



# Still ready to give up on life? A longitudinal phenomenological study into wishes to die among older adults

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## ABSTRACT

**Rationale:** There is a paucity of empirical studies exploring wishes to die (WTD) in older adults without a life-threatening disease or psychiatric disorder, especially on how these WTD evolve over time.

**Objective:** This study aims to deepen our understanding of living with a WTD by elucidating multifaceted trajectories of death wishes in older adults without a life-threatening disease or psychiatric disorder.

**Methods:** Interviews were conducted between 2013 and 2019 with Dutch men and women aged 70 and older who expressed a WTD (preferably at a self-chosen moment). Using a phenomenological, longitudinal analysis approach, 35 serial interviews were analyzed.

**Results:** This resulted in four thematic meanings following four trajectories, namely: 1) a realized WTD, facing the ultimate decision with both freedom and a sense of fate; 2) an intensifying WTD, reaching a deadlock; 3) a diminishing WTD, experiencing tentative space for new possibilities; and 4) a vanishing WTD, being surprised by an unexpected turn. In the cases examined, the individuals' WTD was characterized by ambivalence and subject to change over time. Fluctuating, often asynchronous patterns of physical, social, psychological, and existential distress were lived intertwined. The WTD should thus be understood as dynamic and unpredictable, often impacted by external circumstances.

**Conclusions:** An important clinically relevant finding is that even persons with a pronounced WTD can experience openness to new possibilities, leading to a diminished or vanished WTD and/or desire to act on their WTD. Often such changes were related to (re-)establishment of connections with other people and/or society or with themselves. Since most research in this area is cross-sectional, the current longitudinal findings of this study are unique in providing insight into changes over time, thus contributing to the fields of death and suicide studies.

## 1. Introduction

Suicide and suicidal ideation in old age are significant risk factors for health problems and death (Szanto et al., 2013). Studies from the United States (AFSP, 2018; Ritchie et al., 2015) indicate that people aged 70+ are among those with the highest suicide rates compared to other age groups. Consequently, there has been increased interest in the research literature on the phenomenon of suicide, suicidal ideation, and death wishes in later life (Bonnewyn et al., 2009, 2016; Holm et al., 2014; Rurup et al., 2011a, 2011b; van Orden and Conwell, 2011).

Although suicide, suicidal ideation, and suicidal behavior occur in virtually all cultures, there is a wide diversity in patterns and meanings

across cultures. For example, studies show that in several European countries and U.S. states the rate of suicide is higher for men than for women (Ritchie et al., 2015; Steck et al., 2013). The rate of suicidal ideation and behavior, however, is generally higher among women (Canetto, 2008). This phenomenon is called "the gender paradox of suicidal behavior" (Canetto and Sakinofsky, 1998). Divergent cultural expectations and (masculinity and femininity) scripts may affect the scenarios chosen by females and males (Canetto, 2008, 2017; Canetto and Sakinofsky, 1998), which indicates that these are gendered and culture-bound phenomena.

In research and clinical practice, death wishes, suicidal ideation, and suicide are often explained as symptoms of underlying mental disorders

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associated with clinical depression. Other known risk factors for late-life suicide are social factors, disability and functional decline, and prior suicide attempts (Fässberg et al., 2016; Forsell, 2000; Forsell et al., 1997; Harwood et al., 2006; Raue et al., 2010; Scocco and De Leo, 2002; Scocco et al., 2009; Szanto et al., 2013; van Orden et al., 2010, 2013).

There is also a group of scholars who hold the view that, in some cases, death wishes and wishes to end one's own life can be interpreted in terms of rational, coherent, well-informed choices and "reasonable" responses to difficult or hopeless circumstances. This group of scholars reason, for example, that suicide arising from a terminal illness is fairly widely understood as potentially rational, which is reflected in social and legal approval (Nelson, 2017). In addition, some argue that people who suffer due to impending dementia (Battin and Kiouss, 2021; Cantor, 2018; Davis, 2014) may also have rational grounds for wanting to end their lives and have the mental capacity to make such a choice. Also, a group of scholars point to the possibility of "old age rational suicide" (McCue and Balasubramaniam, 2017; Richards, 2012, 2017). Starting from a clinical psychiatric perspective, McCue and Balasubramaniam (2017) indicate more frequently encountering, over the years, older patients without any significant mental illness who express a wish to end their lives. They also point to a growing group of initiatives and organizations in U.S. and European societies advocating that older adults should have the right to determine the timing and manner of their death (Beekman, 2011; McCue and Balasubramaniam, 2017; Span, 2018).

Based on empirical research into psychotherapists' perceptions, some scholars developed an approach to assess whether suicide plans in older adults whose symptoms and behavior do not readily translate to mental disorders, can be seen as rational (Nelson, 2017; Werth and Cobia, 1995). In general, though, the debate on "rational suicide in old age" is still highly theoretical. In particular, there is a serious paucity of empirical studies exploring this notion of "rational suicide" from a first-person perspective. To our knowledge, our 2015 study was the first to explore the lifeworld of Dutch older adults without a life-threatening disease or psychiatric disorder, who considered their lives to be "completed" and no longer worth living, resulting in a wish to die at a self-chosen moment (van Wijngaarden et al., 2015a). In 2016, an additional study, also situated in the Netherlands, elucidated what it meant for them to live in-between intending and actually carrying out such a self-chosen death (van Wijngaarden et al., 2016). This study challenged the idea of "rational suicide" by demonstrating that the decision to die was wrought with underlying ambiguities and ambivalences. Rather than a coherent sum of rational considerations, the in-between period was shown to be experienced as a considerable existential struggle.

