. De fenomenologische interviews hadden een open, explorerend karakter en onderzochten de ervaring van de ouderen van binnenuit. Nadruk lag daarbij niet op percepties en gedachten, maar op de wijze waarop participanten de ervaring dagelijks doorleefden; oftewel op het uitvragen van gebeurtenissen en situaties. Het onderzoek laat zien dat de essentie van het fenomeen voltooid leven kan worden omschreven als een klue van onvermogen en onwil om nog langer verbinding te maken met het leven. Dit proces van losraken (van de wereld, anderen en jezelf) levert permanente spanning en verzet op en het versterkt het verlangen om het leven te beëindigen. Deze ervaring is geëxplie teerd in vijf thema’s die terugkomen in alle verhalen en samen de ervaring van losraken verder invulling geven.

Het eerste thema is een diep gevoel van existentiële eenzaamheid; ouderen voelen zich afgescheiden van anderen. Soms zijn er nog wel contacten, maar het lukt ouderen niet meer om echt verbinding te maken. De wereld komt steeds verder van ze af te staan. Het tweede thema is het gevoel er niet meer toe te doen; ouderen hebben het gevoel dat het leven doorgaat, maar dat zij niet meer meedoen. Ze staan aan de zijlijn; uitgerangeerd. Het der-
de thema dat de ervaring van losraken bepaalt, is een groeiend onvermogen tot zelfexpressie; ouderen hebben de ervaring dat zij zich niet meer kunnen uiten op de voor hen zo kenmerkende wijze, een manier die bij hen paste, waarmee ze uiting gaven aan hun identiteit. Langzamerhand verliezen ze hierdoor ook zichzelf. Het vierde thema is existentiële en lichamelijke moeheid: ouderen zijn moe vanwege lichamelijke problemen waarmee de ouderdom gepaard gaat, maar in veel gevallen is er ook sprake van existentiële moeheid en verveling. Ze zijn oud en der dagen zat. Het vijfde thema is een innerlijke afkeer van en weerstand tegen (gevreesde) afhankelijkheid. Het betreft een angst om afhankelijk te worden van anderen en de controle uit handen te moeten geven, terwijl je niet zeker weet of jouw belangen straks wel goed behartigd worden. Bij veel ouderen is er ook sprake van een diepe schaamte voor en weerzin tegen hun eigen aftakelende lichaam. Een opvallende bevinding is dat ons onderzoek laat zien dat de stervenswens bij voltooid leven een duidelijk sociaal-positionele kant heeft; gevoelens van sociale uitsluiting en nutteloosheid spelen een belangrijke rol.

Hoofdstuk 4 beschrijft een fenomenologische casestudy die inzicht geeft in de ervaringen van een echtpaar dat toeleeft naar een gezamenlijk zelfgekozen levenseinde waarmee zij verdere aftakeling willen voorkomen. Het echtpaar maakt deel uit van de onderzoeksgroep die beschreven is in hoofdstuk 3. Deze case is daarnaast apart geanalyseerd en beschreven met behulp van de volgende leefwerelddimensies: zelf, betrokkenheid, belichaming, tijd en relaties. Deze studie laat zien dat de beslissing voor een gezamenlijk levenseinde grotendeels gebaseerd is op de anticiperende angst voor een verdere aftakeling en controleverlies. De keuze wordt door het echtpaar energiek geduid als een rationele, logische, nuchtere enweloverwogen beslissing die zij jaren geleden hebben gemaakt na ampel beraad. Anderzijds blijken zij grote moeite te hebben om de emotionele impact van de beslissing te bespreken met elkaar en met hun kinderen. Ook verschilt de wijze waarop zij toeleven naar het ultieme moment aanzienlijk; met name de mate van onthechting en de tijdervaring lopen sterk uiteen. Ze houden elkaar in de greep met hun beslissing en raken in een impasse. De casestudy toont aan dat de beweegredenen van een gezamenlijke zelfdoding vaak ambigu en complex zijn. Daarnaast bevestigt het eerder wetenschappelijk onderzoek waaruit blijkt dat een gezamenlijke zelfdoding lang niet altijd gebaseerd is op een volledig gezamenlijke beslissing. Er is vaak sprake van een zekere mate van druk die partners op elkaar – of op zichzelf – uitoefenen. Ook kan
er sprake zijn van onzichtbare, innerlijke druk waardoor een evenwichtig besluit bemoeilijkt kan worden.

