



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



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## ABSTRACT

In the Netherlands, there has been much debate on the question whether elderly people over 70 who are tired of life and who consider their life to be completed, should have legal options to ask for assisted dying. So far there has been little research into the experiences of these elderly people. In order to develop deliberate policy and care that targets this group of elderly people, it is necessary to understand their lifeworld. The aim of this paper is to describe the phenomenon 'life is completed and no longer worth living' from a lifeworld perspective, as it is lived and experienced by elderly people. Between April to December 2013, we conducted 25 in-depth interviews. A reflective lifeworld research design, drawing on the phenomenological tradition, was used during the data gathering and data analysis. The essential meaning of the phenomenon is understood as 'a tangle of inability and unwillingness to connect to one's actual life', characterized by a permanently lived tension: daily experiences seem incompatible with people's expectations of life and their idea of whom they are. While feeling more and more disconnected to life, a yearning desire to end life is strengthened. The experience is further explicated in its five constituents: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion towards feared dependence. This article provides evocative and empathic lifeworld descriptions contributing to a deeper understanding of these elderly people and raises questions about a close association between death wishes and depression in this sample.

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## 1. Introduction

In recent years, there has been a growing scientific interest in elderly people wishing to die without the presence of a life-threatening disease or a severe psychiatric disorder. Several quantitative studies have been undertaken to determine prevalence rates, characteristics and risk factors associated with the development of death ideation and death wishes in elderly people who are tired of living (Harwood et al., 2001; Jorm et al., 1995; Rurup et al., 2011a). In addition, some qualitative studies have been conducted to understand suicidal feelings in elderly people (Crocker et al., 2006; Harwood et al., 2006; Kjøseth et al., 2009; Kjøseth et al., 2010; Rurup et al., 2011b; Rurup et al., 2011c). These studies indicate that age-related losses, decreasing sociality, depressive

feelings, personal characteristics and beliefs are associated with the development of a wish to die.

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

Chabot and Goedhart (2009) studied individuals who have a strong desire to control and hasten death by committing auto-euthanasia. Auto-euthanasia refers to an intentional act of a

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

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

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

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

## 2. Methods

### 2.1. Reflective lifeworld approach

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

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

### 2.2. Participants and sampling

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

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

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

Gender	Participants (n)
Male	11
Female	14
Age (average 82 years)	Participants (n)
65–70	1
70–80	11
80–90	8
90–99	5
Partner status	Participants (n)
Partner (living together)	5
Partner (living in an elderly home)	1
LAT relationship (living apart together)	1
Widowed	14
Divorced	2
No partner	2
Children	Participants (n)
Children	14
Children (but no contact at all)	2
Children (deceased)	2
Childlessness (both involuntary or by choice)	7
Living situation	Participants (n)
Independent	19
Semi-dependent	4
Retirement home	2
Belief	Participants (n)
Humanism	4
Christianity	6
Anthroposophy/Esoterism	3
Agnosticism	2
No belief	10
Most important former occupation	Participants (n)
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	Participants (n)
No serious illness	10
Sensory disorders <sup>a</sup>	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 <sup>b</sup>	6
Serious itchiness	2
Outcome of screening for depression (HADS)	Participants (n)
1–7 (no indication)	15
8–10 (mild)	6
11–15 (moderate)	2
16 or above (severe)	1
Outcome of screening for anxiety (HADS)	Participants (n)
1–7 (no indication)	21
8–10 (mild)	3
11–15 (moderate)	0
16 or above (severe)	0

Note. n = Number of participants. HADS = Hospital Anxiety and Depression Scale.

<sup>a</sup> Sensory disorders included: anosmia, hyperacusis, tinnitus, deafness, macular degeneration.

<sup>b</sup> Valvular heart diseases included: cardiac failure, transient ischemic attacks (TIAs), valve repair.

participants.

Regarding the safety of people who disclosed a death wish, it is important to underline that participants were targeted among mentally competent citizens, and not psychiatric patients. Excluded

respondents had the possibility to contact the first author for referral to professional help at any time.

