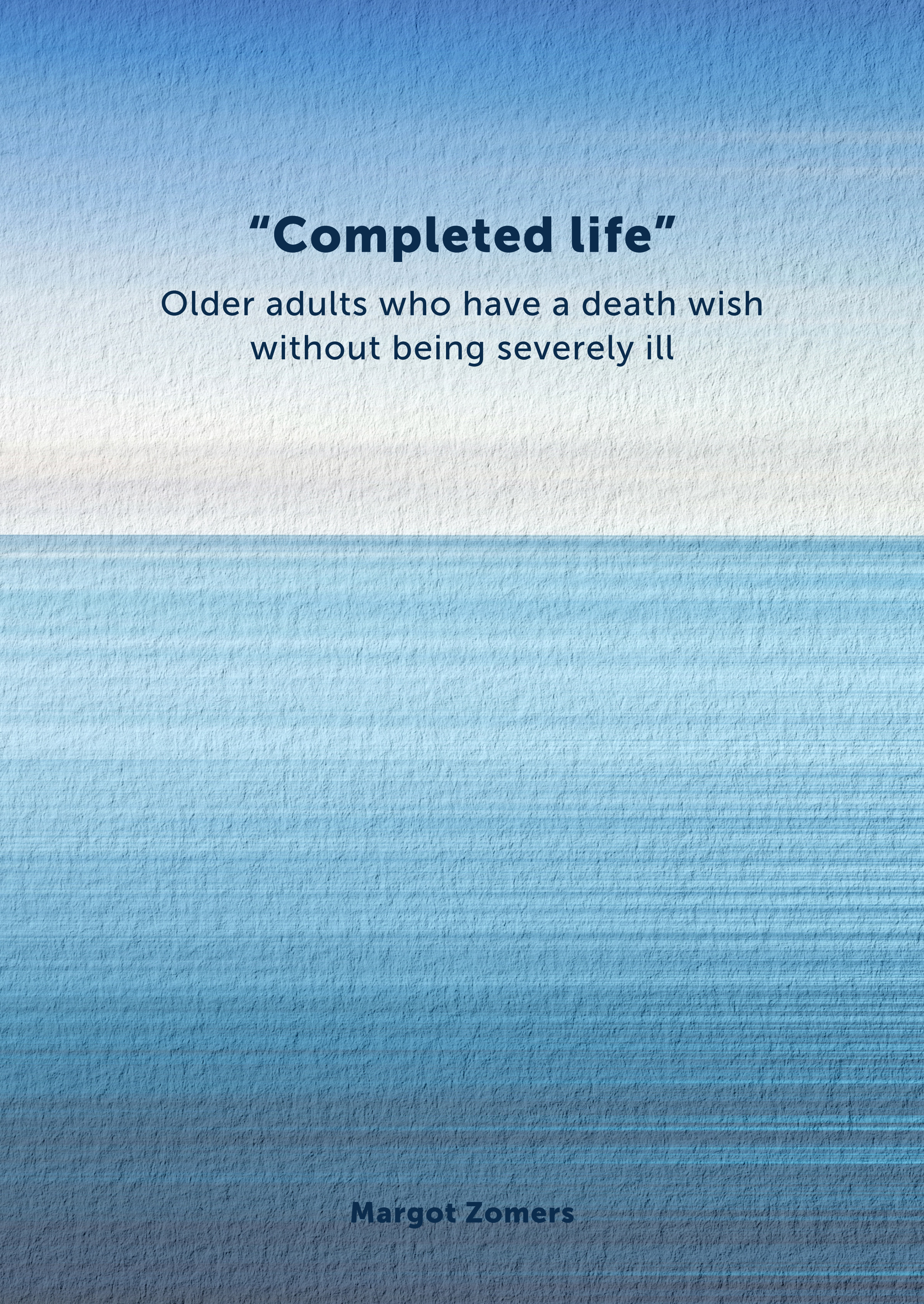

“Completed life”

Older adults who have a death wish without being severely ill

Margot Zomers

“COMPLETED LIFE”

Older adults who have a death wish without being severely ill

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“Completed life”
Older adults who have a death wish without being severely ill

“Voltooid leven”
Ouderen die een doodswens hebben zonder dat zij ernstig ziek zijn

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de
Universiteit Utrecht
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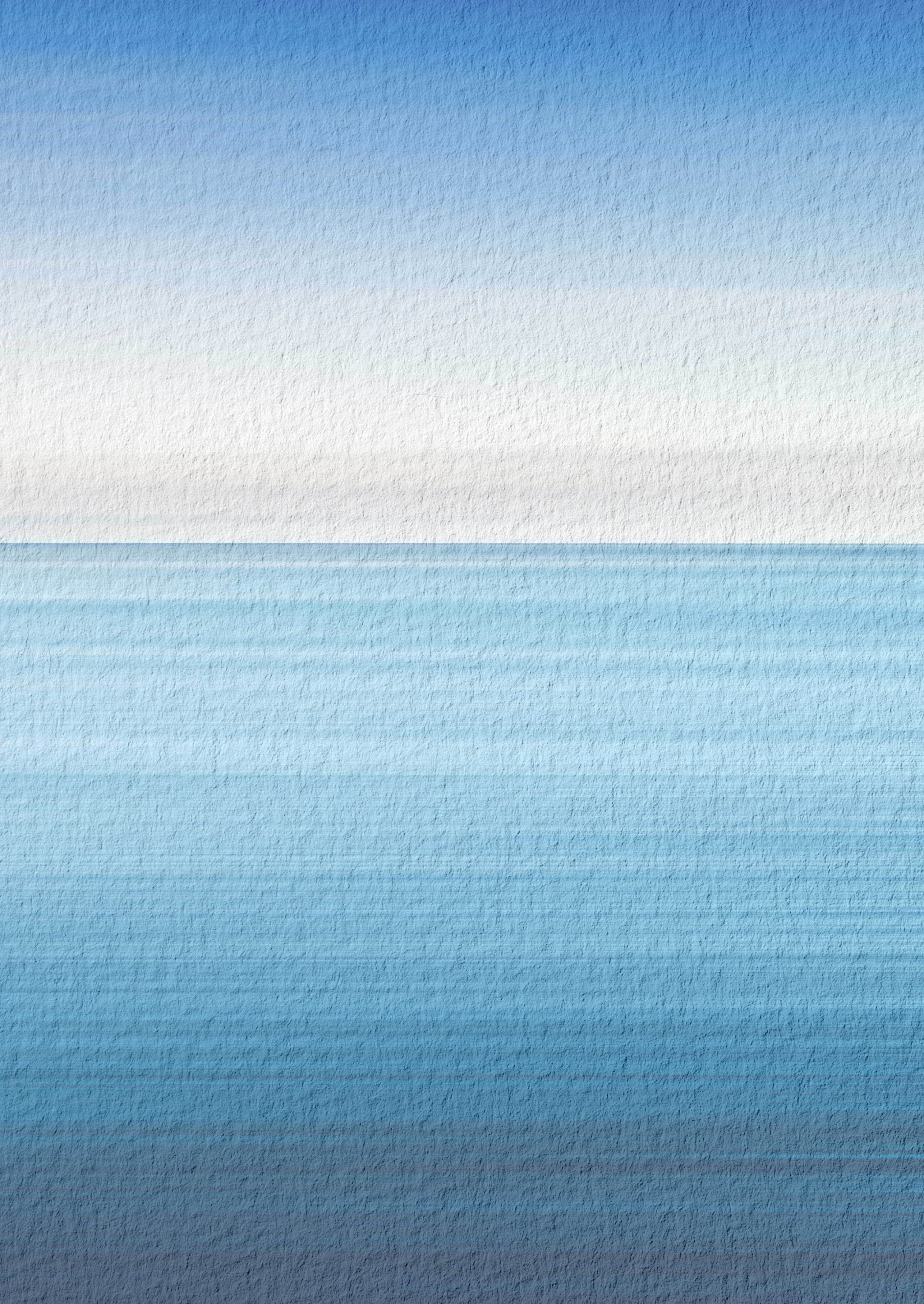

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General introduction

Contribution of the author of this dissertation:
I designed and wrote the general introduction and revised it based on two feedback rounds with my supervisory team.

This dissertation is about older adults who have a death wish without being severely ill. Some older adults may come to the conclusion that even though they are not severely ill, the quality and the meaning of their life has deteriorated to such extent that they do no longer see a future for themselves and prefer death over life, leading to a death wish and sometimes also to a wish for a self-directed death. One commonly used expression for this experience is “completed life”.

When older adults with “completed life” do not mainly suffer from somatic or psychiatric diseases or conditions, they are, under the current legislation in the Netherlands, not eligible for euthanasia and assisted suicide (EAS). There are people who hold the view that this should be changed. They believe that the EAS legislation should be expanded or otherwise legal options for assisted dying should be provided for older adults with “completed life” who are not eligible for EAS but wish for a self-directed death.

In the beginning of 2019 when the work for this dissertation started, there was an ongoing public and political debate about the question whether older adults with “completed life” who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. At the same time, due to the limited empirical knowledge that was available, arguments for and against offering such legal options were mainly ideological and theoretical in nature. For well-informed policymaking on how the death wish of older adults with “completed life” can be appropriately responded to, more empirical knowledge was required on how many older adults have a death wish without being severely ill, who these older adults are, what the background of their death wishes is, and how their requests for EAS are handled by medical professionals. This dissertation aimed to address this knowledge gap.

EUTHANASIA AND ASSISTED SUICIDE (EAS) IN THE NETHERLANDS

Over the past 20 years, the practice of assisted dying, including euthanasia and assisted suicide (EAS), has increased significantly around the world (1-2). The Netherlands was the first country in the world that legalized EAS performed by a physician (3). In 2002, after acceptance by the parliament in 2001, the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (WTL) came into force (4). This Act holds legislation on the voluntary termination of life (euthanasia; the physician administers the lethal substances to the patient) and assisted suicide (the patient himself takes the lethal substances provided by the physician) (5-6). According to the WTL, a physician has to comply with six due care criteria for EAS to be legally permissible:

“Under section 2 (1) of the Act, the physician must:

a. be satisfied that the patient’s request is voluntary and well considered;

b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
c. have informed the patient about his situation and his prognosis;
d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
f. have exercised due medical care and attention in terminating the patient's life or assisting in his suicide" (5).

If a physician complies with these due care criteria and notifies the municipal pathologist afterwards, the performance of EAS is not considered a criminal offence (5-6). The Criminal Code makes an exception for physicians only. For every other person, assisted suicide, including the provision of means to this end, is a criminal offence (7). After each EAS case, physicians must write a notification form and the municipal pathologist who receives this form must send it to one of the Regional Euthanasia Review Committees (RTEs) (5-6). In each reported case of EAS, one of the RTEs assesses whether it was performed in accordance with the due care criteria of the Act. If the physician did not meet one or more due care criteria, the RTE informs the Public Prosecution Service and the Health and Youth Care Inspectorate. These bodies then determine appropriate next steps.

SUFFERING BASED ON MEDICAL GROUND: A STRICT PREREQUISITE FOR EAS

A specification of due care criterion b ("the physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement") resulted from a Supreme Court ruling in 2002 in the Brongersma case (8). In this case, a general practitioner provided an 86 years old man named Brongersma at his own request with the lethal substances for assisted suicide. This took place after a series of conversations between the general practitioner and Brongersma, and after two colleagues (another general care practitioner and a psychiatrist) had also examined him. Brongersma expressed a longstanding death wish related to feelings of meaninglessness, loneliness, a lack of perspective, and (the fear of further) physical decline. While there were some age-related physical problems such as incontinence and balance problems, the general practitioner declared that Brongersma did not have a disease.

In the Brongersma case, the Supreme Court ruled that the performed EAS was not allowed under the WTL. The main argument was that for legally permissible EAS, the patient's suffering has to predominantly stem from one or more medically classifiable somatic or psychiatric diseases or conditions (5, 9). Since then, case law determines that suffering mainly based on medical ground is a strict prerequisite for EAS (5-6, 10). This means that patients who do not have one or more medically classifiable somatic or psychiatric diseases or conditions, or whose suffering does not mainly originate from those, are not eligible for EAS.

This 'medical ground'-boundary of EAS does thus not require that the patient has a somatic disease or condition; in cases of a psychiatric disease or condition, the due care criteria might also be met (5-6). Moreover, the 'medical ground'-boundary of EAS does not require that the patient has a short life expectancy. It does not rule out granting a request for EAS from a patient who could have many more years to live. There is thus no statement that EAS may only be granted to a patient with a life-threatening medical situation or in a terminal stage. Furthermore, the 'medical ground'-boundary of EAS does not require that the patient suffers from one single, dominant medical problem. Medical ground for the suffering can also be formed by the combination or sum of several somatic or psychiatric diseases or conditions.

In line with these notions, the 'medical ground'-boundary of EAS does not exclude EAS in patients whose suffering mainly originates from multiple geriatric syndromes, such as hearing impairment, sight impairment, balance problems, osteoporosis, and cognitive deterioration (5-6). Suffering from multiple geriatric syndromes can be judged as suffering mainly based on medical ground. For multiple geriatric syndromes is described: "These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement" (5).

"COMPLETED LIFE" AND THE 'MEDICAL GROUND'-BOUNDARY OF EAS

Some older adults may come to the conclusion that even though they are not severely ill, the quality and the meaning of their life has deteriorated to such extent that they do no longer see a future for themselves and prefer death over life, leading to a death wish and sometimes also to a wish for a self-directed death. This experience is often referred to with the terms "completed life" or "tiredness of life" (5-6, 9, 11-17). Other expressions used are, for instance, "weariness of life", "finished with life", "suffering from life", "the thought or feeling that life is not worth living", and "life fatigue" (5-6, 9, 11, 14, 16-19).

Strictly speaking, "completed life" may occur both in cases with and cases without suffering mainly based on medical ground (9, 17). Therefore, it has been described that "completed life" may fall both inside and outside the scope of the WTL, respectively (9). In 2016, committee Schnabel stated in their report on "completed life" that the WTL offers sufficient scope to mitigate the majority of "completed life" cases; in many cases there will be suffering from multiple geriatric syndromes, which means that in many cases there will be suffering that can be judged as suffering mainly based on medical ground. Euthanasia Expertise Center (EEC) describes that in cases of "completed life", multiple geriatric syndromes often cause the wish for EAS (20).

However, the public and political debate focuses on older adults with "completed life" without a medical ground that predominantly accounts for their suffering, which means that they fall outside the scope of the WTL because of its 'medical ground'-boundary (7, 9, 18, 21-22). The RTEs describe that: "the concept of a 'completed life' falls outside the scope of the Act as it goes beyond the medical domain. Physicians do not have the specific expertise that is necessary to be able to form a judgment on this matter" (5). With regard to cases of "completed life", the RTEs describe that insofar as these refer to suffering without medical dimension, cases of multiple geriatric syndromes, conversely, do have a medical dimension (5-6).

In practice, the majority of requests for EAS are based on suffering from cancer or another somatic condition (17, 23). Requests for EAS in the absence of a severe somatic or psychiatric condition or medical ground and requests for EAS based on multiple geriatric syndromes are much less common. Research further indicates that it is less likely for physicians to grant a request for EAS to patients with "completed life" or "tiredness of life" if compared to patients with cancer or another somatic condition (17, 24-26). Also multiple geriatric syndromes are associated with a lower likelihood of having a request for EAS being carried out (24). Far from all requests for EAS based on multiple geriatric syndromes are granted (17, 24, 27-28).

EEC typically receives complex, less common requests for EAS, in which many physicians outside EEC have reservations (17, 23, 27, 29). While requests for EAS based on "completed life" or "tiredness of life" alone are in principle not granted (also not by EEC), a number of requests for EAS of persons who suffer from multiple geriatric syndromes are granted every year (17, 23, 24, 27). From 2013 to 2021 between 172 and 307 cases of EAS for multiple geriatric syndromes were notified to the RTEs each year (172 was 2.7% of the total number of 6,361 notifications in 2019 and 307 was 4.0% of the total number of 7,666 notifications in 2021) (23).

DEBATE ABOUT "COMPLETED LIFE" AND A SELF-DIRECTED DEATH

Over the past few decades, there has been public and political debate about the question whether older adults with "completed life" who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying (9, 12-13, 16). There have been individuals, a citizens' initiative, organizations, and political parties pleading for legal options such as the availability of a "Drion pill" or "last-will-pill" and permitting assistance from a physician, another healthcare professional, or loved one to commit suicide (18, 30-35). They wish for more self-determination, autonomy, and emphasize the right of older adults to end their own lives (16, 36-37). Debated proposals range from options inside or outside the current EAS legislation, with or without presence of the assistant at the actual moment of committing suicide, and including or excluding certain due care criteria.

Previous research shows that the public is divided regarding termination of life in cases of "completed life" or "tiredness of life", yet the group of proponents seems to be growing (16-17, 38). In a study from 2016, 51% of Dutch citizens reported to be in favor of allowing the oldest old to obtain lethal substances at their own request from a physician to end their own lives (26% neutral and 23% against) (17). In 2010, a lower percentage (35%) was in favor is this. Besides, in 2016, 58% reported to be in favor of allowing euthanasia at their own request to older adults who are "tired of living" (26% neutral and 17% against). The same study subsequently also presented a case description of a 86 years old man with a good physical and mental condition but with suffering from loneliness, the loss of his friends, and the prospect of living for many more years. The reactions of the respondents indicate that they tend to be more hesitant when such a concrete example is shown; less Dutch citizens (38% in 2016 and 26% in 2010) were in favor of providing this man at his own request with the lethal substances to end his own life.

In 2016, committee Schnabel recommended in their report on "completed life" to not expand the current EAS legislation for cases of "completed life" (9). The committee stated that their recommendation was formed, among others, by taking into account the well-functioning and careful EAS legislation and practice that already has a broad scope, the potential commotion and uncertainty that might be caused by expanding the legal options for assisted dying, and the probably small number of people who consider their lives to be "completed" and whose wish to end their lives is unrelated to medical problems.

Also after publication of this report, the public and political debate continued about the question whether older adults with "completed life" who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. Despite the recommendation of committee Schnabel, the government argued that legal options for assisted dying should be expanded for this group (22). The subsequent government asked for additional research into the group of people with "completed life" for whom the by committee Schnabel mentioned broad scope of the WTL does not offer sufficient solace (7, 36). The Minister of Health, Welfare and Sport concluded that there was a lack of sufficient information for well-considered and transparent policymaking, and he therefore ordered, in accordance with the coalition agreement, additional research (7, 39).

POLICYMAKING ON "COMPLETED LIFE" HAMPERED BY A KNOWLEDGE GAP

In 2014, two studies were published in which Dutch researchers set out to review and synthesize publications on older adults who have a death wish without being severely ill (12, 40). First, a research synthesis that aimed to bring together knowledge on older people with a wish to end their lives unrelated to suffering from a severe medical condition (40). This research synthesis focused on qualitative and quantitative literature about the Dutch situation up to and including part of 2014. The authors found that there were no studies that specifically targeted older people with a wish to end their lives without (severe) medically classifiable condition. Second, parallel to the research synthesis, a review of internationally published qualitative literature up to 2012 was published on older people with a wish to die without having a life-threatening disease or severe psychiatric disorder (12). This study found that age related losses, personal characteristics, biographical factors, perceptions and values, and social context are factors influencing the development of a death wish.

Both studies indicated that there was limited empirical knowledge on older adults who have a death wish without being severely ill (12, 40). They particularly mentioned that (quantitative) knowledge was lacking on the size and characteristics of the group of older people with a wish to end their lives without (severe) medically classifiable condition, and on the nature of their death wishes (40). Besides, there was a limited extent of qualitative knowledge on the experiences and lifeworld of older people with a wish to die without having a life-threatening disease or severe psychiatric disorder (12).

Since then, two new qualitative studies on the experiences and lifeworld were published (13, 41). The studies show that the daily experiences of older people who consider their lives to be "completed" and wish to die while not being terminally or mentally ill, seem incompatible with their expectations of life and their ideas of the persons they are (13). They may suffer from aching loneliness, the aversion towards becoming dependent, the inability to express themselves, multidimensional tiredness, and a painful feeling of not mattering. The period between intending and actually performing a self-directed death (or not) emerged as an existential challenge in which one can feel torn between feeling simultaneously detached and attached to life (41). In this period, older people may be driven by both rational and non-rational considerations, they may experience being in control while also being uncertain and worried about the dying process, they may on the one hand resist interference and on the other hand long for support, and their death wish may feel both legitimate and illegitimate.

In 2016, committee Schnabel summarized in their report on “completed life” the limited empirical knowledge that was available on how many older adults wish to end their lives due to “completed life” without suffering mainly based on medical ground, who these older adults are, and what the background of their death wishes is (9). In the report was stated that the group of older adults who consider their lives to be “completed” and wish to end their lives seems small, especially if it concerns older adults whose wish to end their lives is unrelated to medical problems. There was no research available on the actual size of the group though. For example, while one study showed that in 2011 in the Netherlands approximately 400 people without severe medically classifiable condition requested EAS from their general practitioner, it is unknown how many of these requests were from older adults and to what extent these requests are related to multiple geriatric syndromes (9, 42).

Besides, while there were a few sources providing indications for some characteristics, there was no quantitative knowledge on what the characteristics of these older adults are (9). Regarding the background of their death wishes, the report summarized several relevant sources, yet quantitative insight into the background of the death wish of specifically older adults without a medical ground that predominantly accounts for their suffering was lacking.

Finally, there was limited empirical knowledge on actual requests for EAS of older adults who have a death wish without being severely ill, and how these are handled by medical professionals. For example, there were only two studies into people who requested EAS in the absence of a severe disease and for whom “tiredness of life” played a major role in the request, and into the reasons for physicians to either grant or refuse these requests (14-15). These two studies were not very recent, while in the meantime there had been clarifications on the scope of the WTL, for example, with regard to EAS in cases of multiple geriatric syndromes (5, 9).

RESEARCH QUESTIONS AND APPROACH OF THIS DISSERTATION

In the beginning of 2019 when the work for this dissertation started, there was an ongoing public and political debate about the question whether older adults with “completed life” who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. At the same time, due to the limited empirical knowledge that was available, arguments for and against offering such legal options were mainly ideological and theoretical in nature. For well-informed policymaking on how the death wish of older adults with “completed life” can be appropriately responded to, more empirical knowledge was required on how many older adults have a death wish without being severely ill, who these older adults are, what the background of their death wishes is, and how their requests for EAS are handled by medical professionals. This dissertation aimed to address this knowledge gap by answering the following research questions:

1. What is the prevalence of older adults with a death wish without severe illness?
2. How can older adults with a death wish without severe illness be described in terms of characteristics and circumstances?
3. What is the background of the death wish of older adults without severe illness considering the nature of the death wish, motivations and needs behind the death wish, and communication about the death wish?
4. How are requests for euthanasia and assisted suicide (EAS) of older adults with a death wish without severe illness decided upon by Euthanasia Expertise Center (EEC) and assessed by the Regional Euthanasia Review Committees (RTEs)?
5. In what ways can be appropriately responded to the death wish of older adults without severe illness in light of empirical findings?

In our studies we searched for older adults with a death wish without severe illness. Committee Schnabel described in their report on "completed life" that it concerns persons mostly of old age (9). Besides, also previous studies into the group of interest focused on older adults (12-14, 16, 40-43). Previous studies have, among others, examined death wishes, wishes to die, death thoughts, suicidal ideation, suicidal behavior, and suicide in old age (12-13, 41). In line with committee Schnabel's used term "doodswens" in their description of the group of interest, we chose to use "death wish" (9). With death wish we refer to a longing for death for oneself. Lastly, we searched for persons without severe illness following previous studies in which the group of interest was delineated by focusing on persons: without a severe disease (14, 16), without a severe medical condition (40), without a life-threatening disease or severe psychiatric disorder (12), without a serious medical condition (43), without terminal or mental illness (13, 41).

Also older adults who have a death wish related to multiple geriatric syndromes might be viewed as older adults with a death wish without severe illness. This means that in our search for older adults with a death wish without severe illness, also older adults falling inside the scope of the WTL might be included because their suffering can be judged as suffering mainly based on medical ground. While this is not the group of older adults with "completed life" on which the public and political debate focuses, it is interesting to study this group of older adults as well. As described above, cases of "completed life" are considered to be cases that overlap with or are closely related to cases of multiple geriatric syndromes (5-6, 9, 20). For the question in what ways can be appropriately responded to the death wish of older adults without severe illness, also the needs of older adults falling inside the scope of the WTL are relevant. After all, not everyone falling inside the scope of the WTL might actually wish to end life, and even if they wish to end life, they may (also) have other needs that can be responded to.