**Hoofdstuk 5** beschrijft het tweede deel van de resultaten van een fenomenologische interviewstudie naar de geleefde ervaring van 25 ouderen met een voltooid leven. De interviews zijn hier geanalyseerd met behulp van de vraag hoe mensen de periode tussen het voornemen van een zelfgekozen levenseinde en het al dan niet daadwerkelijk uitvoeren ervan ervaren. De resultaten van de interviews laten zien dat deze periode door de onderzochte groep ouderen wordt ervaren als een ambivalent en dubbelzinnig proces; een constant dilemma. Dit dilemma komt naar voren in de volgende thema’s: 1) heen en weer geslingerd worden tussen gevoelens van onthechting en gehechtheid; 2) een mix van rationele en niet-rationele overwegingen; 3) een voortdurend streven naar controle en tegelijk de aanhoudende onzekerheid; 4) verzet tegen bemoeienis van anderen en tegelijk ook een sterk verlangen naar ondersteuning; 5) de wens voor openheid en legitimiteit, en tegelijk gevoelens van taboe en onwettigheid. Onze bevindingen nuanceren eerder wetenschappelijk onderzoek naar zogenaamde ‘rationele suïcides’. De periode tussen voornemen en doen toont zich als een grote, existentiële uitdaging waarin mensen heen en weer geslingerd worden tussen tegenpolen in zichzelf, en minder als een coherent, calculerend proces van cognitief-rationele oordeelsvorming. Onze studie sluit de mogelijkheid van rationele suïcides niet uit, maar wijst op zijn minst op de noodzaak van erkenning van alle dubbelzinnigheden en ambivalenties waarmee mensen worstelen bij hun keuze voor een zelfgekozen levenseinde.

**Hoofdstuk 6** beschrijft de metaforische beelden die ouderen gebruiken om hun gevoelens en zorgen over de (gevreesde) ouderdom te uiten. In deze metaforenstudie zijn de 25 verbatims opnieuw bestudeerd. Alle metaforen met betrekking tot ouderdom zijn verzameld en geanalyseerd. De volgende tien centrale metaforische beelden kwamen uit de interviews naar voren: 1) strijd; 2) slachtofferschap; 3) leegte; 4) stagnatie; 5) gevangenschap; 6) krakemikkigheid; 7) overbodigheid; 8) sub-humanisering; 9) last; 10) kinderlijkheid. Onze studie laat zien dat de groep onderzochte ouderen zeer negatieve beelden gebruikt over ouderdom. Hun angst en afschuw voor ouderdom betrekkend zij ook op hun eigen leven. De analyse van de gebruikte metaforische beelden verdiept het inzicht in de leefwereld van ouderen met een voltooid leven en de ervaring van losraken en verbinding verliezen (hoofd-
stuk 3). Ook geeft het verder inzicht in de anticiperende angst waarmee de stervenswens gepaard gaat: ouderen lijden nu al sterk onder het mogelijke onheil van wat hun in de toekomst zou kunnen overkomen (hoofdstuk 4 en 5). Daarnaast vragen de resultaten van deze studie aandacht voor het feit dat het negatieve discours dat ouderen gebruiken voor hun zelfverstaan lijkt te corresponderen met een negatief maatschappelijk discours (met nadruk op kosten, tekort en gebrek) over de vergrijzing en veroudering. Hiermee geeft de studie indirect empirische aanwijzingen dat wijdverbreide stigmatiseringen niet alleen kunnen bijdragen aan een devaluatie van ouderdom in het algemeen, maar ook effect kunnen hebben op persoonlijk welbevinden.