### 2.3. Data collection

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

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

### 2.4. Ethical considerations

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

All participants received an information letter outlining aim, procedure, the right to withdraw at any moment, privacy, contact details and the possibility of receiving aftercare (i.e. an extra conversation at their home or referral to professional help). They were also informed that additional information was available on the research website. Prior to the interview, the researcher contacted them by phone to make an appointment for an interview and to check whether the information was clear. They were asked to give written informed consent to participate in the study. Every participant received a narrative interview report of about two pages, on average two months after the interview. After they had

received it, we contacted the participants. The majority of participants not only fully agreed with the report, but also explicitly underlined that participating had been a positive experience, because the interview had helped them to express their thoughts and feelings, which gave them a sense of relief and recognition. Also, most considered it an honour to have the opportunity to contribute to the scientific and public debate. In two cases, aftercare was provided.

### 2.5. Data analysis

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

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

## 3. Results

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

The essential meaning of the phenomenon is understood as 'a tangle of inability and unwillingness to connect to one's actual life'. A permanently lived tension penetrates all participants' stories: their daily experience seems to be diametrically opposed to and incompatible with their expectations of life and their idea of who they were. Living in the present is almost impossible, because the 'here-and-now' evokes significant feelings of disconnection, reflected in feelings of loneliness, not mattering, fear of dependence, self-estrangement and alienation. 'Life is completed and no longer worth living' is an expression of an – often quite desperate – desire that life-as-it-is should stop as soon as possible because of the unbearable burden it embodies. It is difficult to unravel the tangle of inability and unwillingness to connect to one's actual life.

Sometimes it appears to be an active resistance, at other times – even in the same life story – a passive inability. Sometimes it appears as an intertwining of being unwilling and unable, at other times it presents itself more like a continuum: unwillingness seems to shift gradually into inability.

The impossibility to connect to one's actual life is strengthened by a personal life motto: most participants were outspoken, proactive people who highly value their independence and consequently fear dependence, who want to maintain control over their own life and to whom it feels unnatural to sit and wait for the end to come. They simply cannot surrender to life, suffering and dependence as it is/comes. Instead they feel ready to give up on life, actively ideating on ways to hasten death. The following description of five constituents, which should be seen as components of the essential meaning of the phenomenon, further explicate the meaning of the phenomenon: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; 5) a sense of aversion towards feared dependence.

### 3.1. A sense of aching loneliness

All participants expressed feelings of loneliness: a sense of distance from others, a lack of valuable relations and companionship: *"Deep inside, you are very much alone. Totally, totally alone"* (i\_5). Some gradually withdrew into themselves more or less deliberately, for others losing connectedness was less intentional. Participants spoke of deep, heartfelt lonely feelings, regardless of whether there were others around (such as children, spouse, friends, caregivers). A 94-year-old man reported:

*I have two sons. My youngest son, who is quite close, keeping an eye on me, is very dear to me. (...) And I also have a partner with whom I have a very good LAT [living apart together] relationship. So those two bonds still exist. But for me, it's no longer a reason to go on living. You only go on living, if you want to. (...) I feel like a sawed-off tree. Completely sawed-off. But a sawed-off tree still has roots. I have no roots anymore, no strong bonds anymore, and no close connection to life anymore. (...) Of course, I value those bonds, but hey, you fall in love, you get married, you have a LAT relationship. Well, that's it, that's as far as it goes. It's a gilded edge, a nice dessert. But it's not something to keep you alive(i\_4).*

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

*My children are all managing on their own. Nobody lives a shabby life, thank God. But you know, they don't need me anymore. I know I'm not supposed to say it out loud, but if I visited my kids, I think they would say: "God damn, it's the old man again." (...) I'm just getting in their way (i\_10).*

Other participants spoke of some remaining, worthwhile contacts with peers, but those contacts were becoming increasingly sporadic, leaving lonely feelings. Despite people being present, they felt a lack of reciprocity and support.

*In the last years, I have strengthened two social contacts. Nice outings, uh, with that friend. Uh, I mean going to concerts, cabaret, that kind of outing. But actually, I have come to the conclusion that this does not help enough. These things, it helps, it helps a lot, it's great fun, but it's not enough ... These outings, they are only occasional, maybe once or twice a month (i\_11).*



### 3.2. The pain of not mattering

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

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

*It's just that, uh ... I cannot utilize my talents. I'm a techie, that's what I like to do. (...) So yes, I feel that I have a lot of experience and knowledge in that area, but society doesn't need me anymore. At the moment I strongly feel: my life is of no consequence anymore... (i\_11).*