To further deepen our understanding of death wishes in old age (see Box 1 for the definition) and the ambivalences that characterize such wishes, we present a longitudinal follow-up study in this article. The main purpose was to explore how older adults' wishes to die evolved over time. Further insight into these trajectories is not only important to better tailor care to the needs of those concerned, but also to inform the ongoing intense Dutch public debate regarding the question of whether or not older adults with a so-called "completed life" should be given legal options for assisted dying (van Wijngaarden et al., 2017a).

## 2. Methods

A phenomenological, longitudinal analysis of serial interviews was performed (Murray et al., 2009; Vogl et al., 2017), as this is the most suitable approach to provide a detailed, contextualized description and interpretation of the phenomenon concerned, and how it is experienced over time (Dahlberg et al., 2008). In the analysis, special attention was given to narrative change and possible reinterpretation (Vogl et al., 2017). In this study, interviews from three rounds (2013, 2017, and 2019) were brought together. For the original study, 25 Dutch older adults were interviewed in-depth about their WTD (van Wijngaarden et al., 2015a). In the second (2017) and third (2019) rounds, we reinterviewed every traceable person from the original group.

### 2.1. Selection of participants

The original sample consisted of 11 male and 14 female participants, with a mean age of 82 years in 2013. They were selected from a group of 144 people who responded to a research advertisement stating the context, aim, and inclusion criteria of the study. Inclusion criteria were that participants (1) considered their lives to be "completed"; (2) suffered due to the prospect of living on; (3) actively wished to die (preferably at a self-chosen moment); (4) were 70 years of age or older; (5) were not terminally ill; (6) considered themselves to be mentally competent and (7) deemed their WTD to be reasonable and well-considered. All 144 respondents were approached by the first author with a personal message and information about the selection procedure. Participants were purposefully sampled based on short descriptions of their personal situations. Rather than aiming at representativeness with regard to background sampling, the main rationale behind our sampling was: the more variations the data reveal, the greater the likelihood of detecting patterns of meaning structure and how a phenomenon may be constituted. A heterogeneous sample is therefore required (Dahlberg et al., 2008). Sampling criteria were: richness and diversity of cases; differences in (physical) health; different worldviews and demographic backgrounds (e.g., relational status, having children or not), and nationwide coverage (van Wijngaarden et al., 2015a).

### 2.2. Description of participants

Participants were predominantly white, Dutch, older adults, with one female participant from the Indo-European community. Most participants had no partner (widowed, divorced, or single for life). More than half of them had children. Most participants lived independently or semi-dependently. The majority had had a paid job. Approximately 40% of the participants reported having no serious illness. The others mentioned several physical problems (such as sensory disorders, chronic fatigue, arthritis, or valvular heart disease). Most participants had no indication for depression or an indication for mild depression. Over the years, 9 of the 25 participants ended their lives (See *Supplemental file 1* for a detailed overview of male and female participant characteristics).

#### Box 1 Definition WTD

In this study, a "wish to die" (WTD) is defined as a wish for death to come, understood against the backdrop of various forms of consciousness: a range of conscious thoughts, perceptions, emotions, and memories as well as more elusive bodily experiences and tactile sensations. Moreover, a WTD is understood as a phenomenon having distinctive appearances, ranging from passive to active WTD (Hartog et al., 2020), and consisting of various reasons, meanings, functions, and possible intentions (Ohnsorge et al., 2014a, 2014b).

2.3. Interviews

All interviews were conducted in the participant’s home environment, as this was considered the place where participants would feel most at ease talking about their WTD. In 2013, interviews averaged 116 min in length; in 2017, they averaged 112 min, and in 2019, the average was 102 min. In the first round, the interviews focused on exploring how the phenomenon “life is completed and no longer worth living”, resulting in a wish for a self-chosen death, was experienced in everyday life (van Wijngaarden et al., 2015a, 2016). In the second and third rounds, the focus was on exploring how experiences had evolved and developed over time: To what extent was the experience of a “completed life” and a sense that “life was no longer worth living” still present? And what changes, if any, occurred that could be related to these experiences?

In line with a phenomenological interview approach, questions were asked in each round to explore concrete moments and experiences in order to trace lived thoughts, feelings, and sensations (Dahlberg et al., 2008; Supplemental file 2 for a more extensive description). Between the interview rounds, contact (via email, mail, or telephone) between the first author and the participant occurred only at the participant’s initiative.

2.4. Selection of interviews for this longitudinal study

Fig. 1 provides an overview of the participants involved in each round. Of the participants we interviewed just once in 2013, we included only those who had ended their lives (of which we were notified). The other one-off interviews were excluded from this study, as these did not provide information on the development of the individuals’ WTD. In sum, in this longitudinal interview study, we analyzed 35 in-depth interviews with older adults (18 interviews from the first round, 11 from the second, and 6 from the third), supplemented with 3 interviews with close ones of deceased participants, emails from participants and obituaries. These added sources of information provided more insight into the participants’ processes.