DEEL 3: FENOMENOLOGISCHE EN ETHISCHE REFLECTIES

Hoofdstuk 7 reflecteert op de fenomenologische aanpak die ten grondslag ligt aan dit onderzoek. In de literatuur wordt de stervenswens van ouderen veelal begrepen vanuit een medisch-psychopathologisch paradigma en aangeduid als een depressieve stoornis, pathologische rouw en/of suïcidaliteit. In dit hoofdstuk bespreken we drie beperkingen van dit dominante paradigma. Het eerste risico is ‘epistemische transformatie’: doordat taal verandert of verdwijnt, ontberen mensen mogelijk geschikte hermeneutische middelen om belangrijke (existentiële of morele) ervaringen te interpreteren en hierover te communiceren. Dit kan resulteren in een beperkter zelfverstaan (in dit geval een medicalisering van het zelf, en van de stervenswens). Het tweede risico van een medisch-pathologisch paradigma is de reductie van de persoon met een stervenswens. Diagnostische classificatieschema’s en bijbehorende symptomenbeschrijvingen zijn manieren om het (in dit geval suïcidale) gedrag van een persoon te beschrijven, te objectiveren en te abstraheren met als doel om het te verklaren. Door deze objectiverende, instrumentele en probleemgerichte kijk op het leven bestaat het risico dat de subjectieve, geleefde ervaring van mensen buiten beeld blijft. Dit kan leiden tot een ervaring van miskkening of mismatch. Het derde risico van een pathologisch paradigma is de neiging tot een louter individuele benadering; problemen zouden voortvloeien uit een disfunctioneerde mentale toestand. Deze geïndividualiseerde interpretatie kan leiden tot het marginaliseren of negeren van de sociale en culturele inbedding van de stervenswens. Dit is problematisch, zeker omdat in dit geval sociale en positionele aspecten een grote invloed blijken te hebben.
In dit hoofdstuk pleiten wij daarom voor een aanvullend fenomenologisch perspectief op de stervenswens. Zonder af te doen aan de betekenis van goede diagnostiek van suicidaliteit en depressie, beschrijven we dat een aanvullend fenomenologisch perspectief de problematiserende effecten van medicalisering van de stervenswens kan tegengaan. Een fenomenologische benadering biedt een ander soort kennis, zogenaamde ‘pathic knowledge’ (waarmee bedoeld wordt: gesitueerde, belichaamde kennis). De stervenswens wordt begrepen vanuit de geleefde contextuele ervaring, waarbij ook sociaal-positionele aspecten belicht worden. Dit aanvullend perspectief is onmisbaar voor een goed begrip van de thematiek.