Most participants used to be full and active members of society, they had a certain grip on the world, but slowly recognized they were becoming outsiders and increasingly lost their sense of belonging: “your influence is gone, nobody listens to you anymore, old axioms fall away, you are not able to keep up”. More and more they lost connection with the surrounding world. One participant compared his feelings with “looking through the wrong end of a pair of binoculars”: instead of things getting closer, everything is moving further and further away. Over the years, he felt more distance to the world around him. “It is like the end of a curve, a vacuum... Not my world anymore.” (i\_15) It evoked feelings of alienation and disconnectedness from life. Another man (92), a former superintendent in the shipping industry, talked about how his recent experiences on a cruise enhanced mournful feelings of exclusion and not mattering:

*You have no effect on anything, you know. The ship sets sail and everyone has a job, but you just sail along. (...) I am cargo to them. That's not easy. Not easy. No, no, no. That's not me! No, no, no, no! (...) Yeah, it is difficult to fully express, huh, what I'm feeling. Humiliation is too strong a word, but it is bordering on it. Huh, I simply feel ignored, completely marginalized. You know, in the past, when I went aboard ship, I was the superintendent with full authority, carrying out important work. But now, I feel like a third wheel. Yeah, completely side-lined in all areas. I have no idea in which area someone my age is able to seriously participate. No. That is over (i\_6).*

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

*If only I could express myself! I could give lectures, I could do lots of things, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death. I do want to reincarnate to restart my school and then I will tell my story again. My story! (...) But now, I just sit here in my own silence, it's very quiet. Many days go by that*

*I don't hear my own voice. And definitely, you have to go through this yourself to really understand, you know. This voice, my voice, which so strongly wants to talk... Well that's very difficult. I love people but I'm just sitting here all alone (i\_9).*

### 3.3. The inability to express oneself

The experience of no longer being able to carry out the activities one was committed to during life, clearly emerged in participants' stories. Participants regarded these activities and capacities as central to life, not only as a reason to matter as described above, but also as a way to express one's individuality. Therefore, the loss of these identifying activities meant a loss of self to them: “This is no longer me.”

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

*You're no longer human, I think. You cannot care for people anymore. (...) You lose so much that you are no longer human, I think. That's how I feel about myself. I am treated as a person, that's not my point, but for myself... (...) I see nothing, I see nothing but blackness. (...) When I was 58, I retired. Then they said: “What are you going to do?” I said: “I am going to paint.” Everyone laughed at me. But I used to draw when I was little. In a way, it has always been my talent. (...) In spring, it's so beautiful out here. That little pond with those trees and the daffodils all in bloom, it's such a rustic spot, so beautiful. The delicate green of the weeping willows... But now, it's all black... (i\_13).*

### 3.4. Multidimensional feelings of tiredness

Most elderly people mentioned feelings of mental, physical, social and/or existential tiredness. In most cases, tiredness turned out to be a complex, multidimensional and overwhelming fatigue often accompanied by a gloomy and despondent mood. One participant felt extremely tired, just totally worn out, fed up with life-as-it-is: “...if I only have to lift an arm to get something done, I already feel completely overworked” (i\_4). Participants mentioned different (sometimes intertwined) reasons for tiredness:

- Struggling with serious but non-life-threatening diseases, physical deterioration and pain.
- Emotional grief or a (past) trauma that comes to the foreground in the silence of old age.
- Continuous fretting about a very tough life, missed opportunities and disappointments.

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

*It gives me a pain that can be compared with carrying a very heavy bag of cement on my shoulders, you know, a bag of Portland weighing 50 kilos, all day, anywhere and anytime. I wake up with*

it, I go to sleep with it. But I have learned to downplay it to a certain extent. (...) It is a deadly fatigue. A painful feeling of being dead tired. Very heavy fatigue. It is pain. Well, you cannot understand it, as you are not carrying a bag of cement in your hands... It's so extremely heavy. But not only that, it's extremely painful as well. (...) So that's not very stimulating, that pain does not encourage you to stay alive (i.14).

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

### 3.5. A sense of aversion towards feared dependence

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

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

*I went out with Anita, watching birds, and uh, I said: “Oh, I need to pee”, so I walked out of the bird hide, stood there and then I peed. But then, I'll just say it, I suddenly pooped too. Then I deeply, deeply cried, standing there outside in nature. I became intensely sad. (...) I do not know, I burst into tears, I felt so sad about this happening to me. (...) Yes, it was, so I think, I had no control at all, it just happened without my involvement... I stood there and it just happened unintentionally, it just happened... (i\_23).*

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

*Look at the condition of those old ladies in the building opposite. Gaunt and half dead, pointlessly driven around in a wheelchair, it is simply horrible... In my eyes, it has nothing to do with being human anymore. They don't even know it, they just go through the process, and then suddenly ‘the black car’ arrives again. It is a stage of life, I simply don't want to go through (i\_23).*

Several participants even talked about losing their “raison d'être”: they were distrustful and feared their lives would be taken over by others (like caregivers or family), deciding what is best for them, because they are no longer able to “guard their own individuality”. Some participants nearly panicked at the thought of being too late with “taking precautions” to avert a state of total dependence. For most, there seemed to be only one desirable option to retain control: a so-called “flight-forward” to stop this “humiliating process” as quickly as possible by a self-chosen death.