Various sources were used to answer the research questions in this dissertation. First, a review of the literature was conducted to study the state of affairs of international scientific knowledge on older adults with a death wish without severe illness. (**Chapter 2**) Second, a cross-sectional survey among a representative sample of 32,477 Dutch citizens aged 55+ was executed for insight into older adults with a death wish without severe illness in the Dutch general population. (**Chapter 3**) Two sub studies of this survey were performed. One studied the subgroup of older adults aged 75+ because this group was targeted by a new legal framework that was proposed to facilitate assisted dying for older adults who are not severely ill (18). (**Chapter 4**) The other studied the relatively large subgroup of older adults with a lifelong death wish that emerged from the main study, as differentiating this group from older adults who developed a death wish later in life can be relevant for the provision of adequate help and support. (**Chapter 5**)

Also two other sources were consulted that particularly focused on active acting upon the death wish by means of requesting EAS. The third source was the record at EEC of requests for EAS that did not result in EAS. (**Chapter 6**) By means of this source, actual requests for EAS in the categories “multiple geriatric syndromes” and “no medical ground”, and the decision-making process of EEC in these types of requests could be studied. EEC was a logical place to study requests for EAS in these categories, as EEC typically receives complex, less common requests for EAS in which many physicians outside EEC have reservations (17, 23, 27, 29). Lastly, the fourth source was the national open access database of the RTEs. (**Chapter 7**) In this database, case summaries of granted requests for EAS in, among others, the category “multiple geriatric syndromes” are published. Besides studying actual requests for EAS that were granted in the category “multiple geriatric syndromes”, the database of the RTEs provided the opportunity to study the assessment of the RTEs in these types of requests.

Chapter 8 brings empirical findings from this dissertation and from other studies together to start with an answer to research question 5. This beginning of the answer to research question 5 is further elaborated in the general discussion of this dissertation.

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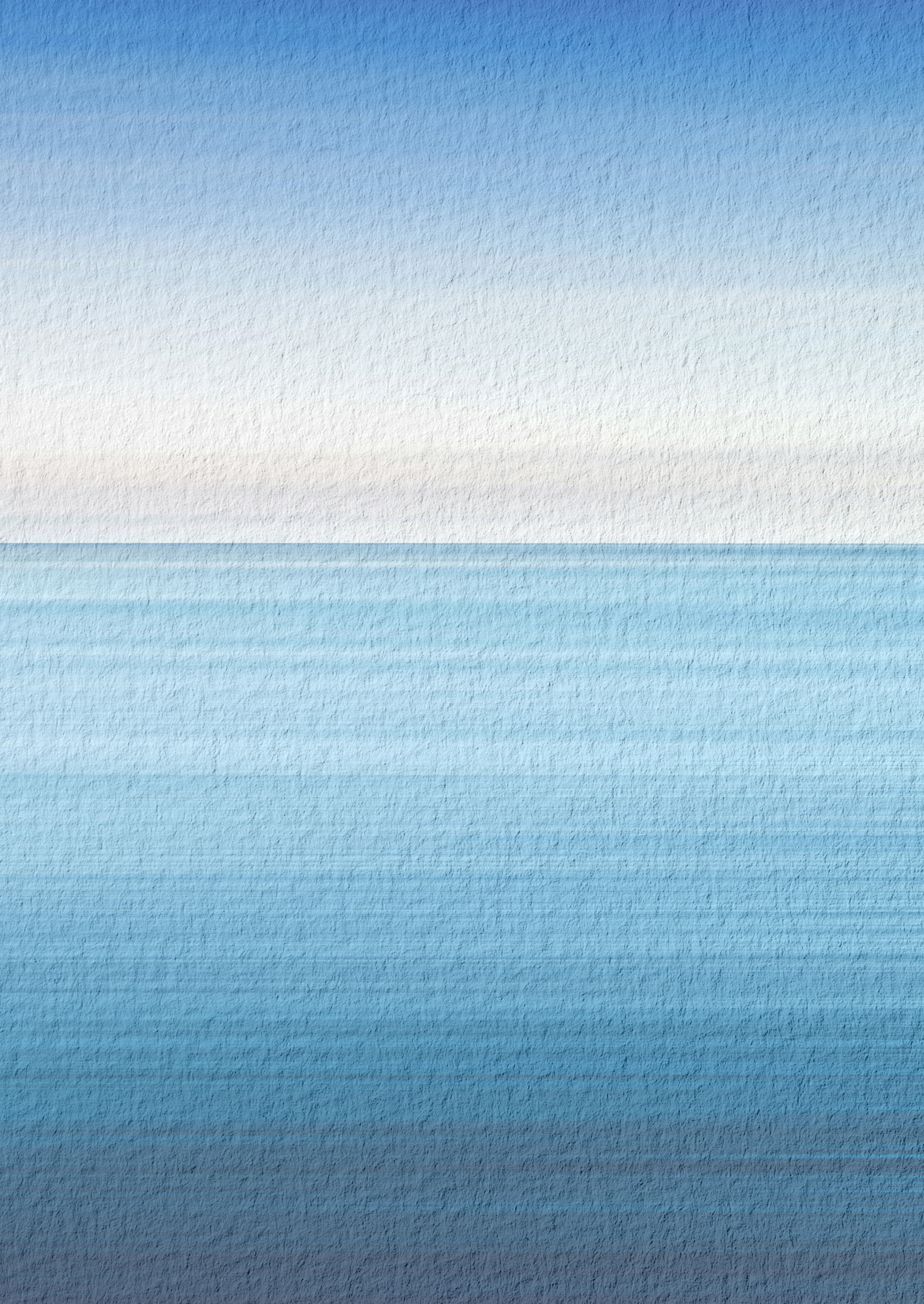

2|

Experiences and circumstances of older adults who have a death wish without being severely ill: a review of the literature

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Contribution of the author of this dissertation:
Together with VvdB, I updated and extended a previous version of this article that was published in the report "Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: de mensen en de cijfers". We updated and extended the data collection and analysis, and revised the text of the article.

ABSTRACT

Older adults who have a death wish without being severely ill pose a dilemma for healthcare professionals, policymakers, and others involved regarding how can be appropriately responded to this death wish. Lack of knowledge on the experiences and circumstances of these older adults hampers a well-informed public and political debate about this issue. We reviewed the literature and found that death wishes among older adults without severe illness seem to occur in different places and cultures, and are related to problems in physical, mental, social, and existential life domains. In order to be able to adequately help and support these older adults, more research into their problems, and good ways in which can be taken care of these problems, would be of great added value. Future research should, therefore, more often specifically target these older adults by distinguishing death wishes of older adults with and without severe illness.

INTRODUCTION

Prosperity, improved social conditions, and enhanced medical care have enabled many to reach an advanced age. While this is generally experienced as positive, some older adults may come to the conclusion that even though they are not severely ill, the quality and the meaning of their life has deteriorated to such extent that they do no longer see a future for themselves and prefer death over life, leading to a death wish and sometimes also to a wish for a self-directed death. It has been suggested that this death wish is mainly associated with “completed life”, “tiredness of life”, meaninglessness and/or worthlessness (1-3). Moreover, some people have a pre-emptive death wish, to prevent anticipated suffering in old age (4-5).

In the past decades in the Netherlands, relatively small but influential groups of citizens and politicians have advocated the right of older adults to choose their own time of death via euthanasia or assisted suicide (EAS). Dutch law regulates EAS under strict conditions which are laid down in the law as due care criteria (6). With regard to the criterion of unbearable suffering without prospect of improvement, the Dutch Supreme Court ruled in 2002 that EAS is permissible only if the patient’s suffering predominantly originates from medically classifiable diseases or conditions (7). Since then, the presence of medical ground as main basis for the suffering is required for EAS.

However, there are older adults who request EAS while not being severely ill (8-9). Moreover, there are proponents of legalizing EAS for these older adults. In 2010, the citizens’ initiative *Out of Free Will* received 116,871 signatures of support for their proposal to grant a right to EAS for older adults who consider their lives to be “completed” (10). The issue of “completed life” or “tiredness of life” among older adults without severe illness and legalization of EAS for these older adults has subsequently been publicly and politically debated.

The public and political debate may benefit from knowledge about the prevalence of older adults with a death wish without severe illness, and the characteristics, experiences, and circumstances of the people concerned. Our aim with this review is to account for the developments in internationally published research on this topic.

METHODS

Our review builds on two former studies in which Dutch researchers set out to review and synthesize publications on this topic. First, a research synthesis that aimed to bring together knowledge on older people with a wish to end their lives unrelated to suffering from a severe medical condition (11). This research synthesis focused on qualitative and quantitative literature about the Dutch situation up to and including part of 2014. Second, parallel to the research synthesis, a review of internationally published qualitative literature up to 2012 was published on older people with a wish to die without having a life-threatening disease or severe psychiatric disorder (12).

Building on this research synthesis and review, we limited our search to literature published between January 1, 2012 and July 12, 2021. We consulted an information specialist from the Utrecht University Library on the database search in PubMed, EmBase, and PsycInfo. A broad search strategy was used in order to maximize the probability of identifying potentially relevant articles. Indeed, research into death wishes among relatively healthy people was expected to be scarce, and may be part of studies with a broader research question and sample. Titles, abstracts, keywords, and subject headings were searched combining two blocks of search terms, referring to (1) older adults and (2) death wishes (**Table 1**).

We included English or Dutch internationally published quantitative and qualitative peer-reviewed studies if these described empirical research on the prevalence of older adults with a death wish without severe illness and/or on the self-reported characteristics, experiences, and circumstances of the older adults concerned. For the criterion "older adults" we did not use age limitations but chose to include articles in which the authors themselves classified respondents as older adults or used similar wording. Furthermore, for the criterion "death wish" we chose to not only include articles describing death wishes or wishes to die, but also articles describing suicidal ideation, feelings, and/or thoughts, since these concepts are closely connected. Finally, for the criterion "without severe illness" we chose to include quantitative studies only if the authors themselves classified respondents as not severely ill or used similar wording. Because qualitative studies usually not report on the prevalence and provide rich descriptions, we chose to include qualitative studies not only if the authors themselves classified respondents as not severely ill or used similar wording, but also if (a great part of) the self-reported characteristics, experiences, and circumstances seemed to be unrelated to being severely ill.

We excluded studies in which the study population or setting were too specific. For example, study populations existing of Bhutanese refugees resettled in the United States, ex-prisoners of war, or German veterinarians were excluded, as well as studies conducted in the setting of severe lockdown restrictions during the COVID-19 pandemic. Furthermore, we excluded publications describing samples mainly recruited in hospitals, as this is not a logical setting to recruit older adults without severe illness. However, we did not beforehand exclude samples that were recruited in institutions such as nursing homes because in several countries, residents of nursing homes are not necessarily severely ill.

Table 1 shows the list of search terms used. Reference lists of all included studies were screened in search of additional relevant articles. We also checked whether the authors of the included studies in the previous research synthesis and review had published new work on this topic (11-12).

TABLE 1. List of search terms

Search query, block 1[a]
Subject headings: Aged (PubMed and EmBase), Aging[b] (PsycInfo) Titles/abstracts/keywords: Old OR older OR elder OR elderly OR aged OR ageing OR aging OR senior OR seniors OR "later life"
Search query, block 2[a]
Subject headings (combined with 'or'): Suicide (EmBase, PsycInfo), Right to die (PubMed, EmBase), Euthanasia, Active (PubMed, EmBase), Euthanasia (PsycInfo), Suicide (EmBase), Assisted suicide (PsycInfo), Suicidal Ideation (PsycInfo) Titles/abstracts/keywords[c]: Suicide OR suicides OR suicidal OR euthanasia OR "tired of life" OR "completed life" OR "wish to die" OR "death thought" OR "death thoughts" OR "death wish" OR "death wishes" OR self-euthanasia OR "death ideation"

[a] Search blocks 1 and 2 combined with AND.
[b] Subject heading searched with subheadings ("explode") excluded.
[c] Search terms excluded because they did not yield other potentially relevant results published after 2011: auto-euthanasia, Drion-pill, last-will-pill, suicide-pill, "weary of life", "weariness of life", "finished life", "finished with life", "life finished", "life to be finished", "tiredness of life", "tired of living", "life completed", "life to be completed", "wishes to die", "self-directed dying", "end-of-life pill", non-terminal.

RESULTS

The database search resulted in a total of 24,535 potentially relevant publications. After removing duplicates, 14,629 studies remained. An overview of the reasons for exclusion of studies based on full text is shown in the flow chart of the study selection (see **Figure 1**) (13). Title and abstract screening resulted in 116 publications eligible for full text screening. Ultimately, six qualitative and four quantitative studies were included in this review. Data extraction from these studies was performed in a collaboration between IH, VvdB, and MZ and discussed with all authors.

Description of included studies

An overview of the included studies is presented in **Table 2**. The quantitative studies show data obtained via surveys and medical interviews. Two quantitative studies describe data of 817 and 1,879 Chinese older adults aged 60 years and above (14-15), one quantitative study describes data of 21,294 Dutch older adults aged 55 years and above (16), and one quantitative study describes data of 1,563 Dutch older adults aged 57 years and above (17). The qualitative studies present data obtained in in-depth interviews. Four of these studies included between 14 and 63 respondents who were drawn from a larger study among 87 older adults in Brazil (18-21). The remaining two studies describe interview data from a group of 25 Dutch older adults aged between 65 and 99 years old (22-23).

PRISMA 2009 Flow Diagram

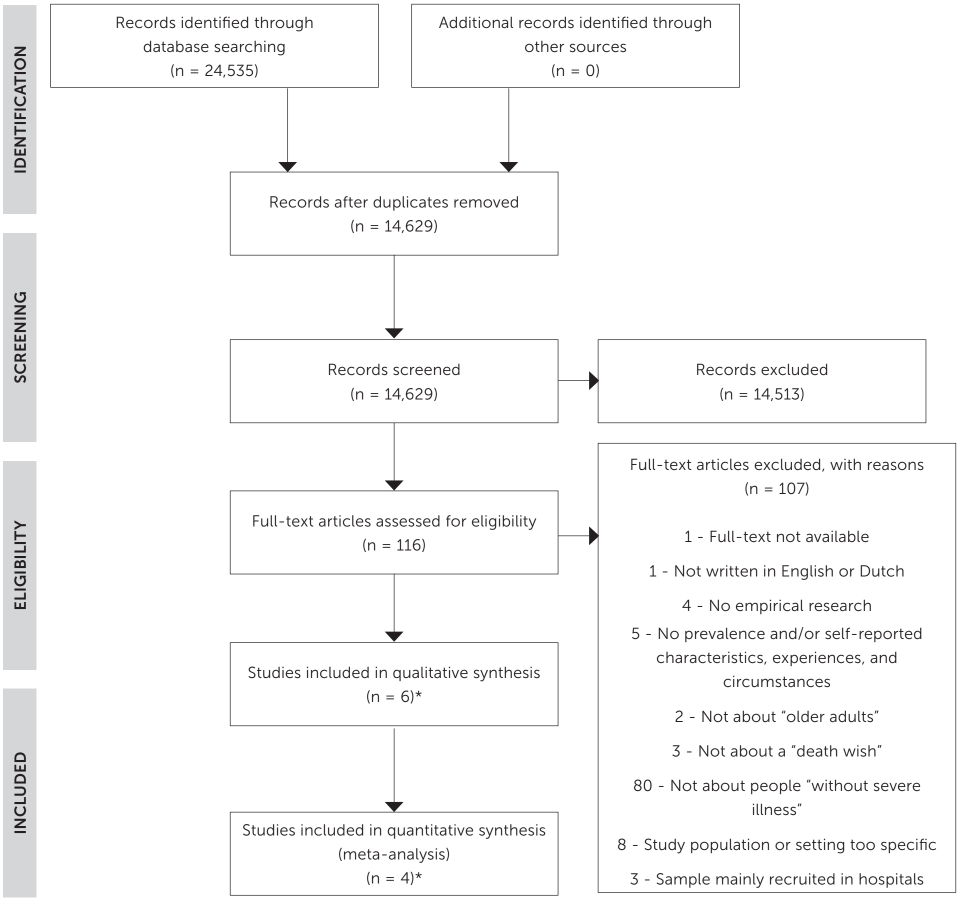

FIGURE 1. Flow chart of the study selection
*One of the included studies was identified separately from the above database search through checking the references of included studies

TABLE 2. Description of included studies

A. Quantitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
1. **Title:** A cross-sectional study on risk factors and their interactions with suicidal ideation among the elderly in rural communities of Hunan, China. **Authors & year:** Xu et al. 2016. **Journal:** BMJ Open.	**Data collection:** Multi-staged cluster random sampling of areas. Face-to-face interviews (surveys). **Data analysis:** Univariate and multivariate non-conditional logistic regression.	**Aims:** To identify risk factors, and their interactions, for suicidal ideation among the elderly in rural communities of Hunan, and provide some scientific basis for suicide prevention. **Inclusion criteria:** ≥ 60 years. **Exclusion criteria:** Having "severe physical or mental illness" (undefined).	**Prevalence:** 1,879 participants without "severe physical or mental illness" were included in the data analysis of this study. The incidence of suicidal ideation among these participants was 14.5% (95% CI 12.9-16.1). The incidence of suicidal plan, suicidal preparation and attempted suicide was 4.0%, 1.9%, and 0.8% respectively. The prevalence of suicidal ideation among participants without "severe physical or mental illness" and without a major depressive disorder (MDD) was 7.7%.
2. **Title:** A cross-sectional study of the prevalence of and risk factors for suicidal ideation among the elderly in nursing homes in Hunan province, China. **Authors & year:** Nie et al. 2020. **Journal:** Frontiers in Psychiatry.	**Data collection:** Multistage cluster random sampling method to select a representative sample of elderly adults living in nursing homes in Hunan province, investigated using a set of structured questionnaires. **Data analysis:** Descriptive statistics, Wald test binary logistic regression, odds ratios, confidence intervals, significance tests.	**Aims:** To investigate the prevalence of suicidal ideation among the elderly in nursing homes in Hunan province, China and to explore the risk factors for suicidal thought and their interactions. **Inclusion criteria:** (1) age 60 years and above; (2) duration since entering the nursing home of more than one year; (3) physical and mental ability to participate in interviews. **Exclusion criteria:** (1) a severe hearing impairment or a language barrier; (2) a history of severe cognitive deficits diagnosed by a physician; (3) a terminal illness. Participants were excluded on the basis of "severe physical or mental illness" (undefined).	**Prevalence:** 817 elderly adults without "severe physical or mental illness" were included in the data analysis of this study. The prevalence of suicidal ideation among these elderly adults was 17.9% (95% CI 15.2-20.4). Among them, 129 elderly adults reported having active suicidal ideation, for a prevalence of 15.8% (11.0% mild and 4.8% strong), and 143 elderly adults had passive suicidal ideation, for a prevalence of 17.5% (8.8% mild and 8.7% strong). The prevalence of suicidal ideation among elderly adults without "severe physical or mental illness" and without depressive symptoms was 3.6%.

TABLE 2. Continued.

A. Quantitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
3. Title: Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey. **Authors & year:** Hartog et al. 2020. **Journal:** BMC Geriatrics.	**Data collection:** Web-based survey among a representative sample of Dutch citizens. **Data analysis:** Descriptive statistics, confidence intervals, and significance tests.	**Aims:** To investigate the prevalence of older adults with a persistent death wish without severe illness and their characteristics, existential issues and the nature of their death wishes. **Inclusion criteria:** ≥ 55 years. To demarcate the group of interest with a persistent death wish without severe illness, the following criteria were used: confirming the qualifications 'seeing no future for oneself, longing for death, while not being_severely ill'; not reporting severe health problems VAS ≥ 4 and EQ-5D-5L < 17; no indication for severe depression HADS-D <16; having a persistent death wish ≥ 1 year. To determine whether this wish was active or passive, the following criteria were used: having made concrete plans/taken steps and/or having seriously considered attempting suicide in the past 12 months = active; not having made concrete plans/taken steps and not having seriously considered attempting suicide in the past 12 months = passive. **Exclusion criteria:** Not reported.	**Prevalence:** Of the total of 21,294 respondents, 267 respondents had a persistent death wish without severe illness (PDW-NSI). In percentages this is 1.25% (95% CI 1.11-1.41) and weighted to represent the Dutch population 1.34% (95% CI 1.20-1.51). For 93 respondents this wish was passive (0.44% weighted 0.47%), for 155 active (0.73% weighted 0.77%), and for 19 it was of an unknown (passive/active) nature (0.09%). Of those with an active wish, 36 respondents described their wish as a wish to end their lives (0.17% weighted 0.18%). *PDW-NSI group in comparison to the group not confirming the qualifications 'seeing no future for oneself, longing for death, while not being severely ill':* **Health/illness:** The PDW-NSI group qualified themselves as "not severely ill". However, nearly all health variables indicate that the PDW-NSI group had worse health. They reported more diseases and complaints and a higher total burden of these diseases and complaints. Their VAS, EQ-5D-5L and HADS-D scores also indicated worse health._ **Death wishes and existential issues:** In response to the question how long they had had the death wish, 18.7% of the PDW-NSI group reported having had it their whole lives, 62.9% for a few years, and 18.4% for approximately one year. One third of the group with an active death wish had made concrete plans or taken steps regarding their death wish. When asked how they would describe their wish, a majority of the group with an active wish reported a wish for a natural death (*N* = 108). Almost half of the PDW-NSI group (49.1%) indicated finding life worthwhile at this moment. They scored higher on the preference *not* to experience the future and on being weighed down by the burden of life.

TABLE 2. Continued.

A. Quantitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
4. Title: Current wishes to die; characteristics of middle-aged and older Dutch adults who are ready to give up on life: a cross-sectional study. **Authors & year:** Kox et al. 2021. **Journal:** BMC Medical Ethics.	**Data collection:** Data of 2015/16 from the Longitudinal Aging Study Amsterdam (LASA) were used for this cross-sectional study, obtained through structured medical interviews and self-reported questionnaires. The sample is described as nationally representative. **Data analysis:** Descriptive statistics, bivariate analyses, and multivariate logistic regression analyses.	**Aims:** To estimate the prevalence of a current wish to die and associated factors among middle-aged and older adults in the Netherlands and to assess how many of these older adults do not have a medically classifiable condition and/or an accumulation of age-related health problems. **Inclusion criteria:** ≥ 57 years. To determine the part of the total study population with a current wish to die, four questionnaire items were combined (from the Paykel suicide scale and The Scale of Suicide Ideation). Three experienced physicians assessed whether the participants with a current wish to die could be classified as having a medically classifiable condition and/or an accumulation of age-related health problems. **Exclusion criteria:** Missing values on the dependent variable; a current wish to die.	**Prevalence:** Of the total of 1,563 participants, 62 participants (4.0%) had a current wish to die. Six out of these 62 cases (9.7%) were assessed with neither a medically classifiable condition nor an accumulation of age-related health problems. This means that of the total of 1,563 participants 0.38% had a current wish to die without a medically classifiable condition and without an accumulation of age-related health problems.

TABLE 2. Continued.

B. Qualitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
5. Title: Qualitative study on suicide attempts and ideations with 60 elderly in Brazil. **Authors & year:** Cavalcante et al. 2015. **Journal:** Ciencia & saude coletiva.	**Data collection:** In-depth interviews, using an interview guide with specific themes (social, physical, mental situation; reasons for suicidal behavior). Research team of 53 people. **Data analysis:** "Hermeneutic and dialectic approach" (not further specified). Cross-categorization with "diagnoses" of the "gravity of suicide attempts".	**Aims:** To discover the reasons and interpretations of elderly people for attempting to take their own life. **Inclusion criteria:** "Elderly people at risk of suicide" (selection procedure and criteria not specified). **Exclusion criteria:** Not reported. *Sample obtained from a larger study among 87 elderly people (selection procedure and criteria not described).*	**"Reasons" given for suicidal ideation/attempts:** **1) "Depression as an illness or associated with losses"** among 20 respondents. Depression was placed "in a pluricausal context of suffering in the course of life", associated with physical, family, and financial losses. **2) Suffering as a result of chronic or painful diseases and functional incapacities** among 19 respondents: myocard infarct/bypasses, CVA, diabetes, blindness, prostate cancer, wheelchair, thrombosis (pain), Alzheimer's, labyrinthitis, and nerve disease. **3) Abusive use of alcohol and other drugs** among 8 respondents, sometimes as a reaction to problems, sometimes causing health problems or losing one's job or family. **4) Personal experience of violence and abandonment** among 8 respondents: "cycle of violence and abandonment" between generations or conjugal violence. **5) Tiredness of life** "in some cases", described as: the desire for death in the face of difficulties and being tired of life. Examples mentioned are "being of no use for anything anymore", "waiting to die", and sadness after the loss of a child ("I should have gone before her").

TABLE 2. Continued.

B. Qualitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
6. Title: Suicidal ideation and attempted suicide in elderly people - subjective experiences. **Authors & year:** Gutierrez et al. 2015. **Journal:** Ciencia & saude coletiva.	**Data collection:** Qualitative interview study using semi-structured interviews with open questions about five aspects (social-demographic characterization, way of life, mental state before suicide attempt (SA), atmosphere of SA, and effects on health and family). **Data analysis:** “Reorganization of the qualitative information based on the categories emerging in the empirical process of subjectivization of the subjects“.	**Aims:** To discuss the subjective experiences of elderly people who show suicidal ideation and/or attempts at suicide, based on their own reports. **Inclusion criteria:** Not reported. **Exclusion criteria:** Not reported. *Sample obtained from a larger study among 87 elderly people (selection procedure and criteria not described).*	**“Empirical categories that emerged”:** **1) The feeling of being “nowhere”/in a “non-place”:** feelings of emptiness, merely ‘occupying space’, loneliness, lack of affection and understanding, and being a burden to others. Often as the result of not being able to provide care or financial support for one’s family. **2) Non-acceptance of losses:** “unresolved mourning” over the loss of loved ones, such as husbands, wives, and children. Furthermore, losses that affect one’s role, social identity, and financial security, such as loss of physical abilities, appearance, social function, and financial resources. **3) Suffering due to ungratefulness of family members:** feeling abandoned or rejected by family members, in terms of affection or materiality while being in need of healthcare, company, or personal help. Resulting in loneliness and disappointment, in tension with “not wanting to think ill of one’s family members”, especially one’s children. **4) Sense of existential uselessness in and of life:** desperation, low self-worth, lack of support, loneliness, uselessness, and loss of meaning of life. **5) Constructing new meanings from situations that generate suicidal conduct:** tendency towards depression and disconnection from the world coexists and alternates with an internal force helping in overcoming difficulties and regaining power over one’s environment.

TABLE 2. Continued.

B. Qualitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
7. Title: The influence of family problems and conflicts on suicidal ideation and suicide attempts in elderly people. **Authors & year:** Da Silva et al. 2015. **Journal:** Ciencia & saude coletiva.	**Data collection:** Qualitative interview study using a script with questions on four topics (personal and socio-economic profile, atmosphere and impact of the SA, prior mental state, and consequences of the SA on health and family). **Data analysis:** "Hermeneutic and dialectic approach" (not further specified).	**Aims:** Investigating how family relationships contribute to suicidal ideation and suicide attempts. **Inclusion criteria:** 60+ years old; having suicidal ideation or having attempted suicide in the last 5 years; being able to express oneself. **Exclusion criteria:** Mental difficulty (alterations in memory or consciousness); inability to verbalize one's life history. *Sample obtained from a larger study among 87 elderly people (selection procedure and criteria not described).*	**"Factors", in order of importance given by the respondents:** **1) Significant family losses,** including restriction of autonomy and liberty, "financial usurpation", and "absence of manifestations of affection between members of families". Sometimes as a consequence of moving to a long-term care institution. **2) Family and inter-generation conflicts:** difficulties of generations living together and understanding each other, "disunion" of families, and disagreements about the behavior of the elderly. Sometimes because of difficulties adjusting to new situations of dependence and being controlled. **3) Explicit and veiled violence:** physical, psychological, sexual, and financial violence (often by partners or family members). Some respondents experienced violence from childhood throughout their whole life. These factors are interpreted as an accumulation and worsening of family problems and social conflicts throughout the lives of the respondents.
8. Title: Suicidal ideation and attempt of older women in Northeastern Brazil. **Authors & year:** Da Silva et al. 2018. **Journal:** Revista brasileira de enfermagem.	**Data collection:** In-depth interviews "based on a specific set of guidelines for interviews with older adults which included identification, demographic attributes, family configuration, morbidity, mental state prior to the suicidal ideation and attempt, possible causes, impact on the family, violence suffered and the possibility of overcoming the fact." **Data analysis:** "Hermeneutic and dialectic approach" (not further specified).	**Aims:** To associate the life experiences of older women from the Northeast of Brazil with their suicidal ideation and attempts. **Inclusion criteria:** Not reported. **Exclusion criteria:** Not reported. *Sample obtained from a larger study among 87 elderly people (selection procedure and criteria not described).*	**Themes emerging from the data:** **1) Experiences of abuse throughout life:** being abused and spanked as punishment as a child, suffering from physical and sexual abuse by family members as an adult. **2) Marital fractures and social isolation:** early and arranged marriages resulting in resignation, sorrow, social deprivation, being hostages of household and caring duties, crushed by a culture of sexism. **3) Weakened motherhood:** helplessness, loneliness, and a lack of emotional and social support after child birth. Sometimes leading to postpartum depression and suicidal behavior. In later life: feeling a lack of reciprocity from their children. Feeling abandoned, neglected, and unfortunate.

TABLE 2. Continued.

B. Qualitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
9. Title: Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. **Authors & year:** Van Wijngaarden et al. 2015. **Journal:** Social Science & Medicine.	**Data collection:** Open in-depth interviews, structured in three sequences. **Data analysis:** Reflected life world approach, inspired by the philosophical phenomenology.	**Aims:** To develop an in-depth understanding of the phenomenon 'life is completed and no longer worth living' from a lifeworld perspective, as it is lived and experienced by elderly people. **Inclusion criteria:** Being 70 years or older; considering one's life 'completed' and no longer worth living; strongly wishing to die, while not being terminally or mentally ill. **Exclusion criteria:** Exclusion in the process of purposeful sampling aiming for diversity. Exclusion of people not having an actual wish to die and/or driven by political motives for participation.	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:** a sense of distance from others, a lack of valuable relations and companionship. A lack of reciprocity and support, regardless of whether there were others around. **2) The pain of not mattering:** viewing themselves as dispensable, redundant and not important to people or society. Intense sorrow, feeling marginalized, losing purpose and meaning and the connection with the outside world. **3) The inability to express oneself:** loss of self as a result of losing activities that enabled expressing one's identity. Lack of sharing and gaining new ideas to enrich one's life. **4) Multidimensional tiredness:** feeling mental, physical, social and/or existential tiredness, caused by: - 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. **5) A sense of aversion towards feared dependence:** feelings of aversion, fear and shame about the process of progressive, irreversible decline and subsequent dependence. Regarding involuntary dependence as an unacceptable, abhorrent condition devoid of dignity.

TABLE 2. Continued.

B. Qualitative studies			
Title, authors and journal	**Design and methods**	**Aims and inclusion and exclusion criteria**	**Results**
10. Title: Caught between intending and doing: Older people ideating on a self-chosen death. **Authors & year:** Van Wijngaarden et al. 2016. **Journal:** BMJ Open.	**Data collection:** Open in-depth interviews, using a phenomenological approach (aiming to explore lived experiences), structured in three sequences: 'completed life'; the wish to die; and organizing a self-directed death. **Data analysis:** Phenomenological thematic analysis.	**Aims:** To provide insight into what it means to live with the intention to end life at a self-chosen moment from an insider perspective. **Inclusion and exclusion criteria:** Sample is the same as in 9. Van Wijngaarden et al. 2015, see above.	The liminality or 'in-betweenness' of intending and actually performing self-directed death (or not) is characterized as a constant feeling of being torn. **This feeling is explicated by the following pairs of themes:** **1) Detachment and attachment:** feeling disconnected from their actual life, sensing an inevitable loss of having grip on their life, and decline of physical capacity threatening their independence. At the same time, postponing death and mentioning attachments to life such as a physical drive to live on, responsibilities and duties towards themselves and others, and religious conscientious objections. **2) Rational and nonrational considerations:** a sense that the wish to die was entirely their own and rational, resulting from rationally weighing the pros and cons of living on. At the same time, feeling influenced by inner and much more uncontrolled compulsions, bodily or emotional. **3) Taking control and lingering uncertainty:** feeling a sense of certainty, control, rest and relief in the process of organizing their self-directed death. At the same time, also expressing feelings of worry and uncertainty about the dying process. About the 'right method' for self-euthanasia as well as the extent to which they would be able to stay in charge up to the end. **4) Resisting interference and longing for support:** placing great value on self-determination, independence and autonomy, taking their own responsibility and not wanting to burden others. At the same time, feeling lonely in the preparations for this ultimate decision, and seeking support and assistance from medical professionals in the act of ending life. **5) Legitimacy and illegitimacy:** longing for legitimacy for their death wish so that it would be regarded as something 'quite normal', 'understandable', and 'justified'. At the same time, experience judgments of doing something 'unlawful', 'illegal' and being part of 'an underground movement'. On the interpersonal level, experiencing that talking about their intention to terminate life was a social taboo, often ignored or received with denial and misunderstanding. On the societal level, feeling 'let down' and 'abandoned' by society and the government.

Prevalence

The two Chinese quantitative studies both report on suicidal ideation; one on suicidal ideation among elderly in rural communities of Hunan, China and one on suicidal ideation among elderly in nursing homes in Hunan province, China (14-15). In the first study, suicidal ideation was defined as "the thought of suicide or wanting to take actions to end one's life" (15). The authors report that older adults with "severe physical or mental illness" were excluded, without defining (the measurement of) this exclusion criterion. They found an incidence of suicidal ideation of 14.5% (95% CI 12.9-16.1). This incidence was higher than the incidence of suicidal plan, suicidal preparation, and attempted suicide. The prevalence of suicidal ideation in a group of respondents without "severe physical or mental illness" and without major depressive disorder (MDD) was 7.7%.

In the second study, suicidal ideation was defined as "active or passive thoughts about killing oneself at some point or phase in life" (14). How active and passive thoughts were understood was not explained by the authors. Also here, the authors report that older adults with "severe physical or mental illness" were excluded, without defining (the measurement of) this exclusion criterion. They found a prevalence of suicidal ideation of 17.9% (95% CI 15.2-20.4). Subsequently, the authors distinguished the prevalence of mild and strong active suicidal ideation and mild and strong passive suicidal ideation. The prevalence of suicidal ideation in a group of respondents without "severe physical or mental illness" and without depression symptoms was 3.6%.

In the Dutch quantitative study of Hartog et al. (16), the group of interest was demarcated by means of the question: does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? Furthermore, additional measures were used to exclude severe health problems including an indication for severe depression, and to determine that the death wish had persisted for one year or longer. Among 21,294 respondents aged 55 years and older the prevalence of a persistent death wish without severe illness was 1.25% (95% CI 1.11-1.41) and weighted to represent the Dutch population 1.34% (95% CI 1.20-1.51). The authors distinguished death wishes with an active or a passive nature, and with or without a wish (for help) to end one's life.

The Dutch quantitative study of Kox et al. (17) first determined whether respondents had a current wish to die on the basis of answers to four questions in a questionnaire derived from the Paykel suicide scale and the Scale for Suicide Ideation. Additionally, three experienced physicians assessed whether respondents with a current wish to die had a medically classifiable condition and/or an accumulation of age-related health problems. Of the total of 1,563 participants, six persons (0.38%) had a current wish to die without a medically classifiable condition and without an accumulation of age-related health problems.

Characteristics, experiences, and circumstances

Background characteristics of the respondents such as age, gender, marital status, and social circumstances are presented in **Table 3**.

The studies also provide information on physical and mental health problems, social and relational problems, and existential problems of the respondents. In addition, the studies describe ambivalences in living with a death wish. These results are presented below.

Physical and mental health problems

Physical disabilities/diseases and depression (symptoms): the two Chinese quantitative studies excluded older adults with "severe physical or mental illness". Still, the study population consisted of persons with considerable health problems (14-15). With regard to physical health problems, 67% and 54% reported a disabled ADL status and 76% and 70% a history of chronic disease respectively. With regard to mental health problems, 36% reported depression symptoms and 13% MDD respectively. Among the respondents with a disabled ADL status, a history of chronic disease, depression symptoms, and MDD, the prevalence of suicidal ideation was higher compared to respondents without these health problems.

In the Dutch quantitative study of Hartog et al. (16), older adults with a persistent death wish without severe illness reported considerable health problems, even though they qualified themselves as "not being severely ill" and additional measures were used to exclude severe health problems including an indication for severe depression. For example, those with a persistent death wish without severe illness reported more and a higher total burden of diseases and complaints in comparison to those who did not confirm the qualifications 'seeing no future for oneself, longing for death, while not being severely ill'. They also had considerable higher depression scores.

The two Dutch qualitative studies selected older adults with a death wish without terminal or mental illness. Still, part of the selected participants suffered from serious illness and physical health problems such as sensory disorders, arthritis, rheumatism, and heart disease (22-23). Besides, screening for depression showed one indication for severe depression, two indications for moderate depression, and six indications for mild depression. Respondents expressed "gloomy feelings", grief and sorrow, as well as extreme mental tiredness.

Addiction: some respondents mentioned the use of alcohol as a reaction to problems and as a way to forget one's struggles and sorrow (18). Alcohol was seen as the cause of problems in various domains in life, such as health problems or losing one's job or family. Also suffering from the alcoholism of spouses or family members was mentioned, often accompanied by physical and psychological violence.

TABLE 3. Respondent background characteristics[a]

Study	Xu	Nie	Hartog	Kox	Cavalcante	Gutierrez	Da Silva	Da Silva	Van Wijngaarden	Van Wijngaarden
Characteristic	2016	2020	2020	2021	2015	2015	2015	2018	2015	2016
Sample size	1,879[b]	817[b]	267[c]	62[d]	60[e]	57[f]	63[f]	14[f]	25[g]	25[g]
Country[h]	China	China	NL	NL	Brazil	Brazil	Brazil	Brazil	NL	NL
Age range	60	79.1	55-59	<65 (min 57)	60	57	-	60	67	67
	to	±	to	to	to	to		to	to	to
	97	8.7	90-94	≥85	101	101		>80	99	99
Gender										
Female	-	54%	56%	65%	59%	58%	-	100%	56%	56%
Male	53%	-	-	36%	-	-	-	-	-	-
Marital status										
Married/with partner	71%	-	-	42%	33%	35%	-	-	-	-
Widowed	-	-	-	36%	30%	28%	-	71%	56%	56%
No partner	-	-	-	23%	-	37%	-	-	16%	16%
Stable	-	37%	-	-	-	-	-	-	-	-
Unstable[i]	-	63%	-	-	-	-	-	-	-	-
(Step)Children										
Yes	-	91%	73%	-	-	79%	-	-	72%	64%
No	-	9%	27%	-	-	21%	-	-	28%	28%
Education										
Low	-	-	-	39%	-	-	-	-	-	-
None or (semi)illiterate	35%	-	-	-	20%	19%	-	29%	-	-
Elementary/primary school or below	55%	45%	-	-	33%	46%	-	43%	-	-
High school or above	10%	55%	-	-	-	-	-	29%	-	-
Lower vocational/secondary education	-	-	37%	-	-	-	-	-	-	-
Middle	-	-	-	32%	-	-	-	-	-	-
Intermediate vocational/higher secondary education	-	-	36%	-	-	-	-	-	-	-
High	-	-	-	29%	-	-	-	-	-	-
Higher vocational education/ university	-	-	26%	-	-	-	-	-	-	-
Unknown	-	-	1%	-	-	-	-	-	-	-

TABLE 3. Continued.

Study Characteristic	Xu 2016	Nie 2020	Hartog 2020	Kox 2021	Cavalcante 2015	Gutierrez 2015	Da Silva 2015	Da Silva 2018	Van Wijngaarden 2015	Van Wijngaarden 2016
Living situation										
Alone/own home	12%	-	52%	95%	-	-	-	36%	-	-
Dependent living	-	-	-	5%	-	-	-	-	-	-
With relatives	-	-	-	-	-	-	-	64%	-	-
With partner/LAT	-	-	-	-	-	-	-	-	28%	28%
Household size of 2	-	-	40%	-	-	-	-	-	-	-
Household size of 3 or more	-	-	8%	-	-	-	-	-	-	-
Worldview										
Religious worldview	-	-	38%	-	91%	-	-	-	24%	24%
Non-religious worldview	-	-	29%	-	6%	-	-	-	36%	36%
Worldview, religiousness unknown	-	-	4%	-	-	-	-	-	-	-
No worldview	-	-	30%	-	3%	-	-	-	40%	40%
Urbanization										
Rural	27%	-	-	-	40%	-	-	-	-	-
Urban	73%	-	-	-	60%	-	-	-	-	-
Very high	-	-	29%	-	-	-	-	-	-	-
High	-	-	31%	-	-	-	-	-	-	-
Moderate	-	-	17%	-	-	-	-	-	-	-
Densely populated	-	-	-	66%	-	-	-	-	-	-
Sparsely populated	-	-	-	34%	-	-	-	-	-	-
Low	-	-	16%	-	-	-	-	-	-	-
None	-	-	7%	-	-	-	-	-	-	-

[a] In this table, background characteristics of the total study samples are presented except for the studies of Hartog et al. and Kox et al., as in these studies also background characteristics were presented of a subgroup that better approached our group of interest of older adults with a death wish without severe illness. In the study of Hartog et al., among the total study sample of 21,294 respondents, there were 267 respondents with a persistent death wish without severe illness. Characteristics of these 267 respondents are described in the table. In the study of Kox et al., among the total study sample of 1,563 participants, there were 62 participants with a current wish to die. Characteristics of these 62 participants are described in the table; [b] Without "severe physical or mental illness"; [c] With a persistent death wish without severe illness ; [d] With a current wish to die; [e] At risk of suicide; [f] With suicidal ideation and/or attempted suicide; [g] Strongly wishing to die, while not being terminally or mentally ill; [h] NL refers to the Netherlands; [i] Includes never married, widowed, and divorced.

Social and relational problems

Two of the included studies specifically focused on family problems and women in situations of arranged marriage and very restricted gender roles (19-20). The respondents reported conflict, violence, and gender roles in relation to their suicidal ideation and attempts.

Conflict: conflicts between family members and generations arose in situations where older people had become dependent on family members, or had to move in with their children or to a long-term care institution (19). One dynamic of conflict was the feeling of abandonment or rejection by family members while needing (health) care, company, or personal help. This resulted in feelings of loneliness and disappointment (21).

Violence: being a victim of physical, psychological, sexual, and/or financial violence also contributed to suicidal ideation (18-20). Some respondents, mostly women, experienced violence and abandonment throughout their whole life, being punished and abused as a child and being violated in their marriage or by family members as an adult (19-20).

Gender roles: with regard to gender roles, respondents described how certain roles were forced upon them by "a culture of sexism" (20). Living under the control of their husbands with a role restricted to household duties and motherhood often resulted in social isolation and deprivation among women. In later life, some of these women experienced a lack of reciprocity in the relationship with their children, after having fully dedicated their lives to caring for them. Regarding this as ingratitude and feeling abandoned were mentioned as reasons for these older people to consider suicide.

Existential problems

The existential problems that were described can be divided into four subcategories: feeling disconnected from life, tiredness of life, struggling with loss, and loneliness.

Feeling disconnected from life: several appearances of disconnectedness from life were described. One form may be a feeling of emptiness and existential uselessness, as a result of retirement and children being grown-up and independent (21). This caused intense sorrow, desperation, and loss of self-worth, purpose, meaning in life, and connection with the outside world. Disconnectedness may also manifest as a "loss of self", because activities are lost in which respondents were able to express themselves and in which new ideas were shared, enriching their lives (22). Finally, disconnectedness may be characterized as the feeling of being a burden to others by being dependent and old.

Tiredness of life: tiredness of life is mentioned in one of the studies as something that "sporadically" caused the death wish, as opposed to frequently mentioned causes such as illness, disabilities, and traumatic experiences (18). Another study characterized the tiredness as "multidimensional tiredness", comprising mental, physical, existential, and/or social aspects (22). Respondents felt as waiting in a void for death to come, without much energy or enthusiasm left. The tiredness was caused by physical deterioration, pain, and diseases; emotional (past) trauma and grief; and/or by continuous fretting about missed opportunities, a very tough life, and disappointments in the past.

Struggling with loss: physical, relational, and financial losses were seen as the cause of suffering throughout the course of life, resulting in (or worsening) depressive feelings or depression (18). Respondents spoke of "unresolved mourning" over the death of loved ones, as wounds that were still painful and open (21). Losses affecting their roles, social identity, and financial security were also mentioned, such as loss of physical abilities, appearance, social function, and financial resources. These losses resulted in feelings of a "shrinking world" and hampered choices and possibilities.

A type of loss that appeared to be especially hard to live with for some respondents was the loss of independence, often as a result of irreversible physical decline. Involuntary dependence was regarded as unacceptable, abhorrent, and devoid of dignity, causing feelings of aversion and shame (22). Some respondents were not yet dependent but feared future decline and loss of independence. They expressed disgust about the idea of "ending up in a nursing home", which they regarded as dehumanizing, humiliating, and undignified.

Loneliness: in some studies loneliness was reported as a phenomenon related to the occurrence of death wishes and in others loneliness was mentioned within the context of losses and relational problems (18-21). It was described as a sense of distance from others and a lack of valuable relationships and companionship (22). In addition, not wanting to be a "hindrance" or a "burden" to children played a role (21-22). Despite frequent contact, feelings of loneliness could emerge as a result of violence, conflicts, and feelings of rejection, abandonment, a lack of reciprocity, and being treated in an ungrateful way (18-20, 22).

Ambivalences in living with a death wish

Living with a death wish and an intention to end one's life was described by authors of the included studies as a situation and process full of tension and ambivalences (16, 21, 23). For example, one study described that a persistent death wish without severe illness could go hand in hand with finding life worthwhile and did not always imply a strong preference *not* to witness the future (16). Besides, the stories of respondents about their situation reflected struggling in an "in-betweenness" of intending and actually performing their self-directed death (23). This “liminality” is described in five pairs of themes. First, respondents’ strong sense of detachment from their actual life sometimes goes together with certain attachments to life that make them postpone death. For instance, the feeling of disconnectedness may coexist and alternate with “an interior force that helps to overcome difficulties” and engage in meaningful life projects and social activities (21).

Second, rational and non-rational considerations play a role (23). Respondents expressed their death wish as rational and entirely their own, but also mentioned feeling driven by impulses, such as fear or panic about the idea of living on. The third pair of themes is “taking control versus lingering uncertainty”. Arranging a self-directed death may give a sense of control while, at the same time, the older adults experience feelings of uncertainty and worry about the process. Fourth, older adults with a death wish can be torn between resisting interference and longing for support. Many placed great value on self-determination and independence. However, they also felt lonely and sought support and assistance for their suicide from medical professionals.

Lastly, there is a tension between legitimacy and illegitimacy (23). Most respondents longed for legitimacy for their death wish, meaning that it would be regarded as “something quite normal”, “understandable”, or “justified”. However, they experienced a social taboo in talking about their wish to end their lives, and felt “let down” by society and the government.

DISCUSSION

We identified ten studies from three countries, namely China, Brazil, and the Netherlands. The geographical spread of these three countries suggests that the occurrence of death wishes among older adults without severe illness is not necessarily bound to place or culture.

Estimating the prevalence of older adults with a death wish without severe illness is clearly complicated by the fact that in many studies no distinction was made between people with and without severe illness. In this review only four studies could be included presenting quantitative data on the prevalence in study populations without severe illness. The identified prevalence ranges from 7.7% suicidal ideation without “severe physical or mental illness” and without MDD among Chinese older adults aged 60 years and above (15), 3.6% suicidal ideation without “severe physical or mental illness” and without depression symptoms among Chinese older adults aged 60 years and above (14), 1.34% persistent death wishes without severe illness in the Dutch population aged 55 years and above (16), to 0.38% current wishes to die among Dutch older adults aged 57 years and above without a medically classifiable condition and without an accumulation of age-related health problems (17). The results of these studies suggest nuances of these percentages as the total group can be divided in, for instance, mild or strong active or passive suicidal ideation and active or passive death wishes with or without a wish to end one's life.

The identified prevalence is difficult to compare among the four studies that were included. That is, because the studies focused on slightly different age groups, used different operationalizations of (the duration of) the death wish, and recruited study populations in different settings. Moreover, while in one study MDD could exist among older adults classified as without "severe physical or mental illness" (15), in another study the absence of severe illness implied exclusion of persons with an indication for severe depression (16), and in yet another study all medically classifiable conditions and an accumulation of age-related health problems were taken into account (17).

The previous research synthesis indicates that knowledge on the prevalence of older adults with a death wish without severe illness was lacking (11). Therefore, our current findings about prevalence can only be compared to research in which the prevalence of older adults with a death wish was examined and no distinction was made between people with and without severe illness. For example, the study of Rurup et al. (24) demonstrated that 3.4% of Dutch older adults (58-98 years) had a current "wish to die and/or a weakened wish to continue living". In comparison, the selection of older adults without (severe) illness might, at least partly, explain the relatively lower percentage of 1.34% persistent death wishes found in the study of Hartog et al. (16) and the lower percentage of 0.38% current wishes to die found in the study of Kox et al. (17).