2.5. Data analysis

The aim of this phenomenological analysis was to open up thematic meanings. Several steps were undertaken to achieve this aim. First, all interview transcripts belonging to the same participant were combined into one document, the interview unit. To become familiar with the data, these interview units were read several times. Next, to enable a cross-sectional analysis on the interview level, crucial lived experience descriptions were identified at that same level. These descriptions were used to compose so-called “textual portrayals” (Crowther et al., 2017; van der Meide et al., 2018) (See Supplemental file 3 for a methodological description). These textual portrayals formed the basis for a phenomenological thematization. Each portrayal was read as a whole, and in detail. Comprehensive reading led to assigning an overall title referring to the essential meaning of the story. During detailed reading, sentences and words that revealed meaning were inductively themed (Dahlberg et al., 2008). Subsequently, all textual portrayals were read and reread as a whole for a longitudinal analysis per interview unit, to gain insight into individual developments over time, and to identify the extent to which experiences and themes had changed (or not). These developments were described per participant (Vogl et al., 2017). Finally, for a longitudinal cross-case analysis, the analyses of the interview units were first compared and contrasted to elucidate thematic meanings and thematic similarities and differences (Vogl et al., 2017). The various meanings and developments were further finalized by means of reflective phenomenological writing (van Manen, 2014). To stimulate intersubjectivity and mutual dialogue, phases 1, 2, and 3 were conducted simultaneously by two researchers for 9 interviews. The interviews and analysis were performed in Dutch. After analysis, the study was translated into English.

2.6. Position

As there is no such thing as context-free or value-free research (Bourke, 2014; Levitt et al., 2018), we wish to acknowledge our positionality here. This phenomenological project was embedded in a Care

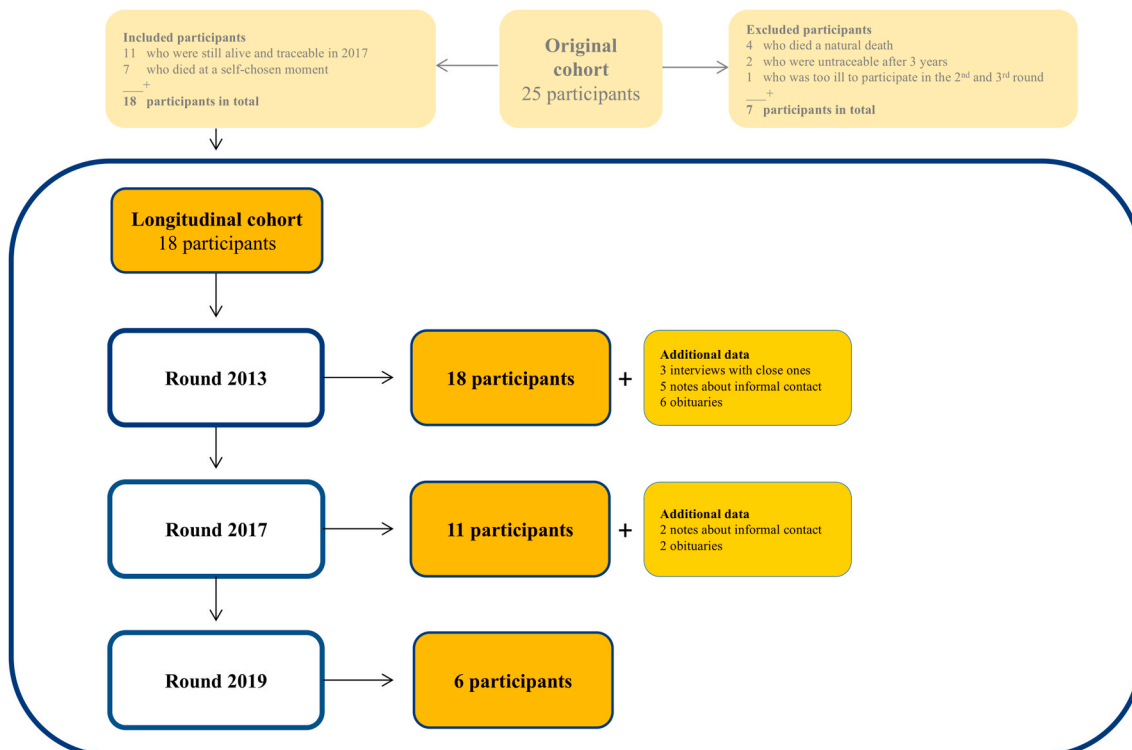


Fig. 1. ‘Flow chart of involved participants and additional data’.

Ethics research group, and culturally situated in the Netherlands, a forerunner country regarding self-chosen death. Since 2011, there is an ongoing public debate on whether older adults who consider their lives to be over should have the right to an assisted death (van Wijngaarden et al., 2017a). All authors are Dutch citizens and are thus part of a society in which open debate about self-chosen death seems less taboo than in many other countries.

In this study, our emphasis is on understanding the shared experiences, particularities, and meanings of the phenomenon. Our sensitivity to the nuances and ambivalences of the lived experience can be traced back to the project's care-ethical and phenomenological underpinnings: Care ethics is an interdisciplinary field of inquiry as well as a political ethic. In line with the empirical turn in ethics, care ethicists emphasize that moral understandings should be grounded in lived experience to be able to conduct a form of ethics that departs from the lives of ordinary people (Leget et al., 2017). A suitable empirical research method used to achieve these ideas is phenomenology.

## 2.7. Quality criteria

Phenomenological research requires that we not only recognize our own position but also try to "bridle" our own understandings. Following Dahlberg et al. (2008), we view bridling as an effort to prevent researchers' understandings from having an uncontrolled effect, and to confine the impact on evolving understandings. This criterium is necessary to enable examination of the phenomenon openly and carefully, and enhance trustworthiness and methodological integrity (Dahlberg et al., 2008; Finlay, 2011).