## 4. Discussion

### 4.1. Reflections on the findings

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

Though there is much literature on suicide and the wish to die in older age, empirical research into the experiences of this specific population of elderly people who wish to die without having a serious medical condition is very limited; only a few studies pay partial attention to it, as our literature review described (Van Wijngaarden et al., 2014). This study probably provides the first in-depth account of this little studied group. It contributes to the literature in several ways: it provides a preliminarily characterization of this population; it nuances the assumption that the wish to die in this population stems from an ethos of rationality; it illustrates that the wish to die is not only about individual experiences, but is also based on social grounds; and it questions the association between death wish and depression in this sample.

First, our study provides a preliminary, phenomenological characterization of the population under research. Disengagement in old age seems to be an inevitable, ubiquitous process of withdrawal of an individual from society, so this raises the question what essentially distinguishes the persons who, during this process, give up on life and those that do not? Our results reveal that the group of elderly people studied is characterized by an inability and/or unwillingness to undergo the process of deterioration. The elderly demonstrate a firm but vain attempt to resist an inevitably growing dependence and to preserve their remaining independence. Being pro-active, independent people, their resistance is strengthened by a set of beliefs and by character. These findings support the idea of Freeman (2000), who frames this kind of experience as “narrative foreclosure”: the conviction that, even though one's life as such continues, in one's mind one's life story

has already ended. Life is not over, but one's life story is considered so. One is unable or/and unwilling to identify with life-as-it-is: it is too alienated, too meaningless, too shameful or frightening, having no pleasant future expectations at all (Freeman, 2000). Being ready to give up on life is thus closely related to the *subjective perception* of the elderly involved and the way they “weight” their life-problems.

Our findings also qualify the common assumption that the wish to die because life is ‘completed’ mainly stems from an ethos of self-determination, autonomy, and reasonability (Van Rein, 2013). The results clearly show the ambiguity of participants' *everyday realities*: their wish to die is indeed driven by the great value they attach to independence and autonomy, but it is also strongly influenced by fears, sadness and loneliness. While the population under research as much as possible wants to run their own affairs without interference from others, paradoxically the findings simultaneously indicate elderly to be highly dependent on others when it comes to their well-being. They are driven by a strong human desire to be visible, recognized, wanted, needed, valued, depended upon, or attended to by others. This desire illustrates the complex ambiguous tension in human life that, regardless of how independent a person might present himself, he is at the same time, a needy, vulnerable who depends heavily on others. To be of significance in the eyes of others and to experience mutual responsibility (by helping, sharing, supporting each other) is of vital importance for one's quality of life and self-esteem.

Sayer (2011) has highlighted the importance of taking peoples' concerns seriously, not merely to recognize them as private emotions, but to view them as illuminations of *what* is happening in our society. He argues that people's concerns suggest an ethical dimension of the phenomenon that also needs to be acknowledged: *What matters? What* needs to be taken seriously? “Needs, desires, suffering and a lack of well-being indicate a state of the world and some aspects of that world that should be changed. They involve an impulse, a drive, a pressure” (Sayer, 2011). Thus the expressed needs – e.g. experiences of marginalization and social exclusion – should not to be reduced to ‘an arbitrary, subjective experience’, but serve as an imperative for an on-going public debate on the place and role of elderly in society.

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

While our study does not directly inform policy makers, it certainly nuances and problematizes the current debate, as it provides insight in the lived ambivalences and ambiguities of this particular population; the shortcomings in the prevailing conception of people as independent, autonomous and self-determining

agents; and the inadequacy of considering this wish to die to be an individual problem. Perhaps a way to partly address the absences of meaning experienced by these interviewees might be by changes to their (social) circumstances and relationships, rather than offering them a legal opportunity to die.

#### 4.2. Reflections on limitations and strengths

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

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

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#### Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2015.05.015>.

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