With regard to characteristics, experiences, and circumstances, our review confirms findings from the previous research synthesis and review. Based on the study of Rurup et al. (24), the previous research synthesis summarized that, among others, physical and mental health problems, loneliness, the loss of loved ones and social context, dependence, and the loss of self-worth, dignity and meaning are associated with having a death wish among older adults (in general, thus not specifically older adults without severe illness) (11, 24). The previous review identified the existential impact of age-related loss experiences, personal characteristics, biographical factors, perceptions and values, and social context as factors influencing the development of a death wish in older adults without a life-threatening disease or a severe psychiatric disorder (12). Our review also identified problems in these physical, mental, social, and existential life domains. Within these domains our review adds several new themes that further enrich our understanding, such as feeling disconnected from life and the multiple ambivalences in living with a death wish.

It is remarkable that even in studies in which the authors classified respondents as not severely ill or used similar wording, and respondents sometimes also did so themselves, still considerable health problems come to the fore. While this finding might be related to the fact that making a clear distinction between severely ill and not severely ill is hard to accomplish, it may also suggest that older adults with a death wish are struggling with considerable health problems even when they are not severely ill.

The strength of our review is the comprehensive search strategy used. A limitation of our review is that three out of the ten studies that were found were conducted by authors of this review. While this could bring valuable expertise to approach the complex topic of our review, it may also introduce disbalance into the reporting. We tried to prevent this by performing the study with a team attentive to this issue. Furthermore, the fact that only ten studies were included may be seen as limited output of our review. However, this may also be seen as an important finding, since it shows how underexposed the death wishes of older adults without severe illness are in research.

In conclusion, death wishes among older adults without severe illness seem to occur in different places and cultures, and are related to problems in physical, mental, social, and existential life domains. Even among older adults with a death wish without severe illness, struggling with considerable health problems seems to play a role. Considering these findings, it seems important to realize that in different places and cultures, even though not severely ill, older adults may need help and support because they live with a death wish with underlying problems in several domains of life. In order to be able to adequately help and support these older adults, more research into their problems, and good ways in which can be taken care of these problems, would be of great added value. Future research should, therefore, more often specifically target these older adults by distinguishing death wishes of older adults with and without severe illness. Furthermore, it would be highly interesting to learn more about the occurrence of death wishes among older adults without severe illness in more places and cultures to find out whether it is a universal phenomenon, or some aspects of certain places and cultures may influence its occurrence.

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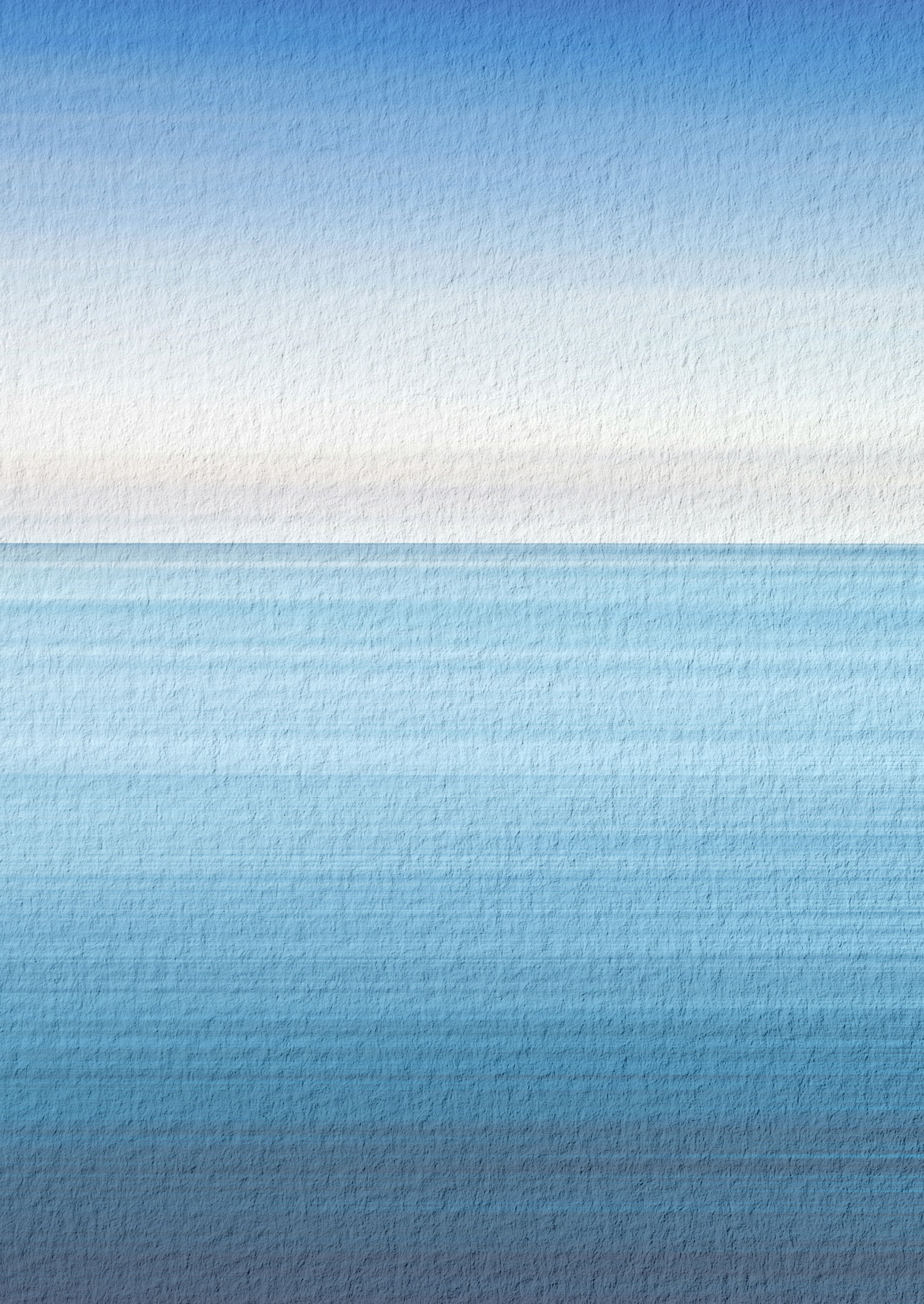

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Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey

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Contribution of the author of this dissertation:
I participated in the revision of the questionnaire that was developed for this study. I performed the statistical analysis and contributed to the interpretation of the findings. The first draft of the article was written by IH and we both revised several versions based on feedback of the co-authors.

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ABSTRACT

Background

Some older persons develop a persistent death wish without being severely ill, often referred to as “completed life” or “tiredness of life”. In the Netherlands and Belgium, the question whether these persons should have legal options for euthanasia or physician-assisted suicide (EAS) is intensely debated. Our main aim was to investigate the prevalence and characteristics of older adults with a persistent death wish without severe illness, as the lack of this knowledge is a crucial problem in de debate.

Methods

We conducted a survey among a representative sample of 32,477 Dutch citizens aged 55+, comprising questions about health, existential issues and the nature of the death wish. Descriptive statistics were used to describe the group with a persistent death wish and no severe illness (PDW-NSI) and several subgroups.

Results

A total of 21,294 respondents completed the questionnaire (response rate 65.6%). We identified 267 respondents (1.25%) as having a persistent death wish and no severe illness (PDW-NSI). PDW-NSI did not only occur among the oldest old. Although qualifying themselves as “not severely ill”, those with PDW-NSI reported considerable health problems. A substantial minority of the PDW-NSI-group reported having had a death wish their whole lives. Within the group PDW-NSI 155 (0.73%) respondents had an active death wish, of which 36 (0.17% of the total response) reported a wish to actually end their lives. Thus, a death wish did not always equal a wish to actually end one’s life. Moreover, the death wishes were often ambiguous. For example, almost half of the PDW-NSI-group (49.1%) indicated finding life worthwhile at this moment.

Conclusions

The identified characteristics challenge the dominant “completed life” or “tiredness of life” image of healthy persons over the age of 75 who, overseeing their lives, reasonably decide they would prefer to die. The results also show that death wishes without severe illness are often ambiguous and do not necessarily signify a wish to end one’s life. It is of great importance to acknowledge these nuances and variety in the debate and in clinical practice, to be able to adequately recognize the persons involved and tailor to their needs.

BACKGROUND

Improvements in living conditions and healthcare have contributed to an aging population. Some persons find it difficult to find meaning in older age (1-3). Some even develop a persistent death wish without being severely ill, which is often referred to as “completed life” or “tiredness of life” (4-6). “Completed life” is described as “persons, mostly of old age, who do not see a future for themselves and, as a result, have developed a persistent, active death wish” (5). It is often associated with suffering that does not (mainly) originate from a medically classifiable condition. “Tiredness of life” is described as “suffering caused by the prospect of having to continue living with a very poor quality of life, not predominantly caused by a physical or psychiatric disease, and closely associated with a death wish” (6).

In the past decades in the Western world, this death wish is increasingly discussed by the public, encountered by healthcare professionals, and debated in academia, law and politics as a social issue (4, 6-8). Even though the issue seems to get less attention in countries without legal options for euthanasia or physician-assisted suicide (EAS), the occurrence of persistent death wishes without severe illness seems to be a universal phenomenon. For example, studies from China and Brazil demonstrate its occurrence in different continents and cultural settings (9-10).

In the Netherlands and (although to a lesser extent) in Belgium, the issue has become highly political. The debate currently centers on the question whether older persons who consider their lives to be “completed” or who are “tired of life” should have legal options for EAS. In the case of euthanasia, a physician administers a lethal substance to terminate the life of a patient at the patient’s own request. Physician-assisted suicide means that a patient at his or her own request takes a lethal substance in the presence of and supplied by a physician (11). A recent survey indicated that 51% of Dutch citizens are in favor of allowing the oldest old to obtain lethal prescription drugs at their own request from a physician to end their own lives (12).

Dutch physicians are allowed to grant a patient’s request for EAS when six due care criteria are met, including the conviction that the patient is suffering unbearably. However, EAS for “completed life” or “tiredness of life” is not allowed because the suffering of these patients does not predominantly originate from a medical condition, either somatic or psychiatric (11-14). Citizens and politicians have protested against this restriction, putting the issue high on the political agenda. In 2016, a committee established by the Dutch government explored the legal possibilities and societal dilemmas with regard to assisted dying in cases of “completed life” or “tiredness of life” in old age. It advised against changing the Euthanasia Act (5). The question how society should respond to the needs and wishes of this particular group of older persons is, however, still intensely debated.

A crucial and under-addressed problem in the debate is the lack of robust knowledge on the prevalence of persons with “completed life” or “tiredness of life” and on their characteristics, existential issues and the nature of their death wishes (14-15). Moreover, insight into these aspects may be of great value to healthcare professionals who are increasingly confronted with older persons who are not severely ill but consider their lives not worth living (6). Recent research among nurses indicated how challenging encounters with these persons can be, for instance in terms of recognizing what is going on (6). Our objective was to provide the knowledge that is needed to further the debate as well as providing healthcare professionals clues that enable them to better recognize cases of “completed life” or “tiredness of life”. To this end, we aimed to investigate the prevalence of older adults with a persistent death wish without severe illness and their characteristics, existential issues and the nature of their death wishes.

METHODS

Study design and sample size

We conducted a web-based survey among a representative sample of 32,477 Dutch citizens aged 55 and older. The sample was taken from the access panel “TNS NIPObase” of research company Kantar Public, a leading provider of data for policymaking around the world (16). The panel comprises 109,642 Dutch respondents including 44,667 persons of 55years and older. The sample was drawn to reflect the known proportions of age, gender, educational attainment, household size, social class and region in the Dutch population aged 55 and older. The societal and political debate in the Netherlands indicates that every age limit for research into our target phenomenon would be arbitrary and perhaps even controversial. For example, proponents of legal options for EAS for older persons who consider their lives to be “completed” or who are “tired of life” suggest different age limits, and every proposed age limit is criticized. Reasons for this criticism are, among others, that also younger people might have a death wish without being severely ill, and that an age limit may unintentionally suggest that life beyond that age is considered not or less worth living anymore. We chose the age limit of 55 and older for two reasons. Firstly, previous research suggests an increase of the prevalence of death wishes with age (17-18). Setting the age limit relatively low, we were able to verify this hypothesis in our sample. Secondly, according to psychological literature, from the age of 55, people increasingly draw up the balance of their own lives, and ask themselves to what degree they have accomplished their life goals (19).

Demarcation of the group of interest

We first demarcated the group of interest, since no clear definitions or operationalizations of “completed life” or “tiredness of life” existed. Currently, the dominant description regarding the health of this group is: “without suffering that (mainly) originates in a medically classifiable condition" or "suffering not predominantly caused by a physical or psychiatric disease", respectively (5-6). As a large survey including self-reported health measures is the appropriate method to estimate prevalence, we chose to rephrase the description of "completed life" or "tiredness of life" referring to people's own perceptions (i.e., "illness") rather than diagnosed conditions (professional's judgments, i.e., "disease") (20). Persons perceiving themselves as "not severely ill" are likely not to be eligible for EAS, which is only allowed in cases of unbearable suffering (mainly) originating in a medically classifiable condition. Therefore, our group of interest was defined as "older adults with a persistent death wish and no severe illness" (PDW-NSI).

Questionnaire

As no validated or accepted questionnaires existed to identify older adults with persistent death wishes without being severely ill, a questionnaire was developed specifically for this study. It comprised questions about physical and mental health, existential issues and, if applicable, about the nature of the death wish. See **Additional file 1** for all the questionnaire items reported in this study. In order to ensure the safety and well-being of the persons in our sample, the questionnaire items about death wishes and suicide attempts were discussed with the research company and the national suicide prevention organization of the Netherlands. As research indicates that including suicidal persons in research or asking questions about suicidality does not increase suicidality (21), these questionnaire items were not considered harmful. The questionnaire introduction and items were carefully built up to prepare respondents for the questions about death wishes, the voluntary character was emphasized and contact details of our research team and the suicide prevention organization in the questionnaire were provided.

To narrow down the sample we asked respondents a "differentiation question" based on our definition of our group of interest mentioned earlier: does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? If they answered affirmatively, the respondents were asked in-depth questions about health, existential issues and the nature of the death wish. For all others, the questionnaire ended, except for what we call the "comparison group": the respondents from an additional random sample who completed the whole questionnaire despite their negative response to the differentiation question.

EQ-5D-5L (Dutch version) was used to assess health state (22). This self-report questionnaire comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

HADS-D, the depression subscale of the Hospital Anxiety and Depression Scale (Dutch version), was included to assess the probability of depressive disorder (23). Due to a logistical error, the last of the seven items of the HADS-D was not included in the questionnaire. Therefore, in a second round, an additional request to complete the whole HADS-D was sent.

Data analysis

Starting with the respondents who answered the differentiation question with "yes", we performed a selection in three steps to identify the PDW-NSI group. We used additional measures of health (step 1), depression (step 2), and the self-reported duration of respondents' death wishes (step 3), to determine the presence or absence of severe illness and the persistence of the death wish.

To identify the group without severe illness (step 1 and 2), validated self-reported measures of overall health and depressive feelings were used. These self-reports are assumed to be the best indication for the possible role of health problems in evaluating one's own quality of life and in developing a death wish. Conservative cut-off points were chosen to only exclude respondents with severe health problems and an indication for severe depression, in order to avoid exclusion of respondents with health problems who would nevertheless be denied EAS because they do not suffer unbearably from a medically classifiable condition.

The three steps are described below. See **Additional file 2** for further details. For a visual representation of the steps, see the Results section.

Step 1 - no severe illness: self-reported health
Respondents were categorized as "not severely ill" if they scored $\geq$ 4 on an 11-point visual analogue scale (VAS) and < 17 on the EQ-5D-5L (sum score).

Step 2 - no severe illness: indication for depression
Following clinical practice, HADS-D sum scores < 16 were used to categorize the respondents with "no indication for severe depression" (24).

Step 3 - persistence of the death wish
In compliance with literature about death wishes and suicidal feelings, we considered a death wish with a duration of $\geq$ 1year as "persistent" (25).

After this selection process, the group PDW-NSI was divided into subgroups of having an *active* or a *passive* persistent death wish. Based on literature about death wishes and suicidal ideation, the death wishes of respondents were considered "active" if respondents indicated having made concrete plans or having taken steps regarding their death wish (14, 26). Respondents who had seriously *considered* attempting suicide in the past 12months were also regarded as having an active death wish (25-26). Respondents reporting no steps/plans and not having considered suicide were categorized as having a passive death wish. The group of respondents who reported no plans or steps and who chose the option "not willing to answer" for the question whether they had considered suicide, were categorized as "passive/active nature of death wish unknown".

As our response sample did not exactly represent the Dutch population, the prevalence calculations were repeated weighted for gender, age, educational attainment, household size, social class and region.

All calculations were performed using SPSS software, version 25.0 (2018). Confidence intervals were calculated using the Wilson method. Significance tests in group comparisons were calculated using the Kruskal-Wallis test for ordinal and Fisher's exact test for nominal variables. All prevalence calculations were checked by a biostatistician.

RESULTS

Prevalence

A total of 21,294 respondents (65.6%) completed the questionnaire between April 3 and April 25, 2019. See **Figure 1** for a flow chart of the sample and response, in which two separate flows are presented. The left side shows the main sample of participants who only completed the whole questionnaire if they answered the differentiation question affirmatively. The right side shows the extra random sample of participants who completed the whole questionnaire regardless of their answer to the differentiation question.

The additional request to complete the whole HADS-D was sent to those with "yes" to the differentiation question (*N*=411) and those in the comparison group (*N*=1,020) and filled out by 89.2% of these respondents between May 23 and June 3, 2019.

Background characteristics of respondents versus non-respondents are presented in **Additional file 3**. Differences between respondents and non-respondents were found on all background characteristics except urbanization.

Figure 2 shows the steps in the selection process of the PDW-NSI group. Four hundred eleven respondents (1.93%) answered "yes" to the differentiation question. The subsequent selection steps led to the identification of 267 respondents (1.25%) with a persistent death wish without severe illness (PDW-NSI).

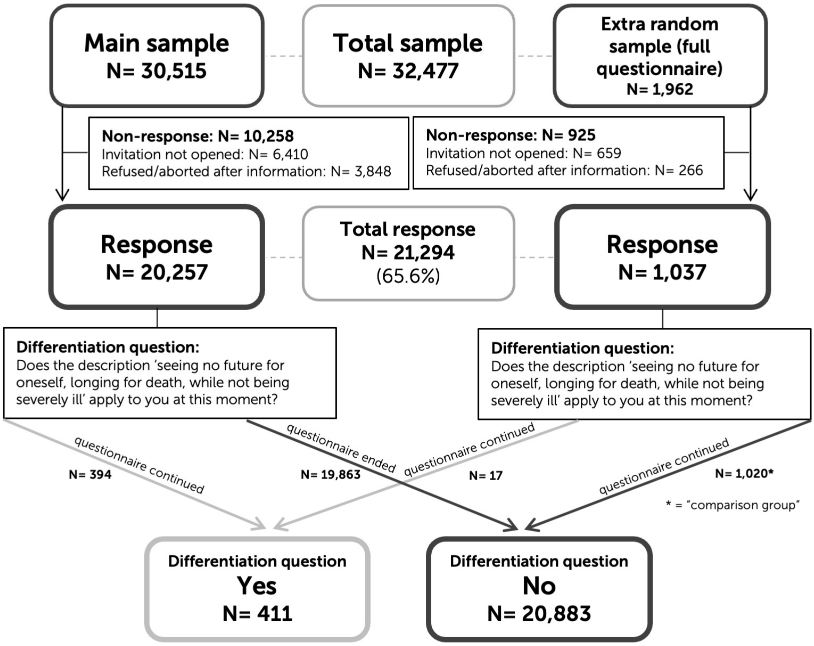

FIGURE 1. Flowchart sample and response

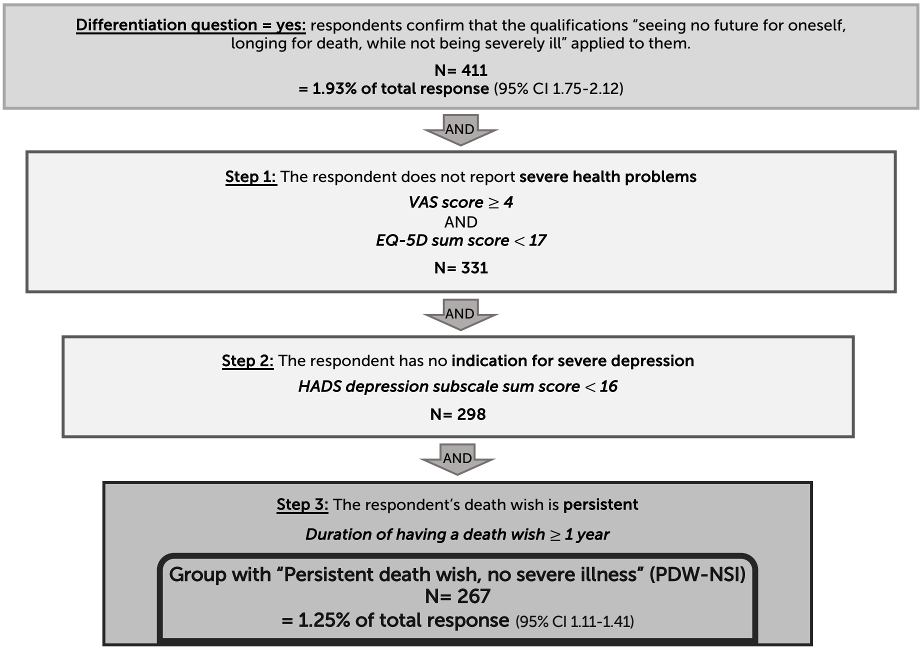

FIGURE 2. Flowchart selection process to identify the group "persistent death wish, no severe illness" (PDW-NSI)
Total response: N= 21,294.

Figure 3 shows the categorization of the group PDW-NSI into subgroups. Of the respondents with a persistent death wish without severe illness, 93 (0.44%) had a passive death wish, 155 (0.73%) had an active death wish, and 19 (0.09%) had a death wish of an unknown (passive/active) nature. Of the group with an active persistent death wish, 36 respondents (0.17% of the total response) described their wish as a wish to end their lives.

Weighted percentages

Weighted percentages representing the Dutch population were 1.34% (95% CI 1.20–1.51) for the entire group PDW-NSI, 0.47% (95% CI 0.38–0.57) for the subgroup with a passive death wish, 0.77% (95% CI 0.66–0.90) for the subgroup with an active death wish and 0.18% (95% CI 0.13–0.25) for the subgroup with an active death wish resulting in a wish to actually end their lives.

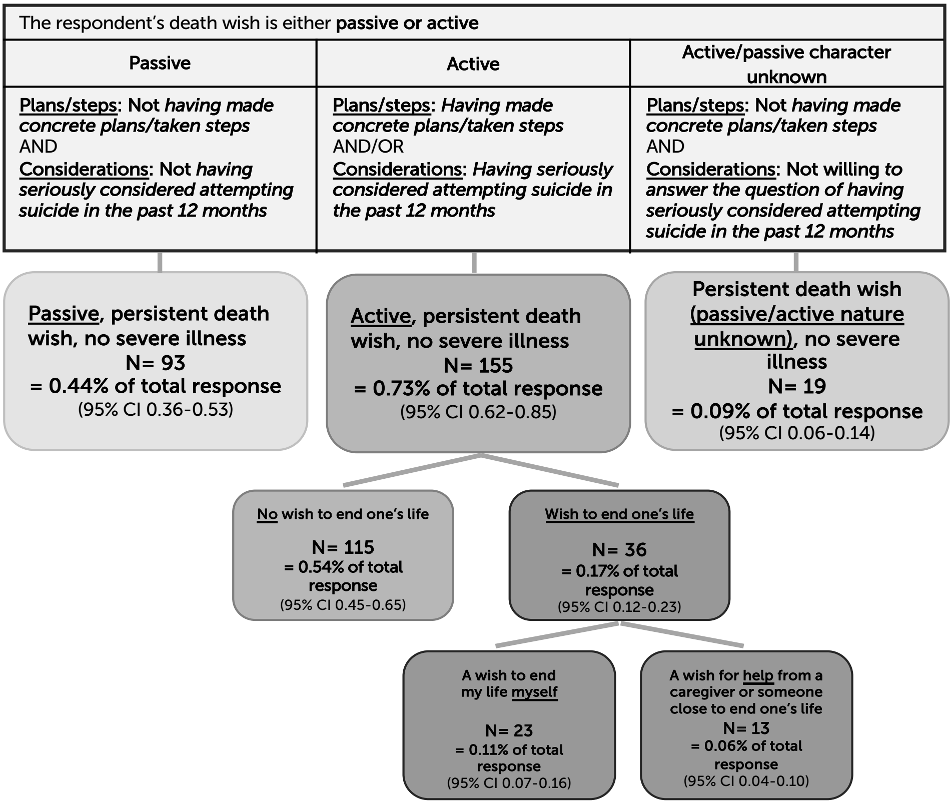

FIGURE 3. Flowchart selection of subgroups of "persistent death wish, no severe illness" (PDW-NSI)
Total response: N= 21,294.
Percentages may not add up to total because of rounding.
Numbers of respondents with and without wish to end their life do not add up to N=155 because 4 respondents answered "I do not know".