To practice such *reflexivity*, we took the following measures: (1) ongoing reflection through keeping a reflective journal; (2) recurring dialogues between the authors; (3) dialogues with stakeholders and experts; and (4) dialogues with international colleagues. These measures all enabled the authors to critically reflect on evolving understandings and to bridle theoretical frameworks, earlier findings, and personal views (Finlay, 2011).

Several other strategies were adopted to enhance the quality of our research. With regard to *rigor*, prolonged engagement was gained by conducting longitudinal, in-depth interviews. Investigator triangulation was achieved by including more researchers in composing the textual portrayals and in the interpretation decisions. Also, we described the analysis process as clearly and transparently as possible. Regarding *resonance*, we aimed to provide thick, evocative descriptions so that the experiences of the older adults concerned become meaningful to the reader (Finlay, 2011).

## 2.8. Ethical considerations

In 2013, the Medical Research Ethics Committee (METC) Utrecht evaluated the original interview study proposal and concluded that the study did not fall under the scope of the Medical Research Involving Human Subjects Act (protocol number: 13-176/C). In 2019, this longitudinal study was part of a larger study proposal that was submitted to the METC. Again, it was concluded that the study did not fall under the scope of the act (protocol number: 19-156/C). During the research process, the team complied with all ethical aspects of responsible research, such as protection of privacy and confidentiality. In each round, participants were provided with detailed written and oral information outlining the aim and procedure of the study, the right to withdraw at any time, the protection of privacy, contact details, and the possibility of aftercare. Furthermore, during all stages, ample attention was paid to the researchers' reflexive attitude and ethical sensitivity (van Wijngaarden et al., 2017b).

## 3. Results

In this section, the trajectories of participants' WTD are thematically

described. The themes not only provide insight into the possible developments of their WTD, but also into the different meanings and aspects that strengthen or reduce such wishes over time (See Table 1 for an overview). After each quotation, we mention consecutively: participant number, sex, year of birth, relationship status, and year of interview (for example: P16-m-1935-partner\_2013).

### 3.1. A realized WTD: facing the ultimate decision

While all participants had been ideating on a self-chosen death to some degree, nine participants eventually did end their own lives. This decision was often fundamentally ambivalent.

#### 3.1.1. Freedom and fate

On the one hand, it was experienced as a "free, proactive choice" that provided some grip, a way to exercise control, or even as "a way of taking responsibility" for themselves or their close ones. Participants defined themselves as "free spirits": planning a self-chosen death was seen as a form of self-realization, and as confirmation of an independent identity. The obituaries of those participants who eventually did choose death illustrate underlying positive desires for "rest", "being with God", "a life in painless warmth", "freedom" and "liberation".

Conversely, during the interviews participants also spoke about this choice in rather negative terms like: "something they could not escape", and an inevitable "kind of doom/fate" they had to call down upon themselves. For some, life had become "unlivable", and realizing their WTD was presented as a "flight forward", as the only means to avoid further loss and deterioration. Others had promised their already deceased partner that they would "follow" them. Such promises often held a deep meaning for participants, as a way to maintain their connection with a loved one, or as an expression of a longing to be together again.

The characteristic ambivalence is reflected in the story of participant-2 (f-1925-widowed\_2013). She entered a hospice to end her life by voluntarily stopping eating and drinking (VSED) under supervision. Surrounded by "lovely volunteers" and family, she unexpectedly experienced the time in the hospice as "a very good time" and her feelings of loneliness became much less pronounced. She was convinced that returning to her sheltered home would confront her with the same solitude she wished to avoid by entering the hospice in the first place. She therefore saw no other option than to "choose" VSED. Ending her life was both a well-considered and "fated" decision.

#### 3.1.2. Postponement

Of the nine participants who ended their own lives, we were only able to speak with two during the second interview round. Both were

**Table 1**  
Trajectories and meanings of the WTD in older adults.

Main trajectories of WTD	Main thematic meaning	Subthemes
A realized WTD	Facing the ultimate decision	<i>Freedom and a sense of fate</i> <i>Postponement</i>
An intensifying WTD	Reaching a deadlock	<i>A paralyzing sense of meaninglessness</i> <i>Fixation on a "way out" that is "blocked"</i>
A diminishing WTD	Experiencing tentative inner space for new possibilities	<i>The situation changes for the better</i> <i>The situation turns out to be less debilitating than feared</i> <i>Taking precautions gives some breathing space</i>
A vanishing WTD	Being surprised by an unexpected turn	<i>From "lack of social relevance" to "being seen by society"</i> <i>From "feeling tired of living" to "things finally fall into place"</i>

Note. WTD = "wish to die".

widowed men who found themselves postponing their plans due to appeals made by loved ones. Participant-25 (m-1943-widowed\_2017), for example, who had the lethal substance at his disposal, sometimes had “a hard time restraining himself from opening his cupboard and grabbing the stuff”. Dragged down by the loss of his beloved partner and the fear of “further deterioration”, he was ideating on “a way out”. On several occasions he had set a date to end his life, but found himself postponing it, among other reasons for his grandson:

*Last May, I gave up, but then my grandson asked me if I would like to help him install electricity in his new home. You know, I really looked forward to that. (...) He doesn't live here, and he has his job, so I don't see him very often. But when he is in trouble, he still turns to grandpa. (...) Gas, water, light and heating, that's my old profession! The fact that I've promised to help him, such things hold me back. In some way, it breathes new life into me.* (P25-m-1943-widowed\_2017)

