

# BMJ Open Caught between intending and doing: older people ideating on a self-chosen death

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## 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 who lived independent or semidependent 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 the participants' everyday home environment (median lasting 1.56 h). 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 characterised as a constant feeling of being torn explicated by the following pairs of 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 to take 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.

## INTRODUCTION

It is not a question of dying earlier or later, but of dying well or ill. And dying well means escape from the danger of living ill.

(Seneca)

## Strengths and limitations of this study

- This study gives voice to older people who wish to die—preferably with medical assistance—although they do not suffer from a life-threatening disease or a psychiatric disorder.
- This study is the first to elucidate what it means to live in-between intending and actually performing a self-chosen act leading to death (or not).
- This study introduces empirical evidence into the largely theoretical debate on rational suicide.
- Our study highlights the need for 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.
- Although transferability to other countries is limited due to cultural differences, the Dutch discussion may inform the debate on (legalisation of) assisted dying in other Western countries.

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.<sup>1</sup>

In the Netherlands, one of the few countries in the world that have legalised euthanasia and assisted dying under strict criteria,



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there is considerable debate whether older people aged 70+ years, who consider their lives to be completed, should have legal options to ask for assisted dying.<sup>2 3</sup> In 2010, the Right-to-Die-NL started a campaign 'Out of Free Will' and placed this discussion on social and political agendas. They argued that based on a 'rational and well-considered choice' older people should have legal options for assistance with the termination of their life. 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.<sup>4</sup> 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'.<sup>1</sup>

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',<sup>5-8</sup> and those opposing it.<sup>9-13</sup> 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'<sup>12</sup> in fact, improving the conditions of these older people might lessen their wish to die. 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.<sup>9</sup>

Many studies on the topic of 'rational suicide' in old age focus on theoretical, ethical and legal arguments. In fact, we found no empirical studies that explore the experiences and struggles of people ideating on a self-chosen death from an insider's perspective. In order to develop conscious policy and good care for this group of older people, 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 as 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.

## METHODS

### Sampling

This study is a qualitative in-depth interview study of 25 older people ideating on ways 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 as they consider their lives to be completed and no longer worth living.<sup>14 15</sup> 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 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 as 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. On

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. However, at the moment of contact they had no active wish to die. Besides, some respondents were driven by strong motivations to advocate legalisation of self-directed death, instead of giving an experiential account of their real-life 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 the aim and procedures 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. [Table 1](#)—which has already been published before<sup>14</sup>—gives an overview of all background characteristics of the selected participants.

### Data collection

The interviews took place from April to December 2013 in the participants’ own home and lasted 2 h 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 online supplementary appendix 1). The interviews were audiotaped and transcribed verbatim. During and immediately after the visits, observational notes were made about contextual characteristics, the home 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).<sup>16</sup> This was done so as to obtain a *preliminary indication* as to whether the wish to die was driven by a severe depression or not, since 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 the participant’s 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 through the participants’ own initiative.

### Statement of ethical approval

The Medical Ethical Review Committee UMC Utrecht evaluated this study. This committee 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 was not required (protocol: 13–176/C).

### Data analysis

The first analysis of all 25 interviews contributed to an earlier study which resulted in a phenomenological characterisation of the phenomenon ‘life is completed and no longer worth living’.<sup>14</sup> For the purpose of this study, all interviews were reanalysed by 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<sup>17–19</sup> was used. The analysis followed a semantic, inductive approach,<sup>18</sup> 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, characterised by a constant forward-backward movement between the entire data set, the coded extracts, and the descriptive analysis in progress. Atlas.ti V.7.5 was used as a tool to compare themes and meaningful fragments.

First, the researchers tried to familiarise 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 summarised into main themes and subthemes. In the next phase, the themes were reviewed to 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 (ie, the extent to which the data are internally consistent), and external heterogeneity (ie, the extent to which the differences among the themes are bold and clear).<sup>18</sup> When needed, a theme was refined and nuanced. The writing was not something that took place at the end, but was an integral part of the analysis as the writing process by itself deepened our understanding, clarified meanings, and highlighted layers and polarities in the data.<sup>18 20</sup> Findings were mutually discussed between all authors and revealed a high consensus. Some minor discrepancies led to a more precise definition of the themes. Intersubjective reliability was sought throughout the analysis process.

**Table 1** Characteristics of the selected participants (n=25)

	Participants (n)
Gender	
Male	11
Female	14
Age (average 82 years)	
Up to 80	12
80–90	8
90–99	5
Partner status	
Partner (living together)	5
Partner (living in a nursing home)	1
LAT relationship	1
Widowed	14
Divorced	2
No partner	2
Children	
Children	14
Children (but no contact at all)	2
Children (deceased)	2
Childlessness (both involuntary or by choice)	7
Living situation	
Independent	19
Semidependent	4
Care home	2
Belief	
Humanism	4
Christianity	6
Anthroposophy/esoterism	3
Agnosticism	2
No belief	10
Most important former occupation	
Supervisor, manager, director, entrepreneur	6
Psychotherapist/nurse/social worker	5
Technician, chemist	2
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	
No serious illness	10
Sensory disorders: anosmia, hyperacusis, tinnitus, deafness, macular degeneration	7
Cranio-mandibular dysfunction, facial pain	2
Arthritis, rheumatism, fibromyalgia, hip replacement, rib and spinal injuries, osteoporosis	6
Chronic fatigue	3
Diabetes	3
Intestinal disease	1
Valvular heart diseases: cardiac failure, TIAs, valve repair	6
Serious itchiness	2

Continued

**Table 1** Continued

	Participants (n)
Outcome of screening for depression (HADS)	
1–7 (no indication)	15
8–10 (mild)	6
11–15 (moderate)	2
16 or above (severe)	1
Outcome of screening for anxiety (HADS)	
1–7 (no indication)	21
8–10 (mild)	3
11–15 (moderate)	0
16 or above (severe)	0
Membership of a right-to-die organisation	
Yes	23
No	1
Unknown	1

HADS, Hospital Anxiety and Depression Scale; LAT, living apart together; TIA, transient ischaemic attack.