**Hoofdstuk 8** reflecteert op de sociaal-politieke dimensies van de thematiek van voltooid leven. We verbinden de empirische uitkomsten van onze fenomenologische studie met het ethische debat. We bespreken een aantal belangrijke ethische noties die aan bod kwamen tijdens de analyse – namelijk: autonomie, kwetsbaarheid, (on)afhankelijkheid en waardigheid. We doen dit vanuit zorgethisch perspectief. Onze zorgethische analyse wijst allereerst op de ontoereikendheid om de wens tot (hulp bij) zelfdoding in termen van rechten en belangen te duiden. Op basis van de uitkomsten van ons onderzoek pleiten wij voor een verschuiving in het vraagstuk over het zelfgekozen levenseinde: van een nadruk op rechten en belangen naar een nadruk op (geleefde) zorgen en behoeften. Op basis van de uitkomsten van ons onderzoek pleiten wij voor een verschuiving in het vraagstuk over het zelfgekozen levenseinde: van een nadruk op rechten en belangen naar een nadruk op (geleefde) zorgen en behoeften. Daarnaast werpt onze ethische analyse van de empirische gegevens licht op de wijze waarop onze veranderende samenleving de gevoelens van vervreemding, zinloosheid, gevoelens van sociale ontbinding en existentiële eenzaamheid mogelijk versterkt. Als laatst belicht het hoofdstuk ook een aantal tekortkomingen in de heersende opvatting van mensen als onafhankelijke, autonome en zelfbepalende wezens. Onze studie roept op tot een verfijnder begrip van menselijke afhankelijkheid: Hoe kan ouderdom met toenemende kwetsbaarheid en afhankelijkheid zodanig begrepen worden dat het menselijke waardigheid niet uitsluit? Een herbezinning op de waarde van ouderdom is essentieel om het probleem van voltooid leven op een verantwoorde wijze te adresseren: Hoe kunnen we bouwen aan een inclusieve samenleving, intergenerationeel vertrouwen versterken, en de impact van de inherente kwetsbaarheden en situationele afhankelijkheid van ouderen zo veel mogelijk minimaliseren?
Hoofdstuk 9 is gewijd aan onderzoeksethiek. Het bevat een ethische reflectie op de vraag hoe je op moreel verantwoorde wijze onderzoek doet naar een zeer gevoelig onderwerp als de wens om te sterven. We pleiten voor een reflectieve onderzoeksethiek – met expliciete aandacht voor ethisch ongemak – als onmisbare aanvulling op de procedurele onderzoeksethiek. Ethische richtlijnen vormen een belangrijke basis, maar gedurende het onderzoek is voortgaande reflectie op morele spanningsvelden essentieel. Vier moreel complexe kwesties worden besproken. Allereerst wordt gereflecteerd op de mogelijk versterkende invloed van ons onderzoek op de stervenswens, oftewel de morele ervaring van het al dan niet medeschuldig zijn. In hoeverre heeft ons onderzoek een bekrachtigende of versterkende werking gehad op de stervenswens? Ten tweede wordt de vraag gesteld of wij als onderzoekers een plicht hadden om in te grijpen (of op hulp aan te dringen) omdat wij weet hadden van serieuze plannen om het leven te beëindigen, terwijl wij ook wisten dat participanten geen prijs stelden op inmenging in hun leven. Dit betreft de morele ervaring van het al dan niet inbreuk doen op iemands autonomie.

Als derde wordt het dilemma van nabijheid besproken: een fenomenologisch onderzoeker probeert in korte tijd vertrouwen op te bouwen om hoogstpersoonlijke zaken te bespreken, in dit onderzoek onder andere de ervaring van eenzaamheid en marginalisatie. Na het interview gaat de onderzoeker weer weg en laat de participant alleen achter. Dit alleen laten roept een gevoel van ongemak op. Het vraagt om een reflectie op de morele ervaring van het vertrouwen beschamen. Als laatst wordt het spanningsveld besproken aangaande de macht van de onderzoeker over de data. Uiteindelijk bepaalt de onderzoeker hoe de data gepresenteerd worden. In ons onderzoek was er sprake van een flinke discrepantie tussen het ‘geleefde zelf’ en het ‘politieke zelf’ bij diverse participanten. In hun ervaringen van voltooide leven kwamen veel meer ambivalenties en kwetsbaarheden naar voren dan in hun (politieke) opinies aangaande de voltooid-leven-thematiek. De weergave van de resultaten riep in sommige gevallen weerstand op bij participanten; men wilde liever het ‘politieke zelf’ verwoord zien dan het ‘geleefde zelf’. Deze ervaring leidde bij de onderzoekers tot bezinning op de vraag in hoeverre we iemand in een verkeerd daglicht hadden gesteld (moral experience of presumed misrepresentation). Een van de conclusies in dit hoofdstuk is dat openheid over (blijvend) ethisch ongemak en niet-sluitende antwoorden een belangrijke constituent vormt van een moreel goede onderzoekspraktijk.
Hoofdstuk 10 vat de belangrijkste resultaten en kernpunten van dit proefschrift samen. Daarnaast worden enkele relevante methodologische afwegingen besproken. De discussie sluit af met enkele aanbevelingen voor toekomstig onderzoek.