Participant-10 (m-1930-widowed\_2013) had lost his partner in a traumatic manner six months before the first interview. He said: “I can't take life anymore. If I don't get euthanasia, I'm afraid I will go completely mad.” Although he had a very pronounced wish to end his life, he also experienced doubt: wasn't he being a coward, did he choose the easy way out? After informing his children and close family members about his plans, his doubts intensified as he was confronted with considerable resistance and emotions. Actually, their emotions surprised him. He was convinced that he was “nothing special” to them anymore and had become a burden. Although he firmly stated that ending his life was his own autonomous choice and that no one could or should interfere, his children's emotions upset him so much that he postponed his plans for the next four years.

### 3.2. An intensifying WTD: reaching a deadlock

For some participants, the wish to end their lives intensified over the years. These participants seemed to be caught in a despondent stream of thoughts, varying from wanting to end their lives to not wanting it right away, not daring to do it, not knowing exactly what to do, or not knowing where to order/get the lethal drugs. Living in a “deadlock”, the wish to end their lives at a self-chosen moment intensified but they did not dare to “take action” (yet).

#### 3.2.1. A paralyzing sense of meaninglessness

Participant-22 (f-1936-widowed) has always been very explicit about her wish for a self-chosen death. Throughout the years, she insisted she no longer had any zest for life. Both her husband and her second partner had passed away many years ago. Although she had almost no physical problems, she was “completely done with life”. She did not experience “real responsibility” for herself or others and felt expendable. The many activities she engaged in - fitness, Zumba, bridge, tennis, concerts, museum visits, traveling, volunteering – were merely to “fill the days”, as nothing had real meaning for her anymore. She experienced these activities as separate moments in time. Sometimes the activities were quite nice or pleasant, but they never offered a sense of coherence or purpose: “I just go through the motions.” (P22-f-1936-widowed\_2013).

During the second interview she used a metaphor from the world of theater to underscore this continued sense of alienation: “I just play a role, this isn't me” (P22-f-1936-widowed –2017). She was living her life based on what she thought others expected of her, while the feeling of disconnection remained. In the third interview, she recounted how her WTD had intensified by a walking impairment:

*I used to go on music trips, you know, visit a city during the day, go to a museum and the like. And in the evening, we would go to a concert. But I don't dare do that anymore because I have increasing difficulty walking. [...] We were supposed to walk to a castle. But when I said: 'I can't walk very well anymore', they said: 'Maybe it is better if you don't come along.'*

*Of course, I understand, but ... Fortunately, there was a forest around the hotel, so I could walk there alone. But, you know, that was my last vacation. I was completely exhausted afterwards ...* (P22-f-1936-widowed\_2019)

The tiredness she spoke of was not only related to the activities she undertook, but also to being part of a group while feeling like an outsider and a burden.

Participant-6 (m-1921-widowed) also experienced a downward spiral of negative thoughts. Despite moving to an apartment with a panoramic view across a lake and having a new girlfriend, his sense of uselessness and meaninglessness was overwhelming. His girlfriend offered him “a lot of practical support”, but did not take away his “grief and loneliness”. A sense of shame and humiliation deepened over the years, he said, and strengthened his WTD:

*I like to go out for dinner. But nowadays the waitress has to read the menu options to me, because I can't read it myself anymore. Well, that's just horrible! I've traveled all over the world. I have managed great projects. I stayed in four-star hotels ... But now, what's left of me? Now I sit there like an old man, or rather like a child. Awful! I used to look at the menu and take my time to decide, but now I often think: let's just have that. It isn't my first choice, but well ... she can't go on reading. Isn't this terrible? I find it humiliating ..., depressing ..., sad ... And when I have to pay, I have to tell them my private code because I can't read the numbers on the machine. Moments like that, I feel like a total nobody ...* (P6-m-1921-widowed\_2017)

#### 3.2.2. Fixation on a “way out” that is “blocked”

Participants also felt “blocked” by outside forces: they were (alternately) angry at politicians, the church, the medical world, or an impersonal counterforce (often referred to as “others”) that made it “impossible” for them to opt for a self-chosen death in a “dignified way”:

*The feeling that my life is complete is getting stronger every year. But I still miss the certainty that I can take control of my death when my time comes. I miss a lifeline! [referring to a reliable lethal drug] If I had a lifeline, it would give me a lot of peace, and possibly a little more joy in life* (P6-m-1921-widowed\_2017)

Although this participant, like a few others, ordered online and now possessed a lethal substance at home, this did not free him at all from worry. He kept thinking about possible risks or side effects, making the drug itself feel unreliable. He even worried whether he had received the right drug in the first place. Being afraid of the possibility that it would go wrong, he, like some others in the same situation, became even more fixated on “the way out” that simultaneously felt “blocked”.

### 3.3. A diminishing WTD: experiencing tentative inner space for new possibilities

All participants had an outspoken, active WTD in 2013, with many of the participants relating their WTD to past and current negative life situations. Death was perceived as a way to end their suffering. Still, for several of them, the desire for death and the intensity of their WTD, as experienced in thoughts and/or preparatory actions, lessened over the years.