## 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 characterised 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 pair 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.

### 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 of considerable concern to the participants, they also sensed an inevitable loss of having a grip on their life. This declining physical capacity threatened their independence and dignity. The interviews portray participants as deeply concerned about finding 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, responsibilities and duties towards themselves and others, and religious conscientious objections. Several participants stated 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 at the same time 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'<sup>1</sup> to strengthen social bonds in her neighbourhood as she was concerned about '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 organise 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' and is, therefore, 'bad karma'; 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'.

## 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

<sup>1</sup>A village-in-the-city [in Dutch: stadsdorp] is a quite recent initiative by and for (older) residents in an urban city neighbourhood to ensure modern neighbourliness. Especially older people aim to organise themselves to ensure that they can continue living an independent, active, healthy and safe life as long as possible.

'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. 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 organising a self-directed death is present in most accounts: participants hoped to die before they lose more control, and organising 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-euthanasia and ways to order the right doses of medicine, or to check the authenticity 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 proactively completing all kind of arrangements to put their personal affairs in order 'as well as possible' before they died. Several participants talked about organising 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 had already bequeathed a legacy to the people they would 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 of their later life 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.

#### 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 as 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 the context of the Dutch Euthanasia law.

#### 5. Legitimacy and illegitimacy

Participants' accounts are full of what good death could be, namely: a self-chosen, self-directed, well-organised, 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 doing 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 also by other older people like neighbours or occupants of the same nursing home who '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 organise 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 emphasised it was "irresponsible to burden a physician with the act of terminating the life of someone like me" (ie, 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 organisation, in the hope that these organisations would 'represent their interests' and force a political breakthrough, namely the legalisation of assisted self-chosen death in older people and the availability of a so-called 'Drion pill' (ie, 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 made 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 said 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 a day in advance to prevent vomiting", which stopped them from making a premature decision.

## DISCUSSION

Our study characterises the 'in-between' phase 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* yet tending to postpone hastening death; they sensed *both* their wish to die was sound and rational *and* simultaneously they felt driven by much more uncontrolled compulsions; and they took all efforts to organise a 'good death' *but* nevertheless were 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 that is characterised by the complementarity between volition and compulsion, 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.<sup>21–23</sup> 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 with 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 the living towards the ultimate decision to opt for a self-chosen death or not.

Our results question the concept of ‘rational suicide’ as an autonomous, free decision without pressure. The self-chosen death wish 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 had made a ‘reasonable’ assessment of their situation. They perceived that they would be better off dead. They were assumed to have the ability to make sound decisions as there was no evidence of severe psychological disturbance. 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.<sup>5–8</sup> On the other hand, however, participants also talked about being ‘forced’ by inner bodily and emotional compulsions and attachments to opt for a strategy. The self-directed death wish emerges as an ultimate escape to safeguard oneself and a way to exert control over the unpredictable future. The older people involved—often strong-willed, autonomous, and rationally oriented persons, and ones 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, and were 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<sup>11</sup> that “rationality may be a very misleading concept for a proper explanation of suicidal behaviour” and that the 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 characterised 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.<sup>24–28</sup> 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.

### 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 characterises these people that makes them so determined to die at a self-appointed moment?

The Interpersonal Theory of Suicide<sup>29</sup> 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 thematised the sense of non-belonging and not mattering in this population.<sup>14</sup> 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 only *cautiously* questioned as there was an indication of a severe depression in only one case. This seems in consonance with other research that also indicate that suicidal ideation in old age often does not meet the criteria for clinical disorders such as

depression or anxiety.<sup>30</sup> However, much more research on this topic is needed to explore this further.

### 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 feel highly challenged.<sup>31</sup> What then 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 realise the possible disastrous impact of empowering people in their 'rational, cognitive' suicide wish,<sup>8 32 33</sup> as this study found that this is probably not a strictly rational consideration. The findings also indicate the need for sustained ethical engagement with these people, and their wishes and desires by recognising that they are highly determined to die at a self-appointed moment, although these wishes appear to be fluid and might shift or change.

### 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 sensitised 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.

### Reflections on strengths and limitations

We took several steps to enhance validity and reliability: we worked in a research team consisting 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 life stories. By giving an in-depth methodological description, we attempt to provide transparency and allow the integrity of results to be scrutinised. 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 organised 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 still going on. Besides 23 participants were members of the Dutch right-to-die organisation. This raises questions whether these outcomes can be generalised 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.<sup>24–28</sup> Although cultural and societal differences may limit transferability of these results to other countries, the Dutch situation can certainly inform the debate on the legalisation of assisted dying in other Western countries.

For the Netherlands, our findings are considered to be generalisable to other similar populations as we maximised 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.

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