Het tweede belangrijke kernpunt is de wijze waarop de periode tussen het voornemen van het zelfgekozen levenseinde en het al-dan-niet daadwerkelijk uitvoeren ervaren wordt. Dit blijkt een ambivalent en dubbelzinnig proces; een constant dilemma. Dat dilemma wordt gevoeld in het lichaam; enerzijds versterkt de aftakeling de wens om te sterven. Anderzijds is er ook een fysieke drive om te blijven leven. Ook relationeel is er sprake van een paradoxe spanning: enerzijds willen de participanten dat hun omgeving zich niet met hun stervenswens bemoeit, anderzijds is er ook een hunkeering naar betrokkenheid en een verdriet omdat ze zich op zichzelf teruggeworpen voelen. De stervenswens is ook dubbelzinnig in temporeel opzicht: er is sprake van een bepaalde urgentie, soms zelfs haast; men wil niet te laat zijn met het beëindigen van het leven en een bepaalde aftakeling voor zijn. Tegelijkertijd was er bij veel participanten ook de neiging tot uitstellen, tot tijdrekken. Als laatst wordt beschreven dat de wens om te sterven ook werd ervaren als een mogelijkheid om nieuwe ruimte te betreden, oftewel het zelfgekozen levenseinde als een vorm van *abiding expanse*, een manier om grip te krijgen, controle te behouden. Alleen al de gedachte aan een moge-
lijke manier om te ontsnappen gaf velen een gevoel van opluchting en leek een soort liminale ruimte te creëren.

Een derde kernpunt is de beschrijving van een aantal belangrijke sociaal-politieke uitdagingen die uit ons onderzoek naar voren komen. Ten eerste wordt in het Nederlandse debat de wenselijkheid van hulp bij zelfdoding bij een voltooid leven voornamelijk onderbouwd met argumenten die gebaseerd zijn op een neoliberaal ethos van zelfbeschikking, autonomie en onafhankelijkheid: een oudere zou het recht moeten hebben om – na wel-overwogen rationele besluitvorming – te kiezen voor een zogenoemde waardevolle dood en daarbij het benodigde hulp te krijgen. Uit ons onderzoek blijkt echter dat de suggestie dat de stervenswens voortkomt uit een rationale, calculatorende en coherente afweging te beperkt is en geen recht doet aan de geleefde ervaring van de ouderen. De afwegingen worden eerder gekenmerkt door grote existentiële uitdagingen die doordrongen zijn van dubbelzinnigheden. Ten tweede hebben de afwegingen een duidelijke sociaal-positieonse dimensie: ze komen mede voort uit gevoelens van onwaardigheid, nutteloosheid en marginalisering. Ten derde toont ons onderzoek aan dat de stervenswens ook deels de makens heeft met wantrouwen ten aanzien van (de ontoereikendheid van) de zorg. Ondanks het feit dat er een sterke lobby is om hulp bij zelfdoding in gevallen van voltooid leven te legaliseren, betwijfelen wij op basis van ons onderzoek sterk of legalisatie een toereikend en moreel juist maatschappelijk antwoord is op voltooid leven en de bijhorende problematiek.

Als een van de laatste punten evalueren we de begrippen voltooid leven, levensmoeheid, en lijden aan het leven. We concluderen op basis van onze studie dat alle drie de termen beperkingen hebben. Het begrip voltooid leven is het meest complicerend. De term heeft een montere klank en suggerert dat het gaat over vervulling, afgerondheid of volledigheid. Daarnaast suggereert de term dat het over een moment in de tijd gaat. Het besluit is genomen. Het is klaar. In de praktijk blijkt echter dat de besluitvorming zich veel meer kenmerkt als een ambivalent dilemma waarin zekerheid en onzekerheid elkaar voortdurend afwisselen en zelfs samengaan. Ten slotte negeert de term het feit dat iemand nog leeft. Biologisch gezien is het leven nog niet afgerond. Er is vaak nog een fysieke levenskracht. Maar zelfs biografisch is het leven nog niet afgelopen. Enerzijds wil men het levensverhaal op tijd afsluiten, geen nieuwe hoofdstukken meer toevoegen omdat
men alleen nog maar narigheid verwacht. Anderzijds wordt het verhaal tegelijkertijd (bewust en onbewust) voortgezet, door het voorbereiden van het levens einde, maar ook door het meewerken aan het onderzoek, het kiezen voor een knieoperatie, een vakantie of toch nog een verhuizing plannen. Wij concluderen dat de terminologie van voltooid leven deze geleefde ervaring miskent en verdoezelt.
DANKWOORD
DANKWOORD

Dankbaar ben ik voor alle ouderen die participeerden in deze studie. Het was een bijzonder voorrecht dat u mij deelgenoot wilde maken van uw persoonlijke ervaringen.