#### 3.3.1. The situation changes for the better

For participant\_17 (f-1946-widowed), death symbolized “peace and deliverance from an arduous life” that she had led until her mid-sixties. In 2013, she talked about a tremendous amount of suffering that left her feeling “numb inside”. She longed for death to come soon, preferably at the moment of her own choosing, although she was rather ambivalent about her own role in this “choice”. She had arranged “everything” (e.g., living will, euthanasia declaration, script for her funeral), but simultaneously waited for a natural death: “When my time comes, wonderful!

Put the flags out!" This ambivalence was also reflected in the way she talked about the successive operations and treatments that she had undergone to reduce her suffering caused by diabetes, lung disease, and foot, knee, and back pain. She said things like: "I dearly hope the doctors won't treat me anymore". But at the same time, she was actively trying to maintain or even improve her physical quality of life by opting for operations and taking potentially life-prolonging medications such as insulin and blood thinners.

Although the undertone of pain and suffering was still there during the interviews in 2017 and 2019, her negative feelings and her WTD seemed to have lessened. In the past, she had been a social worker. In the community center she went to, this role came to the fore again, and she regained a sense of contributing: "I can give solicited and unsolicited advice to everyone". Even with this new opening, her negative feelings did not disappear completely: "Honestly, being sociable is different from really enjoying life. I have some peace for a few years, found my niche, so to speak, but it doesn't offset all the difficult years." (P17-f-1921-widowed\_2019).

### 3.3.2. *The situation turns out to be less debilitating than feared*

Participant-7 (f-1937-widowed), for example, was able to redraw several of the boundaries she had set earlier. In 2013, she explained that she and her husband had decided to die together. She was convinced she would not *and* could not go on alone. Eventually, dying together turned out to be impossible, as her husband developed prostate cancer and the process went too quickly. After he passed away, life continued and she managed to live on her own quite well.

Being alone after her husband's passing, she was "scared to death" of becoming dependent. The fact she might need a walker soon was the ultimate symbol of shameful deterioration: "Can you imagine me with a walker? No way! I will fight to the very end to prevent that! If that time comes, that's it, end of story. I make no concessions here." (P7- f-1937-widowed 2013) Although In 2017, she opened the door standing behind a walker, which she lovingly named "Lida":

I have a lovely house, I feel comfortable there. "Lida" helps me run my house. I like to do a little cleaning. Occasionally I vacuum my room, walking around behind "Lida". Together we operate the vacuum cleaner. If you could see us ... (P7- f-1937-widowed 2017)

For this participant, as for others, "the quality of [her] life had to remain acceptable". However, what was regarded as acceptable was subject to constant change. The walker, originally symbolizing "the unacceptable", now functioned as a way to explore new possibilities by enabling her to move around more freely, without fear of falling, thus maintaining her quality of life.

While the idea of a self-chosen death remained, her desire to die subsided to a degree that it no longer paralyzed her. Indeed, she was able to actively engage with books, films, researching her family tree, and household affairs, and felt her WTD was almost gone. Instead, thoughts about death were now experienced as desires for peace and being reunited with her husband. She still considered self-chosen death a possibility, but more in the shape of an "exit scenario for the future" and undertaking "preparatory measures" in the form of an updated living will and a euthanasia statement.

### 3.3.3. *Taking precautions gives some breathing space*

We mentioned above that some participants felt they had "reached a deadlock" despite having lethal drugs at their disposal: having them at their disposal did not reassure them. For others, taking precautions, such as ordering a lethal substance, did provide a certain peace of mind.

In 2013, participant-21 (f-1935-widowed) was already searching for ways to obtain a lethal liquid that would enable her to end her own life. During the second interview in 2017, she expressed an even more pronounced WTD that led her to take more concrete actions: she consulted her GP and reached out to two counselors of right-to-die organizations

for personal advice. "I'm working on it, but it's a long journey, not something you decide overnight."

In 2019, she was in possession of the lethal liquid, which reassured the participant to such a degree that she did not feel the need to use it in the short term:

The funny thing is: now that I have it at my disposal, it gives me such relief! So much breathing space! Actually, I'm enjoying a bit of a revival, regaining a little zest for life. I don't plan to take it right away. But even if I decide not to use it at all, I still enjoy the fact that I succeeded in buying it. Fun for 529 euros [laughs]!(P21-f-1935-widowed 2019)

### 3.4. *A vanishing WTD: being surprised by an unexpected turn*

For three male participants, unexpected changes throughout the years meant that their WTD disappeared completely, apparently because changes occurred that they thought impossible in 2013; these included getting involved in meaningful voluntary work, a new relationship, a successful move, re-engaging in old interests, or even the death of a partner releasing them from the burden of informal care. Participants felt utterly surprised by their own resilience and the realization that their WTD had vanished.

#### 3.4.1. *From "lack of social relevance" to "being seen by society"*

Some participants experienced an unexpected sense of reconnection to the world. In 2013, participant-11 (m-1932-partner) expressed a very clear WTD. Many years before, he had lost his work, and he was unable to find meaningful daytime activities:

At the moment it feels like: I am no longer of any significance ... I did some voluntary work in a museum, but they didn't recognize my skills there. They had no interest at all in their employees.(P11-m-1932-partner-2013)

In 2017 his mood was completely transformed:

*I have something very astonishing to tell you. The desire to end my life is all gone. Things have happened that allow me to take on life again. I don't know where to start ... I sometimes think, how is it possible that I had these strange thoughts in the past ... ?* (P11-m-1932-widowed-2017)

In a volunteer center, he was made responsible for a wide range of tasks in the department that helped people with their private administration. These tasks suited his personal capabilities, and he started feeling challenged and recognized for his strengths: "I don't have the time to become an old fuddy-duddy anymore!" (P11-m-1932-widowed-2017) Rather than "sitting around being useless", "looking and waiting for activities to perform", he now needed to schedule and prioritize his busy week.