Background characteristics

Table 1 shows background characteristics of the PDW-NSI group and of the respondents who answered “no” when asked the differentiation question whether the description ‘seeing no future for oneself, longing for death, while not being severely ill’ applied to them at that moment.

Of the PDW-NSI group, 79.0% were under the age of 75. Even though percentages for the age categories above 75 were slightly higher for the PDW-NSI group than for the group who gave a negative answer to the differentiation question, there was no significant overall difference in age distribution. Approximately half of the PDW-NSI group (52.1%) lived alone and 27.2% had no (step)children, both higher proportions as compared to the group with a negative answer to the differentiation question (25.2 and 16.3% respectively). Persons in the PDW-NSI group were of lower social class, lived in highly urbanized areas more often, and a significantly smaller percentage had a religious worldview.

Compared to the subgroup with an active death wish, a larger proportion of the group with a passive death wish had a religious worldview. No significant differences between the subgroups were found for the other background characteristics.

Health/illness

The PDW-NSI group had qualified themselves as “not severely ill” through their affirmative answer to the differentiation question. Nonetheless, **Table 2** shows that all measurements for health and illness indicated significantly worse health for the PDW-NSI group as compared to the group that gave a negative answer to the differentiation question, with the exception of the presence of a life-threatening disease now or in the past. 9.4% of the group PDW-NSI reported having none of the diseases listed, against 28.2% of the group who answered “no” to the differentiation question. Of the respondents with at least one of the diseases listed, those in the group PDW-NSI reported a significantly higher total burden of these diseases (median 7 versus 4 on a scale from 1 to 10). In the group PDW-NSI, 50% of the respondents had a HADS-D sum score between 6.7 and 12, and 25% a sum score of 12 or higher on a scale from 0 to 21, with a cut-off point of 16 for severe depression. The group with answer “no” to the differentiation question reported significantly lower levels of depressive feelings: 50% had sum scores between 1 and 5.

Respondents with an active death wish had scores indicating worse mental, physical and overall health than the group with a passive death wish.

TABLE 1. Background characteristics

Aspects and items	**Active persistent death wish, no severe illness** N= 155 (0.7% of 21,294)	**Passive persistent death wish, no severe illness** N= 93 (0.4% of 21,294)	**Persistent death wish (passive/ active nature unknown), no severe illness** N= 19 (<0.1% of 21,294)	**Total group "Persistent death wish, no severe illness" (PDW-NSI)** N= 267 (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Gender							
Female	87 (56.1)	50 (53.8)	12 (63.2)	149 (55.8)	10,500 (50.3)	0.074	0.792
Male	68 (43.9)	43 (46.2)	7 (36.8)	118 (44.2)	10,383 (49.7)		
Age (years)							
Median (Q1-Q3)	64 (60-72)	67 (60.5-74)	68 (61-75)	65 (60-73)	65 (60-72)	0.161	0.267
55-59	37 (23.9)	18 (19.4)	3 (15.8)	58 (21.7)	5,119 (24.5)		
60-64	44 (28.4)	19 (20.4)	3 (15.8)	66 (24.7)	4,569 (21.9)		
65-69	21 (13.5)	19 (20.4)	6 (31.6)	46 (17.2)	4,156 (19.9)		
70-74	23 (14.8)	16 (17.2)	2 (10.5)	41 (15.4)	3,977 (19.0)		
75-79	16 (10.3)	12 (12.9)	4 (21.1)	32 (12.0)	1,796 (8.6)		
80-84	8 (5.2)	6 (6.5)	0 (0.0)	14 (5.2)	890 (4.3)		
85-89	4 (2.6)	3 (3.2)	1 (5.3)	8 (3.0)	320 (1.5)		
90-94	2 (1.3)	0 (0.0)	0 (0.0)	2 (0.7)	51 (0.2)		
95-99	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	5 (<0.1)		
Educational attainment[a]							
Low	54 (34.8)	37 (39.8)	7 (36.8)	98 (36.7)	7,018 (33.6)	0.288[b]	0.507[c]
Middle	59 (38.1)	27 (29.0)	11 (57.9)	97 (36.3)	7,554 (36.2)		
High	41 (26.5)	27 (29.0)	1 (5.3)	69 (25.8)	6,213 (29.8)		
Unknown	1 (0.6)	2 (2.2)	0 (0.0)	3 (1.1)	98 (0.5)		

TABLE 1. Continued.

Aspects and items	**Active persistent death wish, no severe illness** **N= 155** (0.7% of 21,294)	**Passive persistent death wish, no severe illness** **N= 93** (0.4% of 21,294)	**Persistent death wish (passive/ active nature unknown), no severe illness** **N= 19** (<0.1% of 21,294)	**Total group "Persistent death wish, no severe illness" (PDW-NSI)** **N= 267** (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Worldview[d]							
Religious worldview	52 (31.9)	45 (45.0)	9 (45.0)	106 (37.5)	517 (49.1)	**0.002**	**0.023**
Non-religious worldview	49 (30.1)	27 (27.0)	5 (25.0)	81 (28.6)	200 (19.0)	**0.000**	0.776
Worldview, religiousness unknown	8 (4.9)	3 (3.0)	0 (0.0)	11 (3.9)	44 (4.2)	1.000	0.544
No worldview	54 (33.1)	25 (25.0)	6 (30.0)	85 (30.0)	293 (27.8)	0.327	0.208
Number of (step)children[e]							
0	31 (26.5)	20 (26.7)	5 (35.7)	56 (27.2)	124 (16.3)	**0.000**	0.734
1	14 (12.0)	14 (18.7)	1 (7.1)	29 (14.1)	96 (12.6)		
2	56 (47.9)	29 (38.7)	7 (50.0)	92 (44.7)	329 (43.1)		
3 or more	16 (13.7)	12 (16.0)	1 (7.1)	29 (14.1)	214 (28.0)		
Household size (number of persons)							
1	84 (54.2)	46 (49.5)	9 (47.4)	139 (52.1)	5,259 (25.2)	**0.000**	0.504
2	58 (37.4)	39 (41.9)	10 (52.6)	107 (40.1)	12,480 (59.8)		
3 or more	13 (8.4)	8 (8.6)	0 (0.0)	21 (7.9)	3,144 (15.1)		
Social class[f]							
Low	78 (50.3)	49 (52.7)	15 (78.9)	142 (53.2)	8,406 (40.3)	**0.000**	0.934
Middle	26 (16.8)	12 (12.9)	0 (0.0)	38 (14.2)	3,171 (15.2)		
High	51 (32.9)	32 (34.4)	4 (21.1)	87 (32.6)	9,306 (44.6)		

TABLE 1. Continued.

Aspects and items	**Active persistent death wish, no severe illness** **N= 155** (0.7% of 21,294)	**Passive persistent death wish, no severe illness** **N= 93** (0.4% of 21,294)	**Persistent death wish (passive/ active nature unknown), no severe illness** **N= 19** (<0.1% of 21,294)	**Total group "Persistent death wish, no severe illness" (PDW-NSI)** **N= 267** (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Urbanization[g]							
Very high	39 (25.2)	35 (37.6)	3 (15.8)	77 (28.8)	3,829 (18.3)[h]	**0.001**	0.187
High	52 (33.5)	23 (24.7)	8 (42.1)	83 (31.1)	7,290 (34.9)		
Moderate	26 (16.8)	15 (16.1)	4 (21.1)	45 (16.9)	3,813 (18.3)		
Low	28 (18.1)	12 (12.9)	3 (15.8)	43 (16.1)	4,223 (20.2)		
None	10 (6.5)	8 (8.6)	1 (5.3)	19 (7.1)	1,722 (8.2)		

*Results are presented as N (%) unless "Median (Q1-Q3)" is reported.

*Percentages may not add up to 100% because of rounding.

*Medians are reported with 25th-75th percentiles.

*Statistically significant results ($p < 0.05$) are in bold.

[a] Low= lower vocational education, lower secondary education, or less; Middle= intermediate vocational education or higher secondary education; High= higher vocational education or university; Unknown= I do not know/want to answer.

[b] N= 21,049 because category "Unknown" was not included in the test.

[c] N= 245 because category "Unknown" was not included in the test.

[d] Religious worldview= Protestant, Catholic, Muslim, Jewish, Hindu and Buddhist. Non-religious worldview= atheist, agnostic, "spiritual but not religious", humanist, anthroposophical and esoteric. Worldview, religiousness unknown= other worldview. Respondents could give more than one answer and may thus be counted in more than one category. Therefore, N= 163, N=100, N=20, N= 283, N= 1,054 (comparison group) respectively and percentages are based on these numbers. In group comparisons, worldview is tested with separate tests for each category (yes/no).

[e] N= 117, N= 75, N= 14, N= 206, N= 763 (comparison group) respectively for the groups, due to missing values for "Number of (step)children".

[f] Based on educational attainment and profession of the main breadwinner.

[g] Very high= >2,500; High= 1,500-2,500; Moderate= 1,000-1,500; Low= 500-1,000; None= <500 addresses per km^2.

[h] N= 20,877 in this column due to 6 missings for this variable.

TABLE 2. Health/illness

Aspects and items	Active persistent death wish, no severe illness N= 155 (0.7% of 21,294)	Passive persistent death wish, no severe illness N= 93 (0.4% of 21,294)	Persistent death wish (passive/ active nature unknown), no severe illness N= 19 (<0.1% of 21,294)	Total group "Persistent death wish, no severe illness" (PDW-NSI) N= 267 (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Current health state VAS[a]							
Median (Q1-Q3)	6 (5-7)	7 (6-8)	6 (6-7)	6 (6 -7)	8 (7-8)	**0.000**	**0.010**
EQ-5D-5L sum score[b]							
Median (Q1-Q3)	10 (8-13)	8 (7-11)	11 (8-13)	10 (8-12)	7 (5-9)	**0.000**	**0.000**
HADS depression subscale, sum score[c]							
Median (Q1-Q3)	11 (8-12)	8 (6-11.5)	10 (7-14)	10 (6.7-12)	3 (1-5)[d]	**0.000**	**0.001**
Life-threatening disease							
Never	110 (71.0)	76 (81.7)	13 (68.4)	199 (74.5)	16,388 (78.5)	0.196	0.139
Yes, but not anymore	33 (21.3)	14 (15.1)	5 (26.3)	52 (19.5)	3,595 (17.2)		
Yes, at this moment	12 (7.7)	3 (3.2)	1 (5.3)	16 (6.0)	900 (4.3)		
Number of current diseases[e]							
None	9 (5.8)	16 (17.2)	0 (0.0)	25 (9.4)	288 (28.2)[f]	**0.000**	**0.008**
Median (Q1-Q3)	2 (1-4)	1 (1-2)	3 (2-4)	2 (1-3)	1 (0-2)	**0.000**	**0.000**
Burden of current diseases[g]							
Median (Q1-Q3)	7 (5-8)	6 (4.5-7)	6 (5-8)	7 (5-8)	4 (3-6)	**0.000**	**0.005**
Number of current complaints[h]							
None	3 (1.9)	5 (5.4)	0 (0.0)	8 (3.0)	195 (19.1)[i]	**0.000**	0.155
Median (Q1-Q3)	5 (3-7)	3 (2-6)	6 (4-9)	5 (3-7)	2 (1-4)	**0.000**	**0.000**
Burden of current complaints[j]							
Median (Q1-Q3)	7 (5-7)	5.5 (4-7)	6 (5-8)	6 (5-7)	5 (3-6)	**0.000**	**0.000**

*Results are presented as N (%) unless "Median (Q1-Q3)" is reported.
*Percentages may not add up to 100% because of rounding.
*Medians are reported with 25th-75th percentiles.
*Statistically significant results ($p < 0.05$) are in bold.

[a] Visual Analogue Scale ranging from 0 (worst imaginable) to 10 (best imaginable health state).

[b] EQ-5D-5L sum scores range from 5 to 25. Higher sum scores indicate more severe problems on the five domains of health.

[c] HADS depression subscale, sum scores range from 0 to 21. Higher sum scores are related to a possible indication for depression with a greater severity.

[d] N= 1,020 (comparison group).

[e] Chosen from the following list of diseases: joint conditions, osteoporosis, diabetes, neck or back problems, tightness of the chest (e.g., COPD, asthma), Crohn's disease, MS/ALS, skin disease, thyroid disease, heart conditions, consequences of CVA, dementia, Parkinson's disease, cancer, psychological complaints (mood or anxiety complaints, depression), other.

[f] Percentages are based on N= 1,020 (comparison group).

[g] 10-point scale ranging from 1 ("very little") to 10 ("very much"). Diseases are listed above.

[h] Chosen from a list of complaints, such as hearing problems or deafness, tinnitus, headache, dizziness, obesity, incontinence, chronic itching, extreme/chronic fatigue, depressive feelings, obstipation and (chronic) pain, other.

[i] Percentages are based on N= 1,020 (comparison group).

[j] 10-point scale ranging from 1 ("very little") to 10 ("very much"). Complaints are listed above.

Death wishes and existential issues

Table 3 provides insight into the death wishes of respondents with PDW-NSI, and responses on existential issues of both this group and the group with a negative answer to the differentiation question.

In response to the question how long they had had the death wish, 18.7% of the group PDW-NSI reported having had it their whole lives, and 62.9% for a few years.

One third of the group with an active death wish had made concrete plans or taken steps regarding their death wish. Almost half of those reported plans/steps anticipating end-of-life decisions such as refraining from medical treatment or arranging an Advanced Euthanasia Directive (8.9% of the PDW-NSI group). A suicide attempt was reported by 1.1% of the PDW-NSI group.

When asked how they would describe their wish, a majority of the 155 respondents with an active death wish reported a wish for a natural death (*N*=108). Thirty-six respondents (0.17% of the total response) indicated a desire to end their lives themselves or by EAS. Thirteen respondents reported a wish for assisted suicide by a healthcare professional or someone close, representing 0.06% of the total response.

Despite having a persistent death wish, almost half of the respondents in the PDW-NSI group (49.1%) confirmed that they considered their life worthwhile at that moment, which was significantly less than the percentage of respondents who answered the differentiation question with “no” (98.5%). When asked to indicate the intensity of their preference “not to experience the future” on a 7-point scale, 50% of the PDW-NSI group scored between 4 and 6, and 25% scored 6 or higher. Respondents who answered “no” to the differentiation question had significantly weaker preference not to experience the future: more than 50% scored no higher than 2.

Similar differences were found between the groups with an active and a passive death wish. Respondents with an active death wish had significantly higher scores on the preference *not* to experience the future, and significantly less frequently found life worthwhile, than respondents with a passive death wish.

TABLE 3. Death wishes and existential issues

Aspects and items	Active persistent death wish, no severe illness N= 155 (0.7% of 21,294)	Passive persistent death wish, no severe illness N= 93 (0.4% of 21,294)	Persistent death wish (passive/ active nature unknown), no severe illness N= 19 (<0.1% of 21,294)	Total group "Persistent death wish, no severe illness" (PDW-NSI) N= 267 (1.25% of 21,294)	Answer "No" to differentiation question: does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? N= 20,883 (97.8% of 21,294)	P-value PDW-NSI group vs. Diff. question = No	P-value Active vs. Passive
Duration of having a death wish							
Whole life	27 (17.4)	21 (22.6)	2 (10.5)	50 (18.7)	N/A	N/A	0.481
A few years	97 (62.6)	54 (58.1)	17 (89.5)	168 (62.9)	N/A		
Approximately one year	31 (20.0)	18 (19.4)	0 (0.0)	49 (18.4)	N/A		
Characterization of the death wish							
A desire for a natural death that just happens	22 (14.2)	25 (26.9)	3 (15.8)	50 (18.7)	N/A	N/A	**0.008**
A desire to not wake up tomorrow and die in my sleep	86 (55.5)	43 (46.2)	9 (47.4)	138 (51.7)	N/A		
I feel my current situation is unlivable	7 (4.5)	2 (2.2)	2 (10.5)	11 (4.1)	N/A		
A wish to end my life myself	23 (14.8)	6 (6.5)	0 (0.0)	29 (10.9)	N/A		
A wish for a doctor to help me end my life	8 (5.2)	4 (4.3)	2 (10.5)	14 (5.2)	N/A		
A wish for another professional or someone close to help me end my life	5 (3.2)	3 (3.2)	0 (0.0)	8 (3.0)	N/A		
I do not know	4 (2.6)	10 (10.8)	3 (15.8)	17 (6.4)	N/A		

TABLE 3. Continued.

Aspects and items	**Active persistent death wish, no severe illness** **N= 155** (0.7% of 21,294)	**Passive persistent death wish, no severe illness** **N= 93** (0.4% of 21,294)	**Persistent death wish (passive/ active nature unknown), no severe illness** **N= 19** (<0.1% of 21,294)	**Total group "Persistent death wish, no severe illness" (PDW-NSI)** **N= 267** (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Having made concrete plans/taken steps							
No	104 (67.1)	93 (100.0)	19 (100.0)	216 (80.9)	N/A	N/A	N/A
Yes, namely:[a]	51 (32.9)	0 (0.0)	0 (0.0)	51 (19.1)	N/A		
Decisions about end of life[b]	24 (15.5)	N/A	N/A	24 (8.9)	N/A		
Membership of interest group[c]	14 (9.0)	N/A	N/A	14 (5.2)	N/A		
Contact with a caregiver[d]	9 (5.8)	N/A	N/A	9 (3.4)	N/A		
Searched for means to end one's life[e]	6 (3.9)	N/A	N/A	6 (2.2)	N/A		
Searched for information	3 (1.9)	N/A	N/A	3 (1.1)	N/A		
Attempted suicide	2 (1.3)	N/A	N/A	2 (0.7)	N/A		
Other	3 (1.9)	N/A	N/A	3 (1.1)	N/A		
Having seriously considered attempting suicide in the past 12 months							
Never	20 (12.9)	93 (100.0)	0 (0.0)	113 (42.3)	N/A	N/A	N/A
Once in a while	80 (51.6)	0 (0.0)	0 (0.0)	80 (30.0)	N/A		
Now and then	38 (24.5)	0 (0.0)	0 (0.0)	38 (14.2)	N/A		
Often	15 (9.7)	0 (0.0)	0 (0.0)	15 (5.6)	N/A		
Very often	2 (1.3)	0 (0.0)	0 (0.0)	2 (0.7)	N/A		
Not willing to answer	0 (0.0)	0 (0.0)	19 (100.0)	19 (7.1)	N/A		

TABLE 3. Continued.

Aspects and items	**Active persistent death wish, no severe illness** **N= 155** (0.7% of 21,294)	**Passive persistent death wish, no severe illness** **N= 93** (0.4% of 21,294)	**Persistent death wish (passive/ active nature unknown), no severe illness** **N= 19** (<0.1% of 21,294)	**Total group "Persistent death wish, no severe illness" (PDW-NSI)** **N= 267** (1.25% of 21,294)	**Answer "No" to differentiation question:** does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? **N= 20,883** (97.8% of 21,294)	**P-value** PDW-NSI group vs. Diff. question = No	**P-value** Active vs. Passive
Having made a suicide attempt in the past 12 months[f]							
No	125 (92.6)[g]	N/A	N/A	125 (46.8)	N/A	N/A	N/A
Yes	3 (2.2)	N/A	N/A	3 (1.1)	N/A		
Not willing to answer	7 (5.2)	N/A	N/A	7 (2.6)	N/A		
Preference not to have to experience the future[h]							
Median (Q1-Q3)	5 (5-6)	5 (3-6)	6 (4-7)	5 (4-6)	1 (1-2)	**0.000**	**0.001**
Finding life worthwhile at this moment							
Yes	67 (43.2)	56 (60.2)	8 (42.1)	131 (49.1)	20,568 (98.5)	**0.000**	**0.013**
No	88 (56.8)	37 (39.8)	11 (57.9)	136 (50.9)	315 (1.5)		
Being weighed down by the burden of life[i]							
Median (Q1-Q3)	5 (4-6)	4 (3-6)	5 (4.5-6)	5 (3-6)	1 (1-2)	**0.000**	**0.014**

*Results are presented as N (%) unless "Median (Q1-Q3)" is reported;

*Percentages may not add up to 100% because of rounding.

*Medians are reported with 25th-75th percentiles.

*N/A= not applicable.

*Statistically significant results ($p < 0.05$) are in bold.

[a] N=61 because respondents could name more than one plan/step in answering the open question; [b] Includes wish or order "do not resuscitate", wish for euthanasia in due time (in some cases recorded in an Advanced Euthanasia Directive), refraining from medical treatment (in some cases recorded in an advanced directive), having made a testament, having written down something considering end-of-life (not specified); [c] Interest group concerning voluntary end of life; [d] Includes receiving treatment (psychological or psychiatric); [e] Includes respondents who already obtained means to end their life; [f] N= 135 due to the fact that respondents who answered "never" or "not willing to answer" to the previous question (having seriously *considered* a suicide attempt) were not asked this question; [g] Percentages are based on N= 135; [h] 7-point Likert scale ranging from 1 ("not at all") to 7 ("very strong"). Respondents could also answer "I do not know". Therefore, N= 151, N= 83, N= 16, N= 250, N= 989 (comparison group), respectively; [i] 7-point Likert scale ranging from 1 ("not at all") to 7 ("very strong"). Respondents could also answer "I do not know". Therefore, N= 154, N= 90, N= 18, N= 262, N= 1,014 (comparison group), respectively.

DISCUSSION

Our study shows that 1.25% of a representative sample of adults aged 55 and older report having a persistent death wish without being severely ill, based on their own perception of health assessed with validated self-report health measures. Of our sample, we categorized 0.73% as having an active death wish, some because they indicated having seriously considered ending their lives, and others because they reported having made plans or taken steps to realize their death wish in the near or distant future. A minority of the group with an active death wish indicated a desire to actually end their lives (0.17% of our sample). A part of this group reported a wish for assistance in fulfilling this wish (0.06% of our sample).

With regard to respondent characteristics, we found that a persistent death wish in the absence of severe illness occurs not only in the oldest old. There was no significant overall difference in age distribution between the group with PDW-NSI and the respondents not identifying with the qualifications ‘seeing no future for oneself, longing for death, while not being severely ill’ (based on the differentiation question). Previous studies report a higher overall prevalence of death wishes among older persons (17-18, 27-29) and an increase with age (17-18). For example, a Dutch study found that 2.2% of persons aged 58 and above had a wish to die in the past week (27), and a Canadian nationally representative survey among adults aged 55years and over indicated a prevalence of suicide ideation of 2.2% (29). Furthermore, a study among a sample of 12,107 respondents from the general population of Europe, showed an increase of passive death wishes with age (17). Of those aged 50–65, almost 5% had a passive death wish, while this rate was three times higher for those older than 75. However, these studies included persons with severe illness, including depression. Our selection of persons without severe illness may explain the lower percentages of both active and passive persistent death wishes among older persons in our study compared to previous studies. Furthermore, it may explain why our study did not show a significant overall difference in age distribution while previous studies with regard to the prevalence of death wishes among older persons report an increase with age. After all, the older people become the higher the chance of severe illness resulting in a negative answer to the differentiation question and not being included in the group PDW-NSI. On the other hand, people’s expectations based on their age may influence their answers about their health state and to the question if they consider themselves severely ill or not (30). As a result, it is conceivable that older persons may not categorize health complaints and disabilities as “severe illness” while younger persons may do so when in the same health.

The group PDW-NSI reported considerable health problems and possible prevalence of mild (HADS-D 8–10) and moderate (11-15) depression. Comparison with the group with a negative response to the differentiation question indicated significantly worse health for the group PDW-NSI. The group we identified as having a persistent death wish without being severely ill can therefore not be characterized as a group of healthy older persons, but we cannot draw conclusions on the relation between health problems and the death wishes.

Our study shows ambiguity in death wishes of older adults without severe illness, confirming findings in previous qualitative studies among older persons with death wishes (31-32). For example, almost half of the group PDW-NSI (49.1%) indicated finding life worthwhile at this moment, and respondents with a persistent death wish did not always report a strong preference *not* to witness the future. These ambiguities, combined with the finding that a death wish does not necessarily signify a wish to actually end one's own life, make tending to the needs of this group a challenge for physicians and other healthcare providers. This challenge was also described by Van Humbeeck et al. (6). Their research among nurses showed that recognizing what is going on is complicated by the elusiveness of the phenomenon. Besides, the process of responding to the needs of the persons concerned was surrounded by ambiguity and uncertainty.