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ABOUT THE AUTHOR
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Els van Wijngaarden (1976) graduated cum laude in Religious Studies at VU University Amsterdam with specialisation in (non-denominational) spiritual counselling in organisations. Her master thesis concerned an existential and spiritual understanding of professionalism based on the philosophy of Simone Weil. For three years, she worked as an existential counsellor in the care for intellectual disabled people and in the elderly care. Since 2007, she has worked as a lecturer in ethics and existential counselling at two universities for applied sciences in bachelor and post-bachelor programs. In the last four and a half years, she combined her work as a lecturer with a part-time PhD project. Her research was funded by The Netherlands Organisation for Scientific Research.
PUBLICATIONS & PRESENTATIONS

Publications in peer-reviewed scientific journals
1. Wijngaarden, E.J. van, Leget, C.J.W., Goossensen, A. Ethical uneasiness and the need for open-ended reflexivity: The case of research into older people with a wish to die (in review).
2. Wijngaarden, E.J. van, Leget, C.J.W., Goossensen, A. The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living (in review).
8. Wijngaarden, E.J. van, 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.

Book:
Chapters in books:


Other Dutch publications:


Presentations at peer-reviewed, internationally established conferences:

1. The life story is closed but life still goes on: Narrative foreclosure in elderly people who consider their lives to be completed. Part of a panel presentation “The crisis of meaning surrounding the timing of death of Dutch elderly people” at the Annual Meeting of NGG 2015 “Religion And The Crisis Of Meaning” at Radboud University Nijmegen, The Netherlands, 29/30 October 2015.

2. The need for an existential phenomenological approach to the wish to die in elderly people. Presentation and discussion at the European Conference on Philosophy of Medicine and Health Care, in Ghent, Belgium, 22 August 2015.


Other presentations at research meetings or congresses:

1. The lifeworld of older people who are tired of life and ideate on a self-chosen death. Presentation and discussion at the International Euthanasia Conference 2016 in Amsterdam, 13 May 2016.

2. Ready to give up on life, A colloquium at Maastricht University at the Faculty of Health, Medicine and Life Sciences, 20 April 2016.

3. A captive, a wreck, a piece of dirt: Images and metaphors embedded in culture and anchored in the flesh of older people with a death wish. Presentation and discussion at a meeting of research group Ageing Well & The Amsterdam Centre on Ageing, the University of Humanistic Studies, 11 February 2016.

4. Disconnectedness from the here-and-now: A phenomenological per-
spective on the wish to die in older people. Presentation and discussion at a special research meeting with an international guest Finn Hansen, 28 January 2016.

5. **Dignity and trust at risk**: An ethical reflection on the Dutch debate about older people and the self-chosen death. Presentation and discussion at the KU Leuven, Centre for Biomedical Ethics and Law, 16 December 2015.

6. **De ervaringswereld van het voltooide leven**: A public lecture at the University of Humanistic Studies, organised by the Partnership for Humanisation of Care for Older People, 10 December 2015.

7. **Telling secrets, exposing lives: about relational research ethics**: Presentation and discussion at Windesheim University, Faculty of Health Care and Well-being, 3 December 2015.

8. **Mag het alsjeblieft stoppen?** Onderzoek naar de geleefde ervaring van ouderen die hun leven voltooid vinden en op een zelfgekozen moment willen sterven, Presentation at Verenso Gerontological Congres ‘Start & Stop’!, 26 November 2015.