In 2019, well into his 80s, he still had the same job, felt part of a team (talking in terms of "belonging" and "we"), and felt taken seriously by his superior:

In my organization, they speak highly of their volunteers. We meet regularly in order to exchange experiences and give each other support. Our coordinator always says: 'You are the experts.' In fact, it often turns out that we have more expertise than the professionals we are working together with. Just because we are closer to the case and have more time to spend than the professionals. The added value of our work is really acknowledged in this organization.(P11-m-1932-widowed-2019)

#### 3.4.2. *From "tired of living" to "things finally fall into place"*

The unexpected turn also took the form of unforeseen relationships, which provided new impulses to reconnect with oneself, others, and society. In 2013, participant-15 (m-1933-divorced-2013) had "come to

the end of the curve” and had collected lethal drugs. He had no energy left, was tired of living, and felt disconnected from everything. Looking back, he felt he had done “his best”, but believed his somewhat rebellious “commitment to (social) change” had generated “many conflicts”, particularly within relationships. With almost no contacts left, he defined himself as “an absolute loner”.

In 2016 he sent an email: “I am still alive. Why and how is quite a story ...” Aged 83 years, he had a new partner. “It may sound a bit harsh, but if I hadn’t accidentally run into her, I wouldn’t be here.” (P15-m-1933-LAT-2017) The conversations, the cooking and eating together generated new energy, when he was previously convinced that it had all dried up. Feeling revived by this new relationship, he got involved in local activities again.

Unexpected turns did not only manifest themselves as new impulses, but also emerged from a newfound ability to let go and accept what was previously thought unlivable. Participant-23 (m-1938-single-2013) had a well-defined WTD in 2013. “Next year is going to be a milestone in my plans” [to end my own life]. “Exhausted” by the “colossal sorrow” he had been carrying from childhood, he experienced his WTD mostly in the evenings, when painful memories would take control of him. He felt estranged from his current living environment but did not consider relocating a feasible option. He decided to “draw a line” when incontinence confronted him with his age. To him, planning to end his life in June 2014 was a “sacred decision”.

In the spring of 2014, he contacted the interviewer for a follow-up interview. He mentioned good experiences during a recent training at a retreat center that made him change the date:

*The atmosphere was so good, I was able to discover self-love there. Actually, things were coming full circle there. I still have a lot of pain. But to experience love, and to be able to accept myself, make contact with others ... You know, that I can acknowledge what hasn’t been there, that I can just talk about it; that’s a great achievement! Also, at that retreat, I was really able to let go. I fully expressed my anger and sadness. I’d go there again tomorrow. (P23-m-1938-single-2014)*

His self-chosen death was now postponed until September, as “not setting a date is too big a risk. I might be too late then.” (P23-m-1938-single-2014).

Early 2015, the interviewer received a change-of-address card with a photo of a bicycle next to a front door, a tripod under the straps, and the words “Home at last!”. During the 2017 interview, he said that he had fallen in love shortly after the 2014 interview. His girlfriend had encouraged him to move. This move was “the beginning of a new chapter” with a new partner and a new home. These changes did not erase his feelings of sadness and loneliness, as the evenings were still “devilishly difficult” for him, but they no longer resulted in a WTD: “For the first time in my life, I really feel at home. I couldn’t have dreamed of a life like this”.

Like other participants whose death wish had diminished or vanished, he continued to reflect on the option of a self-chosen death in the future. However, the tone of these thoughts changed: they became less determined.

#### 4. Discussion

The present study was designed to uncover the development over time of a WTD among Dutch people aged 70 and older, who did not suffer from a life-threatening disease or psychiatric disorder. We distinguished thematic meanings that follow four trajectories, namely: (1) a realized WTD, facing the ultimate decision with both freedom and a sense of fate; (2) an intensifying WTD, reaching a deadlock; (3) a diminishing WTD, experiencing tentative space for new possibilities; and (4) a vanishing WTD, due to an unexpected turn. Since the majority of research analyzes data collected at a single point in time, our current longitudinal findings provide unique insights into how a WTD actually

evolves over time, thus contributing greatly to the fields of death and (rational) suicide studies.

In all cases, the WTD turned out to be subject to change over time, whether the experience worsened (resulting or not resulting in the ultimate act), diminished, or vanished. This outcome corroborates previous research on the WTD in terminally ill cancer patients that shows (1) how intentions underlying a WTD can differ, varying from “having no intention to hasten death” to “acting towards it” (Ohnsorge et al., 2014b), and (2) that preferences may shift over time, illustrating dramatic changes from an explicit WTD to a newly experienced wish to live (Ohnsorge et al., 2014b).

This study complements these earlier findings by illustrating how older adults *without* terminal illness also experience living with a WTD as dynamic and unpredictable, not as making a clear choice. It also shows that these dynamics and changes are often impacted by physical, relational, and social circumstances.