In the current debate, the dominant image of "completed life" or "tiredness of life" is that of healthy persons over the age of 75 who, overseeing their lives, reasonably decide they would prefer to die (33). This image may not be well suited, as suggested by our findings that those with PDW-NSI reported considerable health problems, that the majority of the respondents with PDW-NSI were under the age of 75, and that a substantial minority of the group PDW-NSI (18.7%) reported having had a death wish their whole lives. Moreover, the death wishes of the respondents were often ambiguous, which indicates that they may not always reasonably decide they would prefer to die. The fact that our results challenge the dominant image has significant implications for public health policies in dealing with the needs of older adults with "completed life" or "tiredness of life". Besides, our results draw attention to the fact that we should be careful using terms such as "completed life" or "tiredness of life", to prevent wrongful connotations. The findings of our study do not substantiate the positive connotation of the term "completed life". The term "completed life" might obscure the health problems and social and existential struggles some people are dealing with. While the term "tiredness of life" does not have this positive connotation, it is still not an accurate representation of these struggles, and therefore seems not befitting as well. Consequently, we propose that a more descriptive definition may be better suited and more representative of the actual death wish under study.

Death wishes were considered active when respondents had seriously considered ending their lives or when they had made plans or taken steps regarding their death wish. Looking at the answers of respondents who indicated having made plans or taken steps, it is noteworthy that a large part of the reported activities can be viewed as anticipating a self-chosen death in due time rather than leading to a self-chosen death in the near future. For example, becoming a member of an interest group regarding voluntary end of life, or writing down one's wishes regarding medical treatment or end-of-life care, are not necessarily steps towards ending one's life in the near future. This corresponds with the finding that the majority of respondents with an active death wish long for a natural death. Only 0.17% of our total sample had an active death wish resulting in a wish to end their lives, divided into 0.11% who had a wish to end their lives themselves and 0.06% who had a wish for assisted suicide.

These results indicate that the boundaries between active and passive death wishes, and also between death wishes and suicidal ideation are not clear-cut. The lines between these concepts are very thin and therefore difficult to draw.

Furthermore, these results indicate a considerable difference between opinions and actual experiences considering death wishes and EAS. Although a growing group of Dutch citizens is in favor of legal prescription drugs for older persons (12), the group of older persons who actually wish to end their lives is small. In addition, it is important to note that opinions may shift depending on the specificity of the question. For example, while 51% of Dutch citizens reported to be in favor of allowing the oldest old to obtain lethal prescription drugs at their own request from a physician to end their own lives, only 38% were in favor of this in a case describing the situation of a 86-year old with a wish to die in the absence of severe illness (12).

The main strength of our study is that it is the first to provide representative data on the prevalence of persistent death wishes among older adults without severe illness. Our large sample, combined with information about non-response, provides robust and representative data. Additional strengths are the analysis in three steps to identify the group with a persistent death wish without severe illness, and the detailed insight into the nature and ambiguity of these death wishes, existential issues and actions towards realization of the death wish.

Our study also has several limitations. First, selection bias is always possible in surveys and when using existing access panels. For example, people with a death wish and a desire to end their lives may be less inclined to participate in surveys. Our sample showed small but significant differences with non-respondents on almost all background variables. However, as unweighted and weighted percentages do not show large differences, we assume that these differences did not have a large impact on the prevalence results and the results presented in **Tables 1, 2, and 3**.

Second, the quantitative method has limitations for the conclusions that may be drawn from our results. The categorization of the persistence of death wishes was based on respondents' own recall which may be influenced by their current mood. Moods may also have influenced the self-perceptions of health. For the respondents in the group indicating a wish to actively end their lives, we are unable to determine whether they would want this wish to be realized immediately or in due time. Moreover, there may be a difference between having this wish and ultimately being willing or able to take the final step to end one's own life. Therefore, the percentages regarding the prevalence may be overestimated and need to be interpreted with caution.

CONCLUSIONS

In the Netherlands and Belgium the question whether older adults with a persistent death wish without severe illness should be allowed to receive EAS is a topic of societal and political debate. The lack of robust knowledge on the prevalence of older adults with a persistent death wish without severe illness and on their characteristics, existential issues and the nature of their death wishes has been an obstacle for decision making on the issue. This study among a representative sample of 32,477 Dutch citizens aged 55 and older reveals that a small - but substantial on a population level - group of older adults have a persistent death wish in absence of severe illness. The majority of these older adults long for a natural death, and a wish for help from a caregiver or someone close to end one's life is rare among the group with an active death wish (0.06% of our sample). The identified characteristics challenge the dominant "completed life" or "tiredness of life" image of healthy persons over the age of 75 who, overseeing their lives, reasonably decide they would prefer to die. Furthermore, the death wishes without severe illness are often ambiguous and do not necessarily signify a wish to end one's life. It is of great importance to acknowledge these nuances and variety in the debate and in clinical practice, to be able to adequately recognize the persons involved and tailor to their needs.

Our findings raise many questions that need to be addressed to inform decision making on how to respond to the needs of this group. For instance, which characteristics are the most important independent and decisive predictors of PDW-NSI? And to what extent do the health problems contribute to the death wishes of persons with PDW-NSI, although they consider themselves not severely ill? What do people mean when stating they have a death wish? How do death wishes of persons with PDW-NSI develop over the years? Future quantitative and qualitative (longitudinal) research is needed to answer these questions.

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ADDITIONAL FILE 1. **Questionnaire items reported in this study**

- <u>Worldview</u>[1]
  Every individual - religious or not - has a worldview. A worldview is the way you look at mankind and the world. A worldview affects how people experience important events in their lives. The following questions address your worldview. Below are the most common worldviews. Can you indicate which applies or apply to you?

  Christian (Protestant)
  Christian (Roman Catholic)
  Muslim
  Jewish
  Humanist
  Atheist
  Agnostic
  Spiritual but not religious
  Buddhist
  Hindu
  Anthroposophical
  Esoteric
  Other
  No worldview

- <u>Number of (step)children</u>
  How many (step)children do you have?

  None
  1 child
  2 children
  3 children
  4 children
  5 children
  More than 5

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[1] Other background characteristics of the study sample were already known.

- <u>Current health state VAS</u>
  Please indicate on the scale below how good or how bad your overall health is <u>at this moment.</u>

  11 point (0-10) Likert scale: 0 = The worst health you can imagine; 10 = The best health you can imagine

- <u>EQ-5D-5L</u>
  For each of the following questions, please choose the answer that best describes your health <u>at this moment</u>.

  To what extent do you have problems walking?
  I have no problems in walking about
  I have slight problems in walking about
  I have moderate problems in walking about
  I have severe problems in walking about
  I am unable to walk about

  To what extent do you have problems washing or dressing yourself?
  I have no problems washing or dressing myself
  I have slight problems washing or dressing myself
  I have moderate problems washing or dressing myself
  I have severe problems washing or dressing myself
  I am unable to wash or dress myself

  To what extent do you have problems carrying out your usual activities? By usual activities we mean, for example, work, study, housework, family and leisure activities.
  I have no problems doing my usual activities
  I have slight problems doing my usual activities
  I have moderate problems doing my usual activities
  I have severe problems doing my usual activities
  I am unable to do my usual activities

  To what extent do you experience pain or discomfort?
  I have no pain or discomfort
  I have slight pain or discomfort
  I have moderate pain or discomfort
  I have severe pain or discomfort
  I have extreme pain or discomfort

To what extent are you anxious or depressed?
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed

- <u>HADS depression subscale</u>
  The following statements are about how you feel. Please indicate which answer best reflects how you have felt <u>in the past week</u>.

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I can laugh and see the sunny side of things
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

I feel cheerful
Not at all
Not often
Sometimes
Most of the time

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I have lost interest in my appearance
Definitely
I do not take as much care as I should
I may not take quite as much care
I take just as much care as ever

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I can enjoy a good book or radio or TV program
Often
Sometimes
Not often
Very seldom

- Life-threatening disease
  Have you ever had a life-threatening disease, or do you have a life-threatening disease at the moment?

  No
  Yes, I did have a life-threatening disease once, but not anymore
  Yes, I currently have a life-threatening disease, namely … *Open

- Number of current diseases
  Please indicate for the diseases listed below whether you are affected by them at this moment. Multiple answers possible.

  Joint conditions (e.g., arthritis, gout, rheumatism)
  Neck or back problems
  Bone decalcification (e.g., osteoporosis)
  Diabetes
  Tightness of the chest (e.g., COPD, asthma)
  Crohn's disease
  MS/ALS
  Skin disease
  Thyroid disease
  Heart failure/heart disease
  Consequences of a cerebral infarction/brain hemorrhage
  Dementia
  Parkinson's disease
  Cancer
  Psychological complaints (mood or anxiety problems, depression)
  Other

None of these diseases

- Burden of current diseases
  How much does this disease/do these diseases bother you? This refers to the disease(s) you indicated in the previous question.

  10 point (1-10) Likert scale: 1 = Very little; 5 = Fairly bothersome; 10 = Very much

- Number of current complaints
  Please indicate for each of the following medical complaints whether you experienced it in the past week. Multiple answers possible.

  Hearing problems or deafness, tinnitus
  Eye problems and visual impairment
  Memory problems
  Difficulty speaking
  Headache
  Sleep problems
  Falls (or fear of falling)
  Problems walking
  Dizziness
  Problems with particular movements
  Depression (depressive feelings)
  Lack of appetite
  Overweight, obesity
  Incontinence (urinary or bowel)
  Obstipation, hard/slow bowel movement
  Impotence
  Loss of sense of smell or taste
  Chronic itching (for example due to dry skin)
  Bedsores
  Extreme/chronic fatigue
  (Chronic) pain
  Other
  None of these complaints

- <u>Burden of current complaints</u>

  How much does this complaint/do these complaints bother you? This refers to the complaint(s) you indicated in the previous question.

  10 point (1-10) Likert scale: 1 = Very little; 5 = Fairly bothersome; 10 = Very much

- <u>Duration of having a death wish</u>

  How long have you had a wish to be dead? Please choose the answer that best describes your situation

  Basically my entire life
  For several years
  About one year
  About six months
  About one month
  About one week

- <u>Characterization of the death wish</u>

  People can long for death in different ways. Which of the following statements <u>best</u> describes you? Please indicate only one answer.

  A desire for a natural death that just happens
  A desire to not wake up tomorrow and die in my sleep
  I feel my current situation is unlivable
  A wish to end my life myself
  A wish for a doctor to help me end my life
  A wish for another professional or someone close to help me end my life
  I do not know

- <u>Having made concrete plans/taken steps</u>

  Have you made any concrete plans or taken steps in this process? If so, which plans or steps?

  No, at the moment I have no concrete plans and I have not taken any steps
  Yes, I have made concrete plans and/or taken steps, namely ... *Open

- <u>Having seriously considered attempting suicide in the past 12 months</u>
  In the past 12 months, have you ever seriously considered ending your life?

  Never
  Once or twice
  Occasionally
  Often
  Very often
  I do not want to answer this question

- <u>Having made a suicide attempt in the past 12 months</u>
  In the past 12 months, have you attempted to end your life?

  Yes
  No
  I do not want to answer this question

- <u>Preference not to have to experience the future</u>
  Here is a statement about how you look at the future. Please indicate the degree to which you can identify with it.

  I would prefer not to have to experience the future
  7 point (1-7) Likert scale: 1 = Not at all; 7 = Very strongly; and I do not know

- <u>Finding life worthwhile at this moment</u>
  Do you find life worth living <u>at this moment</u>?

  Yes
  No

- <u>Being weighed down by the burden of life</u>
  Below you find a statement relating to <u>your current situation</u>. Again, we are interested in your own experiences <u>in the past week</u>. Please indicate the degree to which you can or cannot identify with it.

  The burden of life weighs me down
  7 point (1-7) Likert scale: 1 = Not at all; 7 = Very strongly; and I do not know

ADDITIONAL FILE 2. Additional methodological justification

Selection process to identify the PDW-NSI group (step 1 and 2)

Step 1 – No severe illness: self-reported health

Two self-reported health measures were used for this first step in the selection process. First, we used respondent's scores on a visual analogue scale (VAS), employing an 11-point scale ranging from 0 (worst imaginable health state) to 10 (best imaginable health state). In literature, a cut-off point to distinguish severe illness using VAS scales is not available. Informed by recommended cut-offs for severe pain we defined "no severe illness" as VAS ≥4 (1-3). Second, we used the EQ-5D-5L. The cut-off point was determined based on a scatter plot combining the VAS scores and EQ-5D-5L sum scores of our study sample, see **Figure 1**. As the regression line at the level of VAS = 4 crossed the EQ-5D-5L axe just before 17, we decided to interpret EQ-5D-5L sum scores <17 as "not severely ill".

Combining these two cut-offs, respondents were categorized as "not severely ill" if they scored <4 on the VAS *and* <17 on the EQ-5D-5L (sum score). Respondents categorized as "severely ill" (VAS <4 *or* EQ-5D-5L sum score ≥17) were thus excluded in the selection of the group PDW-NSI.

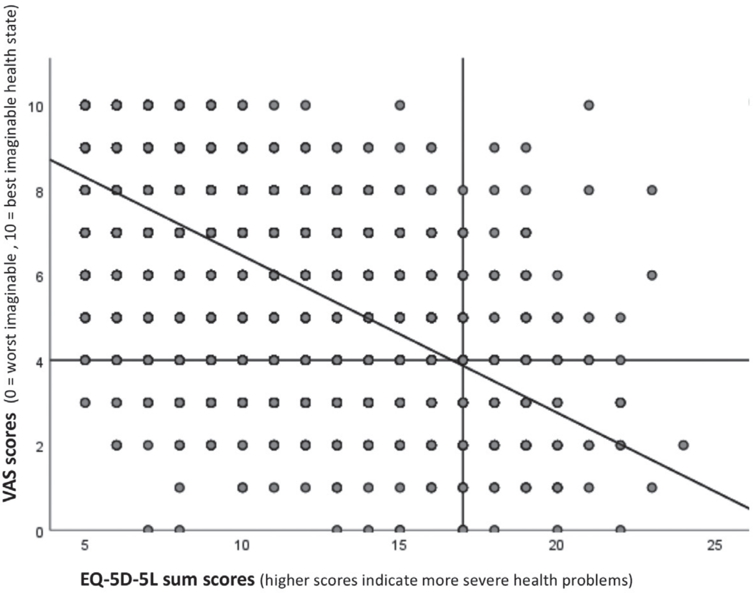

FIGURE 1. Scatter plot of VAS scores combined with EQ-5D-5L sum scores

Step 2 - No severe illness: indication for depression

HADS-D sum scores were calculated using the first six items from the first round, combined with the seventh item of the second round. Test-retest reliability based on the first six items of the first round and second round was high (intraclass correlation coefficient 0.83). For missings in the second round, the "half-rule method" was applied, using the mean of the first six items to calculate the seventh item (4). The value of the seventh item was multiplied by 0.70, as the second round data showed that on average, the seventh item had been scored 0.70 times the mean of the first six items. To classify respondents into one of the four categories, the whole numbers before the decimal points of the sum scores were used.

Respondents with an indication for severe depression (HADS-D sum score ≥17) were excluded in the selection of the group PDW-NSI.

Step 3 - Persistence of the death wish

In compliance with literature about death wishes and suicidal feelings, we considered a death wish with a duration of ≥ 1 year as "persistent" (5). Respondents who recalled a duration of their death wish of less than one year were thus excluded in the selection of the group PDW-NSI.

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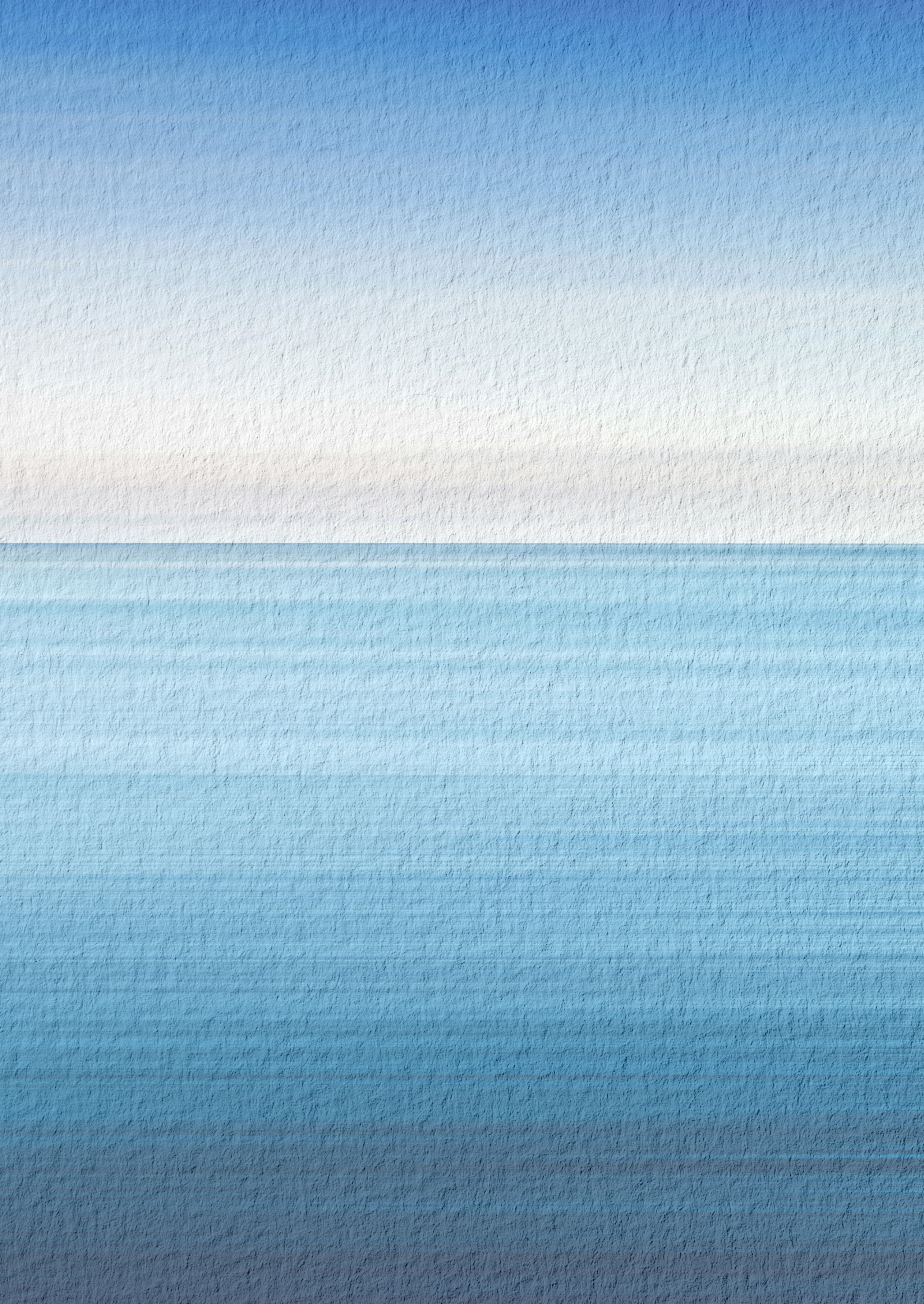
ADDITIONAL FILE 3. Respondents and non-respondents

Background characteristics of respondents and non-respondents

Aspects and items	Respondents N= 21,294	Non-respondents N= 11,183	P-value Respondents vs. Non-respondents
Gender			
Female	10,731 (50.4)	6,090 (54.5)	**0.000**
Male	10,563 (49.6)	5,093 (45.5)	
Age (years)			
Median (Q1-Q3)	65 (60-72)	66 (60-73)	**0.000**
55-59	5,218 (24.5)	2,640 (23.6)	
60-64	4,662 (21.9)	2,197 (19.6)	
65-69	4,232 (19.9)	1,948 (17.4)	
70-74	4,041 (19.0)	2,060 (18.4)	
75-79	1,836 (8.6)	1,176 (10.5)	
80-84	913 (4.3)	726 (6.5)	
85-89	332 (1.6)	321 (2.9)	
90-94	54 (0.3)	104 (0.9)	
95-99	6 (<0.1)	11 (0.1)	
Educational attainment[a]			
Low	7,173 (33.7)	4,646 (41.5)	**0.000[b]**
Middle	7,714 (36.2)	3,775 (33.8)	
High	6,305 (29.6)	2,626 (23.5)	
Unknown	102 (0.5)	136 (1.2)	
Household size (number of persons)			
1	5,463 (25.7)	2,827 (25.3)	**0.046**
2	12,646 (59.4)	6,568 (58.7)	
3 or more	3,185 (15.0)	1,788 (16.0)	
Social class[c]			
Low	8,625 (40.5)	5,289 (47.3)	**0.000**
Middle	3,238 (15.2)	1,677 (15.0)	
High	9,431 (44.3)	4,217 (37.7)	
Urbanization[d]			
Very high	3,941 (18.5)[e]	2,009 (18.0)[f]	0.267
High	7,422 (34.9)	3,935 (35.2)	
Moderate	3,883 (18.2)	1,993 (17.8)	
Low	4,295 (20.2)	2,293 (20.5)	
None	1,747 (8.2)	950 (8.5)	

*Results are presented as N (%) unless "Median (Q1-Q3)" is reported.
*Percentages may not add up to 100% because of rounding.
*Medians are reported with 25th-75th percentiles.
*Statistically significant results ($p < 0.05$) are in bold.
[a] Low= lower vocational education, lower secondary education, or less; Middle= intermediate vocational education or higher secondary education; High= higher vocational education or university; Unknown= I do not know/want to answer.
[b] N= 32,239 because category "Unknown" was not included in the test.
[c] Based on educational attainment and profession of the main breadwinner.
[d] Very high= >2,500; High= 1,500-2,500; Moderate= 1,000-1,500; Low= 500-1,000; None= <500 addresses per km^2.
[e] N= 21,288 in this column due to 6 missings for this variable. Percentages are based on N=21,288.
[f] N= 11,180 in this column due to 3 missings for this variable. Percentages are based on N=11,180.



4|

People aged 75+ who have a death wish without being severely ill: who are they?

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Contribution of the author of this dissertation:
I participated in the design of the study. I performed the statistical analysis and contributed to the interpretation of the findings. The first draft of the article was written and revised based on feedback of the co-authors by EvW in close collaboration with me.

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ABSTRACT

Objective

To map the size of the group of Dutch older persons (75+) who have a death wish without being severely ill, describe the characteristics and circumstances that play a role, and clarify the nature of this death wish.

Design

Cross-sectional survey.

Method

In 2019, a large-scale survey was conducted among a representative group of Dutch citizens aged 55 and older (32,477 individuals via the TNS NIPObase). In April 2019, a comprehensive questionnaire was completed by 21,294 respondents (response rate: 65.6%). This article concerns a sub analysis of the group aged 75+ who participated in the survey.

Results

Of the 3,141 persons aged 75 and older in this study, 56 respondents stated that they had a persistent death wish and no severe illness (PDW-NSI). The corresponding percentage, weighted according to the composition of the Dutch population, represents 2.07% of all persons aged 75+ in the Netherlands. On average, respondents with PDW-NSI were more likely to have low level educational attainment, be from lower social classes, and they slightly more often lived in more urbanized areas. Important aspects strengthening the death wish were dependency on others, worrying, physical and mental deterioration, health problems, and loneliness. The death wish was changeable and varied strongly in intensity.

Conclusion

A considerable proportion of persons aged 75+ with a persistent death wish remain out of sight of care providers because they do not communicate about their death wish. This can hamper timely support. Carefully questioning the meaning and nature of the death wish is essential to understand the background and the underlying needs of these older persons.

INTRODUCTION

In early 2020, we presented the research report '*Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: de mensen en de cijfers*' (1). The reason for our study was the ongoing debate about whether it should be possible to provide assisted suicide to older persons who consider their lives "completed" without being severely ill. A lack of knowledge on the size and characteristics of the group of older persons who have a persistent death wish has repeatedly been identified in the debate as an obstacle to furthering the discussion and the development of policy (2-4). Our study aimed to fill this knowledge gap. We focused on people aged 55 and older. On 17 July 2020, D66 submitted a legislative proposal, *Wet toetsing levenseindebegeleiding van ouderen op verzoek*, which focuses on making assisted suicide possible for persons aged 75+ (5). This calls for a specific analysis of the death wish in this group. In this article we present the results of this sub analysis.