9. **De beleving van ouderen die hun leven als voltooid ervaren**: Presentation at a national Symposium of the Right-to-die NL (NVVE), Maarssen, 26 November 2015.

10. **Disconnectedness from the here-and-now**: A phenomenological perspective on the wish to die in older people. Presentation and discussion at the international research meeting The opening up of the patient world; benefits of phenomenological research, at the University of Humanistic Studies Utrecht, 19 October 2015.

11. **Images and metaphors embedded in culture and anchored in the flesh of elderly people**: Presentation and discussion at a research meeting of the Long Term Care Partnership, at University of Amsterdam (UvA), The Netherlands, 1 July 2015.

12. **Elderly and Completed Life**: Presentation and discussion at a research meeting of the Long Term Care Partnership, at University of Amsterdam (UvA), The Netherlands, 15 May 2014.

**Media coverage:**
This PHD-project has generated quite some news. Highlights were: the headlines / front page of the high-quality newspaper Trouw; two articles in the high-quality newspaper NRC Handelsblad; three live radio broadcasts; and two live television broadcasts. For a full overview of the media-coverage, please visit: http://www.elsvanwijngaarden.com/media/
APPENDIX
THE INTERVIEW GUIDE

Researching the lived experience of older people who feel life is completed and no longer worth living

Introduction of the interview
– Acknowledgments for time and participation
– Information about the research project and the procedure
– Information about the character of the in-depth interview (open structure and the focus on the thorough exploration of the lived experience)
– Possibility for questions about the project and the interview

The interview

Introductory question
– Can you tell me in what way our call to participate in this study did appeal to you?

Sequence 1: About completed life
– Can you describe what it means to experience that life is completed*?
– Can you focus on a particular example of this experience? Can you describe a specific event or particular experience when you (first) experienced that life is completed?
– Can you describe as fully as possible how this experience influences your daily life?”

Sequence 2: About the wish to die
– Can you describe what it means to have a strong desire to die?
– Can you describe as fully as possible how the wish to die influences your daily life?

* NOTE: if a participant used another word, such as ‘life is over, ready to give up on life, tired of life, the interviewer used this way of saying in her questions to stay as close as possible to the participant’s experience.
– Can you describe a moment when the desire for death was very strong?
– Can you describe a moment when it was less pronounced, more at the background?
– What kind of things influence your wish to die?

**Sequence 3: About a self-directed death** (if suitable)

– Tell me about your preference of a self-directed death. Can you explain why it is important to you?
– Tell me about the process of how your decisions / ideas developed.
– What is to like to live in this in-between period: living on while ideating on a self-directed death?

**Elaborating questions**

In order to encourage participants to articulate their experiences in detail, during the interview, the interviewer keeps on posing questions such as:

– Can you describe the experience as much as possible as you live(d) through it?
– Please, try to describe the experience from an insider-perspective, as it were almost like a state of mind. Tell me about the feelings, the mood, the emotions.
– Can you elaborate a bit more on that as concretely as possible?
– What do you mean by...?
– What is it like...?
– In what way?

**After the interview**

– Closing words and summarization
– Voluntary administration of the HADS
– Ask for the completed personal information form
– Acknowledgments
– Appointments about member check and privacy
– Appointments about reciprocal possibility to contact for any additional info
– Appointments about possibility aftercare
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. Remarkably very little empirical research has been done into this specific phenomenon of completed life in old age. In fact, this thesis is 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. It addressed essential questions such as: What exactly does it mean that life is considered to be completed? What are the underlying motivations and experiences?

Els van Wijngaarden (1976) graduated cum laude in Religious Studies at VU University Amsterdam with specialisation in (non-denominational) spiritual counselling in organisations. For three years, she worked as an existential counsellor. Since 2007, she has worked as a lecturer in ethics and existential counselling at two universities for applied sciences in bachelor and post-bachelor programs. In the last four and a half years, she combined her work as a lecturer with a part-time PhD project at the University of Humanistic Studies. Her research was funded by The Netherlands Organisation for Scientific Research.

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