In accordance with other studies (Hartog et al., 2020; Ohnsorge et al., 2012; Rurup et al., 2011b; van Wijngaarden et al., 2015a, 2016), this study further shows how living with a WTD is strongly characterized by ambivalence. Not only did the WTD change over time, but people also lived with “mixed feelings” about it. For example, participants seemed to simultaneously have a longing for a self-chosen death and a wish to live. Fluctuating patterns of physical, social, psychological, and existential distress and relief were lived intertwined. These findings support the argument of Broom et al. (2019), who, in the context of their research into informal care at the end of life, contend that ambivalence constitutes a crucial element of experiences of dying, death, and bereavement. Rather than marginalizing or “attempting to tame” feelings of ambivalence, they rightly posit the importance of integrating such complexity and messiness as inevitable parts of life (Broom et al., 2019). We agree that this complexity and messiness need to be taken into account fully in order to be able to make sense of the experiences under research.

Lastly, this study illustrates how unexpected turns in some participants’ lives took them utterly by surprise. As such changes were thought impossible during the first interview, this study may challenge the dominant one-sided narratives of the (almost inevitable) increasing decline in old age, by adding a counter-narrative of old age as a period of possible change, growth, and personal development. It may therefore possibly function as an agency-enhancing counter-narrative (Laceulle, 2018).

##### 4.1. Practical implications

An important and clinically relevant finding of this study is that even a pronounced WTD can diminish or vanish, creating space for and openness to new possibilities (even when the person concerned may deem it impossible). Often this change was related to the (re-)establishment of connections with other people and/or society, or with themselves. This outcome demonstrates the strong impact that such factors can have on living with a WTD. It also underscores the importance of interventions that promote and strengthen social connectedness between and within the individual, family, community, and broader societal levels (Lapierre et al., 2011; Shah et al., 2016; van Orden et al., 2013; Zortea et al., 2019).

The current findings also acknowledge the complexity of developing adequate and context-sensitive interventions. As we found, engagement in meaningful volunteer work and new relationships did not provide the same sense of revival among all participants. Some participants reported a completely vanished WTD due to these factors. Originating from similar developments (meaningful activities and new opportunities), others experienced a diminished WTD but still longed for peace in death at a self-chosen time. Their WTD lessened but did not vanish altogether: a sense of sadness lingered in the background. This finding raises the question: what exactly determines whether or not someone experiences (re-establishment of) connectedness with other people, society, or with themselves?

Another issue that emerges from the findings is the complexity of communicating about a WTD, and the importance of acknowledging the coexistence of ambivalent and fluctuating wishes and tensions. We agree with Ohnsorge et al. (2012) that such ambivalent, multi-layered experiences can be an intrinsic part of normal human experiences, and can characterize “the process of negotiating personal meanings” (Ohnsorge et al., 2012). Hence, health professionals should be sensitive and responsive to the ambivalences, tensions, and nuances in the person’s lived experience.

#### 4.2. Strengths and limitations

This study breaks new ground by being the first in-depth study on how death wishes evolve over time. The longitudinal approach, capturing the dynamic effects of a WTD, provides a more layered and nuanced picture than is possible with a cross-sectional study. Yet, some limitations also need to be considered. Since our study is the first of its kind, comparison with other longitudinal findings remains impossible for now. Other limitations concern our relatively small sample. Although we sought to interview participants with a wide range of demographic backgrounds, ethnic minorities are underrepresented in this study. With regard to follow-up research, this study shows the importance of including sites and organizations in the recruitment strategy that are easily accessible to minority groups, in order to explicitly inform and invite them, as well as identifying and attempting to address factors that may undermine the participation of minority groups (Wendler et al., 2005). Furthermore, this study reveals the everyday experiences of Dutch (predominately white) older adults living in a society where the end-of-life debate continues progressively, and where expressing a WTD may be less taboo than in other countries. This situation certainly influences the participants’ experiences and should be considered when comparing findings across cultures.

Finally, although we acknowledge the influence of gender and culture on the WTD (as stated in the introduction), it was beyond the scope of this study to perform an intersectionality-based sex and gender analysis. Further research is welcome and needed, both in the Dutch context and beyond, not only to explore the gendered and cultural specifics of our sample group but also to be able to compare them with existing studies on the gendered specificities of living with a WTD in older adults (Canetto, 2008, 2017, 2019).

#### 4.3. Conclusion

This study explored how WTD in older adults evolved over time. The findings add to the growing body of literature that challenges rational suicide theories (Dzeng and Pantilat, 2018; Fiske and Lutz, 2017; Fortin et al., 2001; van Wijngaarden et al., 2015b, 2016). However, they go beyond the previously mentioned literature by demonstrating that WTD appears as continuous and iterative processes, involving all kinds of entanglements, contradictions, and forms of ambivalence that are difficult to foresee.

Considering that diminished or vanished WTD in people often relate to a regained sense of social connectedness, we underline our earlier call for caution and restraint in future health policies on hastening death for those under study (van Wijngaarden et al., 2018). Indeed, the health professionals, politicians, and policymakers involved should take into account the situational and relational contexts in which such WTD emerge and should acknowledge the temporal incongruities that are often experienced with regard to these complex and ultimate decisions.

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#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2021.114180>.

#### Authors contributions

Els van Wijngaarden: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Validation; Writing – original draft; Writing – review & editing. Michal Merzel: Data curation, Formal analysis; Methodology; Project administration; Validation; Writing – review & editing. Vera van den Berg: Methodology; Validation; Writing – review & editing. Margot Zomers: Methodology; Validation; Writing – review & editing. Iris Hartog: Methodology; Validation; Writing – review & editing. Carlo Leget: Conceptualization; Funding acquisition; Methodology; Validation; Writing – review & editing.

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