Our research questions were: how large is the group of persons aged 75+ who have a persistent death wish without being severely ill? What is the nature of this death wish? And what are the characteristics and circumstances that play a role? Since these questions have largely not been quantitatively examined before, this study was mainly descriptive and exploratory in nature.

METHOD

Questionnaire

This study presents a sub analysis of data from a cross-sectional survey conducted among a representative group of Dutch citizens aged 55 years and older (32,477 individuals via the TNS-NIPObase). Between 3 and 25 April 2019 a comprehensive questionnaire was completed by 21,294 respondents (65.6%) (see **Supplement 1**). The content of the questionnaire was based on the results of previous research on death wishes in older persons and validated health questionnaires. The questionnaire included questions about, among others, having a death wish, the nature of the death wish, life perspective, needs regarding and communication about the death wish, illness, health, and depression.

Selection of respondents

The questionnaire asked the following differentiation question: does the description 'seeing no future for oneself, longing for death, while not being severely ill' apply to you at this moment? To identify respondents with a persistent death wish ($\geq$ 1 year) and no severe illness (PDW-NSI) within the group who answered 'YES', we carried out a 3-step selection (see **Supplement 2**) (6-10). In addition, we created subgroups based on the nature of the death wish (see **Figure**). Respondents who had seriously considered attempting suicide in the past year and/or had made concrete plans/taken steps with regard to the death wish, were placed in the active death wish subgroup.

Statistical analyses

We performed all analyses using SPSS software, version 25.0 (2018) and SAS version 9.4 (2012). Our analysis concerned descriptive statistics with calculations of frequencies (percentages) and medians (with interquartile ranges).

Confidence intervals for the prevalence figures were calculated using the Wilson method. For weighted percentages representing the prevalence in the Dutch population we applied a weighting factor for gender, age, educational attainment, household size, region, and social class of persons aged 75 years and older.

Ethical review

The research design was submitted to the Medical Ethics Review Committee (METC) Utrecht, which concluded that the study did not fall within the scope of the Medical Research involving Human Subjects Act (WMO). The METC issued a non-WMO statement for this study (METC protocol number: 19-156/C).

RESULTS

Size of the groups

Of the 3,141 people aged 75 and older in our study, 79 (2.52%) indicated that the description ‘seeing no future for oneself, longing for death, while not being severely ill’ applied to them at that moment (see **Supplement 1**). Sixty-two of these respondents were classified as not severely ill, and 56 indicated that they had had a death wish for one year or longer (see **Supplement 2**). This brings the group of persons aged 75+ with a persistent death wish and no severe illness (PDW-NSI) to 1.78% of the total group aged 75+. Within the PDW-NSI group, 30 respondents (0.96% of the total 75+ group) had an active death wish (see **Figure**). The group of persons aged 75 and older who had an active death wish that - according to them - is best described as a wish to end one’s life, comprised 6 people, i.e., 0.19% of all persons aged 75+.

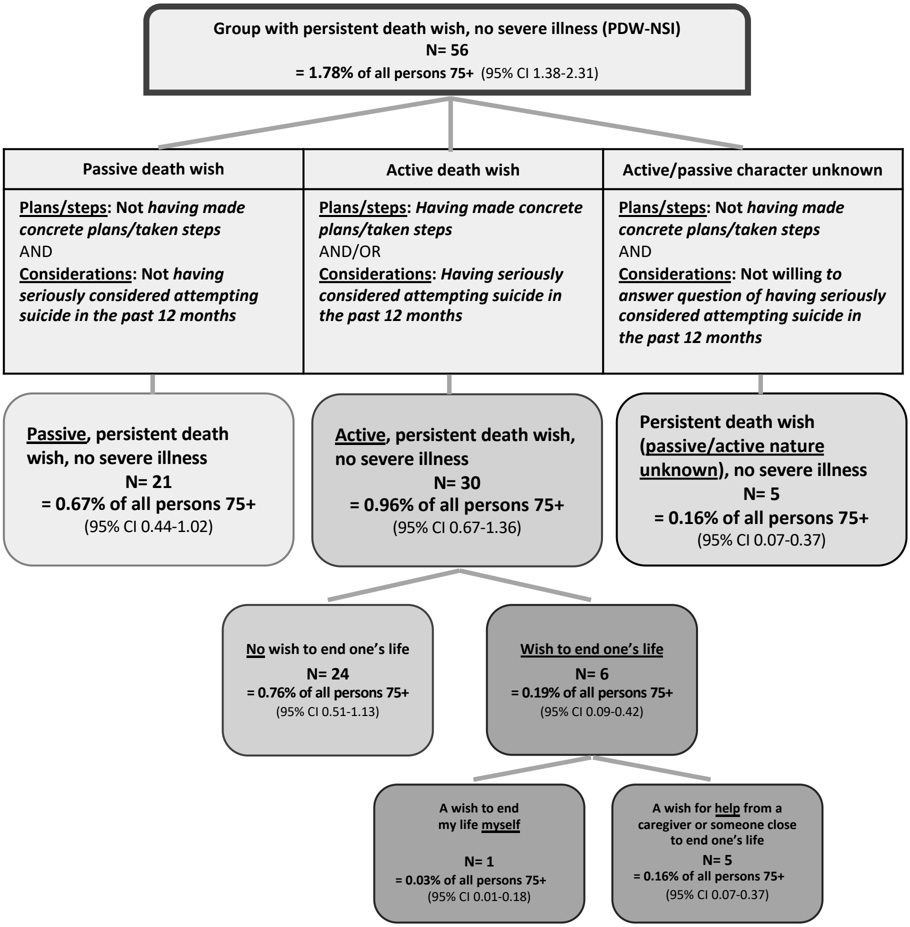

FIGURE. Subgroups of persons aged 75 and older who are not severely ill, but do have a persistent death wish
All persons 75+ refers to the total response of persons aged 75 and older (N= 3,141). Numbers and percentages.

Background characteristics

Table 1 summarizes the background characteristics of the PDW-NSI group. 82% of the respondents were between 75 and 84 years old. Almost two thirds lived alone (64%) and this percentage was slightly higher in the subgroup with an active death wish (70%). Only 10% had no (step)children, a percentage comparable to that of the NO-group (i.e., respondents who did not recognize themselves in the description 'seeing no future for oneself, longing for death, while not being severely ill'). Compared to the NO-group, respondents with PDW-NSI were, on average, more likely to have low level educational attainment, be from lower social classes, and they slightly more often lived in more urbanized areas.

TABLE 1. Background characteristics

		“Persistent death wish, no severe illness” (PDW-NSI)		
	NO-group	**Persistent death wish, no severe illness (PDW-NSI)**	**Passive persistent death wish, no severe illness**	**Active persistent death wish, no severe illness**
	N= 3,062	**N= 56**	**N= 21**	**N= 30**
Gender - N (%)				
Female	1,283 (42)	24 (43)	10 (48)	11 (37)
Male	1,779 (58)	32 (57)	11 (52)	19 (63)
Age (years) - N (%)				
Median (Q1-Q3)	79 (76-82)	79 (77-84)	80 (78-83)	79 (77-84)
75-79	1,796 (59)	32 (57)	12 (57)	16 (53)
80-84	890 (29)	14 (25)	6 (29)	8 (27)
85-89	320 (11)	8 (14)	3 (14)	4 (13)
90-94	51 (2)	2 (4)	0 (0)	2 (7)
95-99	5 (0.2)	0 (0)	0 (0)	0 (0)
Educational attainment[1] - N (%)				
Low	1,140 (37)	24 (43)	10 (48)	10 (33)
Middle	919 (30)	14 (25)	3 (14)	11 (37)
High	981 (32)	18 (32)	8 (38)	9 (30)
Unknown	22 (1)	0 (0)	0 (0)	0 (0)
Worldview[2] - N (%)				
Religious worldview	98 (57)	21 (36)	10 (43)	8 (26)
Non-religious worldview	34 (20)	14 (24)	4 (17)	10 (32)
Worldview, religiousness unknown	8 (5)	1 (2)	1 (4)	0 (0)
No worldview	33 (19)	23 (39)	8 (35)	13 (42)
Number of (step)children[3] - N (%)				
None	11 (11)	4 (10)	0 (0)	2 (9)
1	11 (11)	4 (10)	3 (20)	1 (5)
2	50 (49)	25 (63)	10 (67)	14 (64)
3 or more	30 (29)	7 (18)	2 (13)	5 (23)
Household size (number of persons) - N (%)				
1	1,027 (34)	36 (64)	12 (57)	21 (70)
2	1,972 (64)	17 (30)	7 (33)	8 (27)
3 or more	63 (2)	3 (5)	2 (10)	1 (3)
Social class[4] - N (%)				
Low	1,470 (48)	33 (59)	10 (48)	19 (63)
Middle	326 (11)	7 (13)	4 (19)	3 (10)
High	1,266 (41)	16 (29)	7 (33)	8 (27)
Urbanization[5] - N (%)				
Very high	607 (20)	11 (20)	4 (19)	6 (20)
High	1,045 (34)	22 (39)	7 (33)	11 (37)
Moderate	596 (20)	13 (23)	7 (33)	6 (20)
Low	624 (20)	6 (11)	1 (5)	5 (17)
None	189 (6)	4 (7)	2 (10)	2 (7)

Percentages may not add up to 100% because of rounding.

[1] Low= lower vocational education, lower secondary education, or less; Middle= intermediate vocational education, higher secondary education; High= higher vocational education or university; Unknown= I do not know/want to answer.

[2] Religious worldview= Protestant, Catholic Muslim, Jewish, Hindu and Buddhist. Non-religious worldview= atheist,

agnostic, “spiritual but not religious”, humanist, anthroposophical and esoteric. Worldview, religiousness unknown= other worldview. Respondents could choose more than one answer and may thus be counted in more than one category. Numbers in the four groups are N= 173 (comparison group), N= 59, N= 23, N= 31, respectively. Percentages are calculated based on these numbers.

[3] Due to missing answers for ‘Number of (step)children’, the total numbers in the columns may deviate. Numbers for the four groups are N= 102 (comparison groups), N= 40, N= 15, N= 22, respectively. Percentages were calculated based in these numbers.

[4] Based on educational attainment and profession of main breadwinner.

[5] Very high= >2,500; High= 1,500-2,500; Moderate= 1,000-1,500; Low= 500-1,000; None= <500 addresses per km^2. N= 3,061 in the NO-group due to 1 missing answer.

Perceived health

During the selection process respondents indicated to consider themselves ‘not severely ill’ and additional measures were applied to select respondents without severe illness. Nevertheless, the scores on almost all health variables indicated poorer health among respondents with PDW-NSI than in the NO-group (**Table 2**). The largest difference was found for depression. The PDW-NSI group had a median HADS-D sum score of 9 (on a scale of 0-21), with a sum score of 8 or more indicating mild depression. However, the rating for overall health state (measured by a VAS score) was relatively high among PDW-NSI respondents (median 7).

TABLE 2. Perceived health

		“Persistent death wish, no severe illness” (PDW-NSI)		
	NO-group	Persistent death wish, no severe illness (PDW-NSI)	Passive persistent death wish, no severe illness	Active persistent death wish, no severe illness
	N= 3,062	N= 56	N= 21	N= 30
Current health state (VAS)[1]				
Median (Q1-Q3)	7 (7-8)	7 (5-7)	7 (5-8)	7 (5-8)
EQ-5D-5L sum score[2]				
Median (Q1-Q3)	7 (6-9)	9 (8-13)	8 (8-11)	10 (8-13)
HADS depression-subscale, sum score[3]				
Median (Q1-Q3)	4 (2-7)[4]	9 (6-12)	9 (6-12)	11 (6-12)
Life-threatening disease - N (%)				
Never	2,105 (69)	35 (63)	17 (81)	14 (47)
Yes, in the past	759 (25)	16 (29)	3 (14)	12 (40)
Yes, at this moment	198 (7)	5 (9)	1 (5)	4 (13)
Number of current diseases[5] - N (%)				
None	39 (23)[4]	3 (5)	2 (10)	1 (3)
Median (Q1-Q3)	1 (1-2)[4]	2 (1-4)	1 (1-2)	3 (1-4)
Burden of current diseases[6]				
Median (Q1-Q3)	5 (3-7)	5 (4-7)	5 (4-7)	5 (4-7)
Number of current complaints[7] - N (%)				
None	20 (12)[4]	2 (4)	1 (5)	1 (3)
Median (Q1-Q3)	3 (1-4)[4]	6 (3-8)	5 (3-7)	7 (4-8)

TABLE 2. Continued.

		"Persistent death wish, no severe illness" (PDW-NSI)		
	NO-group	**Persistent death wish, no severe illness (PDW-NSI)**	**Passive persistent death wish, no severe illness**	**Active persistent death wish, no severe illness**
	N= 3,062	**N= 56**	**N= 21**	**N= 30**
Burden of current complaints[8]				
Mediaan (Q1-Q3)	5 (4-7)	6 (5-7)	6 (4-6)	5 (5-7)
Use of medications - N (%)				
Yes	153 (90)[4]	48 (86)	16 (76)	27 (90)
Number of medications[9]				
Median (Q1-Q3)	2 (1-3)	3 (2-4)	2 (1-3)	3 (1-4)

Percentages may not add up to 100% because of rounding.

[1] Visual Analogue Scale (VAS) ranging from 0 (worst imaginable) to 10 (best imaginable health state).

[2] EQ-5D-5L sum scores range from 5 to 25. Higher sum scores indicate more severe problems on the five domains of health.

[3] HADS depression-subscale, sum scores range from 0 to 21. Higher sum scores are related to a possible indication for depression with a greater severity.

[4] N= 170 (comparison group).

[5] Chosen from the following list of diseases: joint conditions; osteoporosis; diabetes; neck or back complaints; tightness of the chest (e.g., COPD, asthma); Crohn's disease; MS/ALS; skin disease; thyroid disease; heart conditions; consequences of CVA, dementia; Parkinson's disease; cancer; psychological complaints (mood or anxiety complaints, depression); other.

[6] 10-point scale ranging from 1 ("very little") to 10 ("very much") for diseases on the list above. A number of respondents reported having no disease. Numbers of respondents who did report disease in the four groups were: N= 131 (comparison group), N= 53, N= 19, N= 29, respectively.

[7] Chosen from a list of complaints, such as hearing problems or deafness, tinnitus, headache, dizziness, obesity, incontinence, chronic itching, extreme/chronic fatigue, depressive feelings, obstipation and (chronic) pain, other.

[8] 10-point scale ranging from 1 ("very little") to 10 ("very much") for complaints on the list above. A number of respondents reported having no complaints. Numbers of respondents who did report complaints in the four groups were N= 146 (comparison group), N= 54, N= 20, N= 29, respectively.

[9] The following list of medications was presented to the respondents who answered "yes" to use of medication,: antidepressants; tranquillizers; sleeping pills; pain killers; blood thinners; anti-hypertensives; anti-inflammatories; blood sugar medication; thyroid medication; lung medication; prostate medication; other.

Nature of the death wish and the wish to live

As shown in **Supplement 3**, the majority of persons in the PDW-NSI group (68%) reported having had the death wish for a few years. A minority (16%) indicated thinking about the death wish every day or all the time. For others this varied (48%). Over a third (38%) of the respondents with PDW-NSI reported that they had seriously considered attempting suicide in the past 12 months. None of the respondents reported having made a suicide attempt in the past 12 months. In terms of needs concerning ending one's life, 'access to a suicide drug' was most frequently mentioned (52%), followed by 'assistance from a doctor to commit suicide' (38%) and 'assistance from another professional or someone close to commit suicide' (25%). However, when asked how the death wish can best be characterized, 79% chose 'a desire for a natural death that just happens' or 'a desire to not wake up tomorrow and die in my sleep'. 'A wish to end my life myself' was chosen by 4% as the best characterization of their death wish, and 'a wish for a doctor, another professional or someone close to help me end my life' by 13%.

Aspects strengthening the death wish or wish to live

Supplement 4 provides an overview of the aspects that according to respondents strengthened their death wish or wish to live. ‘Physical or mental deterioration’ was the most frequently mentioned aspect strengthening the death wish (63%). This was followed by ‘being dependent on others’ (59%), ‘worrying’ (54%) and ‘loneliness’ (52%). ‘Comfortable living conditions (nice house, nice neighborhood)’ was the aspect most frequently mentioned by the PDW-NSI group (77%) as strengthening their wish to live.

Needs and communication

Supplement 5 shows what respondents in the PDW-NSI group indicated regarding their needs for help and support and communication about the death wish. The social needs ‘good conversations with a professional (e.g., GP, psychologist, or spiritual counsellor)’ and ‘acknowledgment and appreciation of my feelings’ were chosen most frequently. The need for better or more contact with (grand)children/relatives was also mentioned relatively often. When asked, more than a third (36%) indicated that they had not discussed their death wish with anyone. Those who had, most often talked to a doctor and/or other healthcare professional (36%) or with children and grandchildren (25%).

DISCUSSION

After weighting, the percentage of people included in the PDW-NSI group came to 2.07% of the population aged 75 years and older (95% CI: 1.63-2.63). Based on 1,407,546 persons aged 75+ in the Netherlands (CBS, 1 January 2019), this would mean that an estimated 29,000 persons aged 75+ in the Netherlands have a persistent death wish without severe illness. The group with an active death wish made up 1.10% (95% CI: 0.79-1.53). It is estimated that this amounts to approximately 15,000 persons aged 75 years and older in the Netherlands.

The weighted percentage of PDW-NSI among the group aged 75+ (2.07%) is slightly higher than in the total group of persons aged 55 and older (1.34%) (1, 11). This finding is consistent with previous research showing that death wishes occur more frequently with advancing age (12). Other international studies mostly show higher percentages in groups of persons aged 70 and older (12-16). An analysis of 11 population studies from various countries showed that 5% of older men and 7% of older women reported having a death wish (17). In all studies severely physically or mentally ill older persons were included, which makes it difficult to compare the percentages with those from our study.

Consistent with previous studies, ‘physical or mental deterioration’ was cited by many respondents (63%) as an aspect strengthening their death wish (14-21). The older persons with PDW-NSI in our study were more likely to have health problems than respondents in the NO-group. The role of loneliness as a strengthening factor in our study is also consistent with the results of previous research (18, 22).

As in other studies, the persistent death wish seems to have gradations: ranging from a passive to an active death wish or a clear wish to end one's life (23-24). The death wish was changeable and varied strongly in intensity. This 'fluctuation' has also been observed in previous studies (1, 19, 25-26).

Concerning communication about the death wish, over one third of the respondents indicated that they did not discuss their death wish with anyone. Yet, the need for acknowledgment, appreciation, and good conversations was also expressed by respondents. If the death wish was discussed, the most frequently mentioned person with whom it was discussed was a doctor and/or other healthcare professional. Difficulties with discussing the death wish also emerge from other studies: older persons do not want to trouble their surroundings with their feelings (25-26).

Comparison with the death wish of persons aged 55 and older

When we compare the results of this sub analysis with the results we published earlier in the research report for the entire 55+ group, there are no major differences. However, 'being dependent on others' was mentioned more often as an aspect strengthening the death wish by persons aged 75+ (59%) than by those aged 55+ (40%) (1). Another remarkable difference is that comparatively fewer person aged 75+ (38%) consider ending their lives than persons aged 55+ (51%) (1, 11). Nearly 1 in 5 persons with PDW-NSI aged 55+ reported having had a death wish their whole life, compared to very few persons aged 75+ (1 in 50). Regarding comparison with the death wish of persons aged 55 and older, it is important to mention that we compared the sub analysis of the group of persons aged 75+ with the total group of persons aged 55+. This might cause less contrast between the two groups.

Strength and limitations of the study

Despite the large, representative sample and the high response rate (65.6%), several limitations need be taken into account when interpreting the findings. First of all, it is important to realize the potential effect of selection bias and response bias in surveys like this. The persons aged 75+ with a death wish may have been less inclined to participate, and how they answered questions may have been influenced by, for example, the order in which the questions were presented, the social desirability of certain answers, and whether or not they correctly remembered things that happened in the past.

Besides, this cross-sectional study is a snapshot. For this reason it is not well possible to draw conclusions on the causality of findings and the development of death wishes and related factors over time.

Furthermore, relatively few people aged 90+ participated in our study, both in comparison with the population distribution and in comparison with the non-response. The unweighted prevalence percentages may therefore be lower than they are in reality. Correcting these percentages with a weighting factor is therefore of extra importance for the reliability of the percentages. Even after weighting the fact is that the group of older people (75+) with a persistent death wish without being severely ill is relatively small. Because of the small numbers, caution is indicated when interpreting the percentages of the background characteristics and other variables.

Implications for practice

It is very important to be aware of the ambivalence of the death wish of people who are not severely ill. The meaning of the statement that someone longs for death, has a death wish, or experiences life as “completed”, can vary strongly from person to person. A considerable proportion of these people remain out of sight of care providers because they do not communicate about their death wish. This may complicate general practitioners or other primary healthcare professionals providing timely support. Particularly an exploratory conversation, with an important role for acknowledgment and appreciation, seems to be needed. In order to understand the background and the underlying needs of these older persons, it is essential to carefully question both the meaning and nature of the death wish - its duration and persistence, stability, intensity, and any activities that may or may not be undertaken to hasten death. Only a small proportion of older persons have a current request for assisted suicide.

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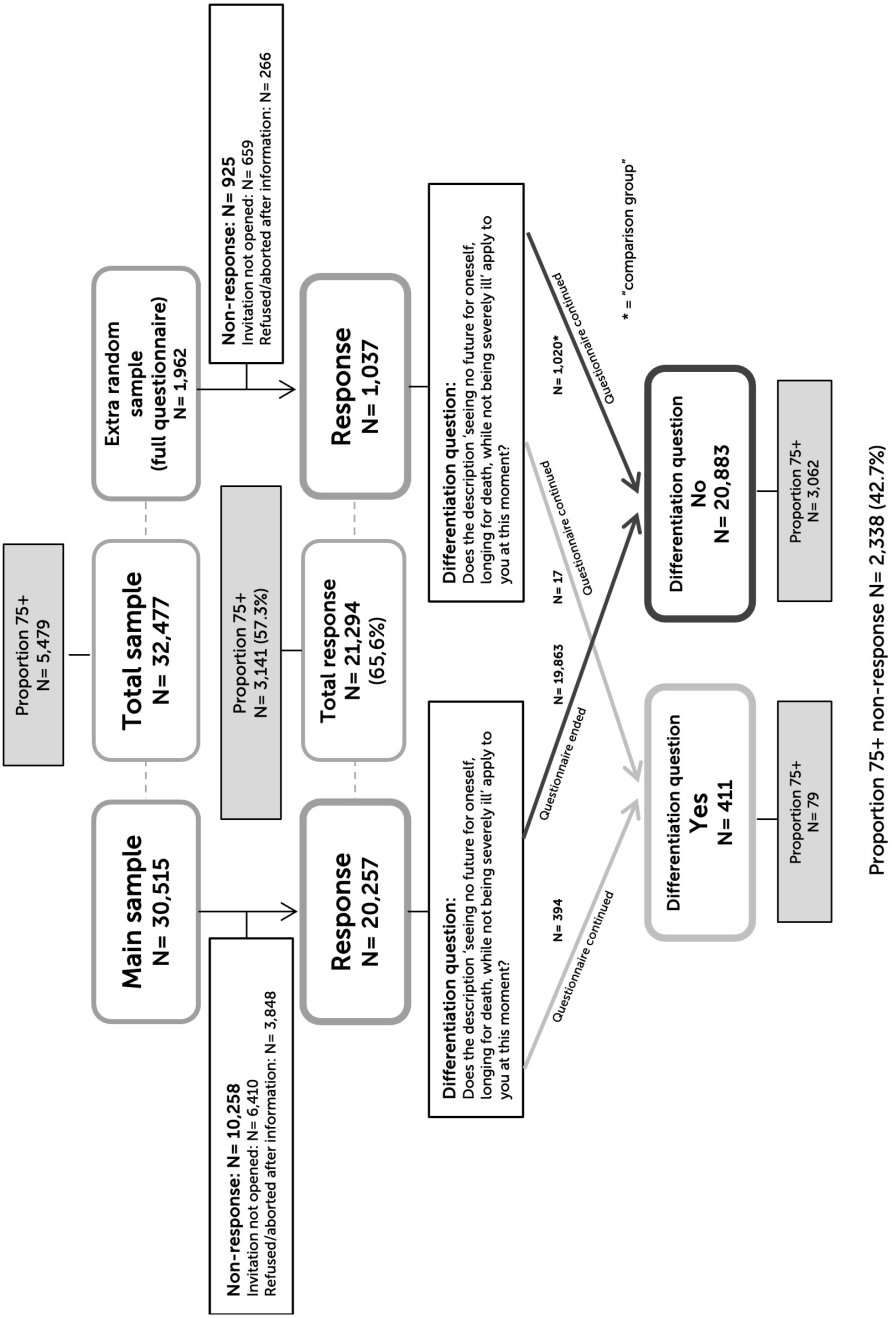
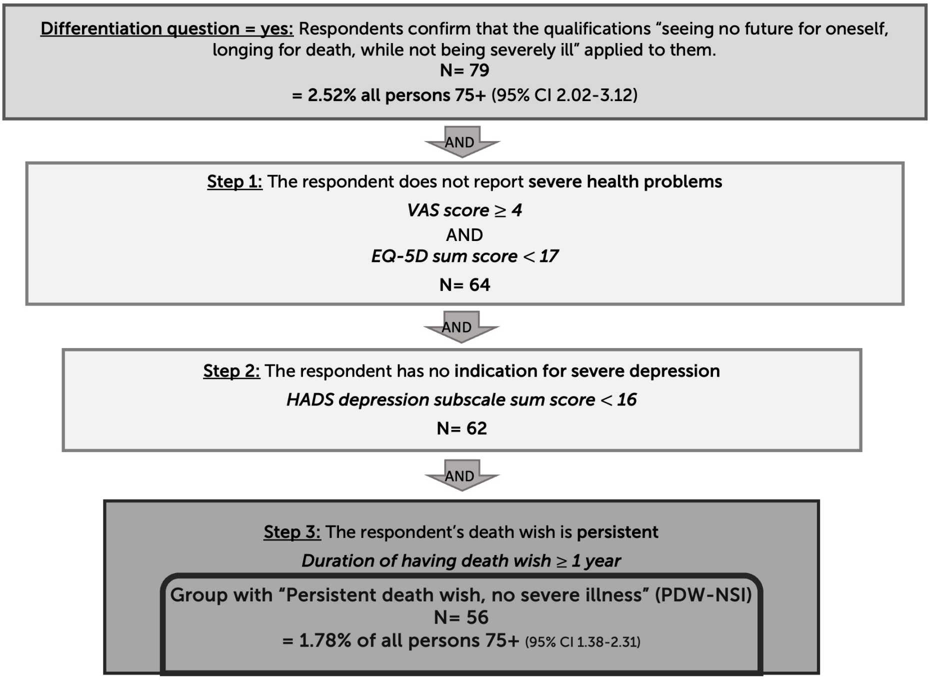
SUPPLEMENTAL MATERIAL



SUPPLEMENT 1. Flowchart sample and response - 75+



Differentiation question = yes: Respondents confirm that the qualifications "seeing no future for oneself, longing for death, while not being severely ill" applied to them.
N= 79
= 2.52% all persons 75+ (95% CI 2.02-3.12)

AND

Step 1: The respondent does not report **severe health problems**
VAS score ≥ 4
AND
EQ-5D sum score < 17
N= 64

AND

Step 2: The respondent has no **indication for severe depression**
HADS depression subscale sum score < 16
N= 62

AND

Step 3: The respondent's death wish is **persistent**
Duration of having death wish ≥ 1 year

Group with "Persistent death wish, no severe illness" (PDW-NSI)
N= 56
= 1.78% of all persons 75+ (95% CI 1.38-2.31)

SUPPLEMENT 2. Flowchart selection process to identify the group "persistent death wish, no severe illness" (PDW-NSI) - 75+
All persons 75+ refers to the total response of persons aged 75 and older (N= 3,141). Numbers and percentages.

SUPPLEMENT 3. Nature of the death wish and the wish to live

	"Persistent death wish, no severe illness" (PDW-NSI)		
	Persistent death wish, no severe illness (PDW-NSI) N= 56	Passive persistent death wish, no severe illness N= 21	Active persistent death wish, no severe illness N= 30
Duration of having a death wish - N (%)			
Whole life	1 (2)	0 (0)	1 (3)
A few years	38 (68)	14 (67)	19 (63)
Approximately one year	17 (30)	7 (33)	10 (33)
Frequency of thinking about the death wish - N (%)			
Rarely	4 (7)	3 (14)	1 (3)
Every month	3 (5)	2 (10)	1 (3)
Every week	13 (23)	3 (14)	10 (33)
Every day	7 (13)	3 (14)	3 (10)
All the time	2 (4)	0 (0)	2 (7)
It varies; sometimes frequently, sometimes not very often	27 (48)	10 (48)	13 (43)
Strength of the death wish in the past week[1]			
Median (Q1-Q3)	5 (3-7)	5 (3-6)	6 (4-8)
Strength of the wish to live in the past week[1]			
Median (Q1-Q3)	5 (3-7)	5 (3-7)	5 (2-6)
Relative strength of the death wish and the wish to live in the past week - N (%)			
The wish to live was stronger	16 (29)	8 (38)	7 (23)
About the same	27 (48)	7 (33)	17 (57)
The death wish was stronger	13 (23)	6 (29)	6 (20)
Alternation between the death wish and the wish to live in the past week - N (%)			
In my case the death wish is always stronger	14 (25)	5 (24)	7 (23)
In my case the wish to live is always stronger	7 (13)	4 (19)	2 (7)
Some periods my wish to live is stronger, at other times my death wish is dominant	35 (63)	12 (57)	21 (70)
Having seriously considered attempting suicide in the past 12 months - N (%)			
Never	30 (54)	21 (100)	9 (30)
Once in a while	11 (20)	0 (0)	11 (37)
Now and then	8 (14)	0 (0)	8 (27)
Often	1 (2)	0 (0)	1 (3)
Very often	1 (2)	0 (0)	1 (3)
Not willing to answer	5 (9)	0 (0)	0 (0)
Having made a suicide attempt in the past 12 months - N (%)			
No	20 (36)[2]	N/A	20 (95)[2,3]
Yes	0 (0)	N/A	0 (0)
Not willing to answer	1 (2)	N/A	1 (5)

SUPPLEMENT 3. Continued.

	"Persistent death wish, no severe illness" (PDW-NSI)		
	Persistent death wish, no severe illness (PDW-NSI) **N= 56**	**Passive persistent death wish, no severe illness** **N= 21**	**Active persistent death wish, no severe illness** **N= 30**
Needs concerning ending one's life - N (%)[4]			
Assistance from a doctor to commit suicide	21 (38)	7 (33)	12 (40)
Assistance from another professional or someone close to commit suicide	14 (25)	1 (5)	12 (40)
Access to a suicide drug	29 (52)	10 (48)	17 (57)
Information or support to stop eating and drinking	4 (7)	3 (14)	1 (3)
Characterization of the death wish - N (%)			
A desire for a natural death that just happens	14 (25)	5 (24)	7 (23)
A desire to not wake up tomorrow and die in my sleep	30 (54)	11 (52)	17 (57)
I feel my current situation is unlivable	0 (0)	0 (0)	0 (0)
A wish to end my life myself	2 (4)	1 (5)	1 (3)
A wish for a doctor to help me end my life	4 (7)	1 (5)	3 (10)
A wish for another professional or someone close to help me end my life	3 (5)	1 (5)	2 (7)
I do not know	3 (5)	2 (10)	0 (0)
Having made concrete plans/taken steps concerning the death wish - N (%)			
No	40 (71)	21 (100)	14 (47)
Yes	16 (29)	0 (0)	16 (53)

Percentages may not add up to 100% because of rounding.
N/A = not applicable.

[1] 10-point scale ranging from 1 ("no wish") to 10 ("very strong wish").

[2] N= 21 in this column because respondents who answered "never" or "not willing to answer" to the previous question (having seriously *considered* attempting suicide in the past 12 months) were not asked this question.

[3] Percentages in this column are based on N= 21.

[4] Percentages add up to more than 100% because respondents could select multiple needs.

SUPPLEMENT 4. Aspects strengthening the death wish or wish to live

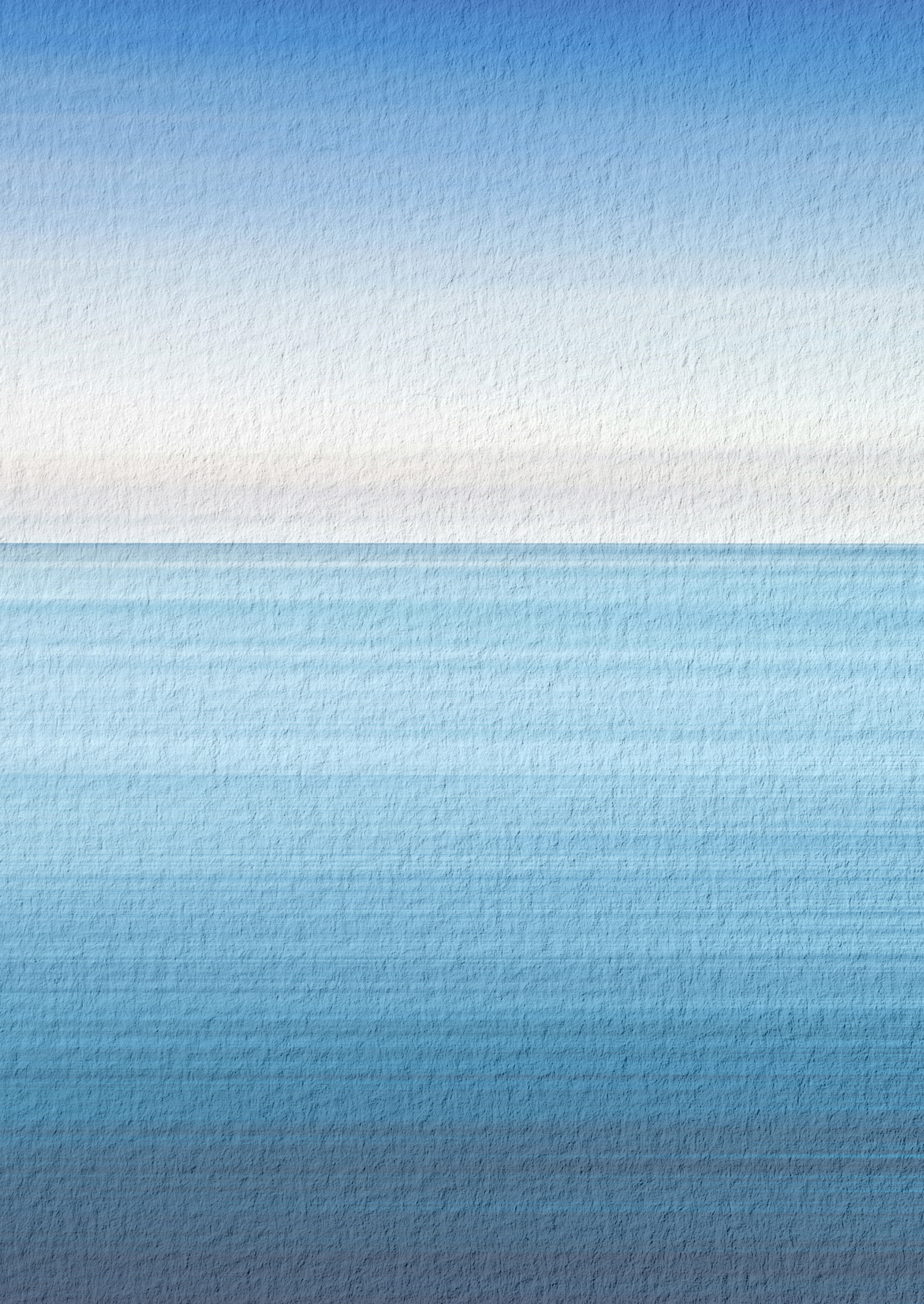
	"Persistent death wish, no severe illness" (PDW-NIS)		
	Persistent death wish, no severe illness (PDW-NSI) N= 56	Passive persistent death wish, no severe illness N= 21	Active persistent death wish, no severe illness N= 30
Aspects strengthening the death wish - N (%)			
Diseases	26 (46)	9 (43)	15 (50)
Physical or mental deterioration	35 (63)	13 (62)	19 (63)
Limitation of my freedom	26 (46)	9 (43)	16 (53)
Being dependent on others	33 (59)	12 (57)	19 (63)
Sense of having little to no influence on my life	26 (46)	10 (48)	14 (47)
Feeling like I am a burden to others	22 (39)	6 (29)	14 (47)
Tension or arguments with people in my immediate environment	16 (29)	6 (29)	10 (33)
Loneliness	29 (52)	11 (52)	16 (53)
Loss (or lack) of status	8 (14)	4 (19)	4 (13)
Boredom	12 (21)	3 (14)	9 (30)
Worrying	30 (54)	8 (38)	19 (63)
Move that is disappointing/turns out badly	7 (13)	2 (10)	5 (17)
Financial problems	7 (13)	1 (5)	6 (20)
Time of year	10 (18)	1 (5)	8 (27)
Aspects strengthening the wish to live - N (%)			
Independence	40 (71)	16 (76)	21 (70)
Sense of freedom	31 (55)	13 (62)	14 (47)
Sense of being connected to other people	25 (45)	8 (38)	15 (50)
Comfortable living conditions (nice house, nice neighborhood)	43 (77)	14 (67)	25 (83)
Social engagement	23 (41)	6 (29)	15 (50)
Making a difference for others	32 (57)	12 (57)	18 (60)
Feeling useful	21 (38)	9 (43)	11 (37)
Sense of self-worth	23 (41)	9 (43)	11 (37)
Being respected and appreciated by others	30 (54)	8 (38)	19 (63)
Good care	31 (55)	10 (48)	18 (60)
Humor, fun	30 (54)	10 (48)	17 (57)
My worldview	14 (25)	4 (19)	8 (27)
The time of the year/the season	16 (29)	2 (10)	11 (37)
Peace	34 (61)	11 (52)	20 (67)

All variables are scored "yes", "no", "I do not know". Numbers and percentages are given for answer "yes".

SUPPLEMENT 5. Needs and communication

	"Persistent death wish, no severe illness" (PDW-NSI)		
	Persistent death wish, no severe illness (PDW-NSI) N= 56	Passive persistent death wish, no severe illness N= 21	Active persistent death wish, no severe illness N= 30
Need for help and support – N (%)			
Social needs			
More social contacts	7 (13)	2 (10)	5 (17)
Better/more contact with my (grand) children/relatives	10 (18)	3 (14)	6 (20)
Acknowledgment and appreciation of my feelings	15 (27)	2 (10)	12 (40)
Good conversations with a professional (e.g., GP, psychologist, or spiritual counsellor)	17 (30)	4 (19)	12 (40)
Good conversations with other older persons/others in the same situation	7 (13)	1 (5)	6 (20)
Needs for activities			
Meaningful activities	8 (14)	3 (14)	5 (17)
Meaningful volunteer work	4 (7)	0 (0)	4 (13)
Opportunities to carry out my hobbies	3 (5)	0 (0)	2 (7)
Needs for care and guidance			
Meditation or mindfulness training	3 (5)	1 (5)	1 (3)
More/better professional care and support (e.g., mental or physical)	5 (9)	2 (10)	3 (10)
Better fine-tuning of medications	9 (16)	3 (14)	4 (13)
Needs for practical or material things			
More financial leeway	5 (9)	1 (5)	4 (13)
Another place to live	4 (7)	1 (5)	3 (10)
Better access to transportation (e.g., public transportation, regional taxi, senior transportation service)	7 (13)	3 (14)	3 (10)
Other			
Other than above	2 (4)	0 (0)	2 (7)
I do not know	2 (4)	0 (0)	1 (3)
No need for support or assistance	5 (9)	4 (19)	1 (3)
Communication about the death wish			
No, I have not discussed it with anyone	20 (36)	11 (52)	9 (30)
Yes, with my spouse/partner	11 (20)	4 (19)	5 (17)
Yes, with (a) sibling(s)	4 (7)	2 (10)	1 (3)
Yes, with (a) friend(s)	11 (20)	3 (14)	7 (23)
Yes, with my child(ren) and grandchild(ren)	14 (25)	5 (24)	8 (27)
Yes, with my doctor and/or other healthcare professionals	20 (36)	4 (19)	14 (47)
Other	3 (5)	0 (0)	2 (7)

Percentages add up to more than 100% as respondents could give more than one answer.



5

Lifelong versus not lifelong death wishes in older adults without severe illness: a cross-sectional survey

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Contribution of the author of this dissertation:
I participated in the design of the study. I performed the statistical analysis and together with EE I took the lead in the interpretation of the findings. The first draft of the article was written by EE and we both revised several versions based on feedback of the co-authors.

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ABSTRACT

Background

Some older adults with a persistent death wish without being severely ill report having had a death wish their whole lives (lifelong persistent death wish; L-PDW). Differentiating them from older adults without severe illness who developed a death wish later in life (persistent death wish, not lifelong; NL-PDW) can be relevant for the provision of adequate help and support. This study aims to gain insight into the characteristics, experiences, and needs of older adults with a L-PDW versus older adults with a NL-PDW and into the nature of their death wishes.

Methods

In the Netherlands, in April 2019, a cross-sectional survey study was conducted among a large representative sample of 32,477 citizens aged 55 years and older. Respondents with a L-PDW (N = 50) were compared with respondents with a NL-PDW (N = 217) using descriptive statistics, Kruskal-Wallis tests, and Fisher's exact tests.

Results

Respondents with a L-PDW were relatively younger and less often had (step)children. They less often looked back on a good and satisfying life with many good memories and more often reported trauma. Older adults with a NL-PDW more often reported loss and bereavement. Overall, the groups showed a lot of similarities. Both groups reported a death wish diverse in nature, numerous health problems, and a variety of needs for help and support.

Conclusions

Some of the differences we found between the groups might be particularly relevant for the provision of adequate help and support to older adults with a L-PDW (i.e., their past and trauma) and to older adults with a NL-PDW (i.e., their loss and bereavement). The heterogeneity of both groups and the diverse nature of their death wish indicate that careful assessment of the death wish, its background, and underlying needs is required to provide personalized help and support to older adults with a death wish.

BACKGROUND

Death wishes occur regularly among older adults. Pooled results from 11 population studies across Europe (15,890 respondents) showed that 6% of adults aged 65 and above reported a death wish. This rate ranged from 3 to 27% across different countries (1). In the Netherlands, 4% of the adults aged between 57 and 99 years old reported a current wish to die or a weakened wish to live and 12% reported having experienced death thoughts or a death wish at some point in their lives (2).

A death wish can be described as a longing for death for oneself. If someone expresses a death wish this can have various reasons, meanings, functions, and underlying intentions (3-4). Death wishes can be both passive and active. Passive death wishes may range from the belief that life is not worth living to thoughts of or desire for death. Death wishes are deemed *active* if people have made concrete plans or taken steps regarding their death wish and/or have seriously considered attempting suicide (5-6). However, a universal and widely acknowledged definition of death wishes and suicide ideation and the distinction between both is lacking (5, 7-8).

Death wishes at an older age can originate from several reasons. Research among older adults showed that death wishes and suicidal feelings are, among others, associated with physical and mental illness (2, 9-12). However, death wishes also occur among older adults who are not (severely) ill (2). The terms “completed life” or “tiredness of life” are often used to describe death wishes of older adults whose suffering is not predominantly caused by medically classifiable conditions (13-14).

In the Netherlands, a cross-sectional survey study was conducted among a large representative sample of 32,477 citizens to gain insight into adults aged 55 years and older who developed a persistent death wish (≥1 year) while not being severely ill (PDW-NSI). This study showed that approximately 1% of the older adults had a PDW-NSI. The authors also detected a subgroup of older adults whose death wish was not specifically related to old age, since almost one in five respondents with PDW-NSI reported having had a death wish their whole lives. To our knowledge, this study was the first to describe a relatively large group of older adults with a lifelong persistent death wish (L-PDW) (6).

Death wishes often represent various ways of suffering and distress (15-18). Experiencing a death wish may increase the likelihood of engaging in suicidal behavior, especially when present from an early age (19-22). This illustrates the importance of identifying and supporting people with a death wish.

Differentiating older adults with a L-PDW from older adults who have a persistent death wish, not lifelong (NL-PDW), can be relevant for the provision of adequate help and support. We, therefore, performed a secondary explorative analysis of data that was gathered by Hartog et al. (6) in which we compared older adults with a L-PDW with older adults with a NL-PDW. The aim of this study is to gain insight into the characteristics, experiences, and needs of older adults with a L-PDW versus older adults with a NL-PDW and into the nature of their death wishes

METHODS

Study design and population

A group of people aged 55 years and older (N=32,477), representative for the Dutch population of older adults, were approached via research company Kantar Public to complete a questionnaire (23). Between April 3 and April 25, 2019, 21,294 respondents (65.6%) completed this questionnaire.

Questionnaire

The questionnaire included items about background characteristics, health and illness, the nature of the death wish, needs for help and support, aspects strengthening the death wish or wish to live, perspective on life, good memories, negative experiences or events, and life goals. For health and illness, several validated health indicators were included: the Visual Analogue Scale (VAS) to measure the current health state of the respondents with scores ranging from 0 (worst imaginable health state) to 10 (best imaginable health state). The EuroQol EQ-5D-5L was used to measure the health state on five different domains: mobility, selfcare, daily activities, pain, and mood. Sum scores range from 5 to 25 and higher scores indicate more severe problems (24). The Depression subscale of the Hospital Anxiety and Depression Scale (HADS), which was used to assess the probability of a depression, ranges from 0 to 21. Higher sum scores are related to a possible indication for a severe depression (25). Respondents were asked whether they (had) suffered from a life-threatening disease. Further, they were asked to select the diseases, complaints, and medications that applied to them from a list and to report the burden of these diseases and complaints using a 10-point scale ranging from 1 (“very little”) to 10 (“very much”).

The nature of the death wish was captured by assessing the duration, respondents’ characterization of the death wish, the frequency of thinking about it, and the (relative) strength and alternation of the death wish and wish to live. Furthermore, respondents were asked whether they had made concrete plans or taken steps concerning their death wishes, had considered or attempted suicide in the past year, and had communicated about their death wishes.

Needs for help and support were assessed and compared by means of a list of response options in which respondents could select multiple needs. The same holds for many items displayed in the tables in the addendum: respondents could select multiple answers from a list to indicate their diseases, complaints, and medications; aspects strengthening the death wish or wish to live; good memories; and negative experiences or events. To describe their perspectives on life and life goals, respondents indicated the extent to which an answer applied to them by means of 7-point Likert scales.

For a full description of the questionnaire, see van Wijngaarden et al. (26).

Participants

The questionnaire included a differentiation question to select the group of interest from the total group of respondents: does the description ‘seeing no future for oneself, longing for death, while not being severely ill’ apply to you at this moment? This differentiation question was based on the descriptions of “completed life” and “tiredness of life” as used in literature (13-14). Having a death wish was operationalized as a “longing for death” for oneself (6).

After selecting respondents who answered the differentiation question affirmatively, three additional inclusion criteria were applied. Respondents who 1) reported no severe health problems (VAS score≥4 and EQ-5D sum score<17), 2) showed no indication for severe depression (HADS depression subscale sum score<16), and 3) reported having a persistent death wish for 1 year or longer (PDW) were selected. This resulted in the group of interest of N=267 (1.25% of the total response). For the current analysis, these respondents were divided into two groups. Respondents who selected “Basically my entire life” as answer to the question “How long have you had a wish to be dead?”, were classified as the lifelong (L)-PDW group; respondents who selected either “For several years” or “About one year”, were classified as respondents with a persistent death wish, not lifelong (NL)-PDW.

Data analysis

In this paper we present descriptive statistics, including frequencies (percentages) and medians (with interquartile range). The two groups were compared using either Kruskal–Wallis tests for ordinal variables or Fisher’s exact tests for nominal variables. Since this is an explorative study for which we did not formulate hypotheses, we did not apply statistical corrections for multiple comparisons. Statistical significance was determined using 0.05-level two-sided tests. All analyses were performed using SPSS software, version 26.0.0.1.

For a more extensive description of the methodology of the primary study, see Hartog et al. (6).

RESULTS

Respondents with a lifelong persistent death wish (L-PDW: *N*=50) were compared with respondents with a persistent death wish, not lifelong (NL-PDW: *N*=217). In the NL-PDW group, *N*=49 (23%) indicated having had a death wish for about one year and *N*=168 (77%) for several years.

Table 1 shows the background characteristics of all respondents. Respondents in the L-PDW group were significantly younger: their median age was 62 years compared with 67 years for respondents with a NL-PDW (*P*<0.001 Kruskal–Wallis test). In addition, they significantly less often had (step)children (38% vs 17% had no (step) children, *P*=0.001 Fisher's exact test).

Table 2 provides information about the health and illness of respondents in the L-PDW and NL-PDW groups. None of these health and illness parameters differed significantly between groups. **Additional table 1** describes the occurrence of certain diseases and complaints in these groups and their use of certain medications. This table shows, for example, that hearing and vision problems were significantly more often reported by respondents with a NL-PDW compared with those with a L-PDW (*P*=0.003 and *P*=0.025, respectively Fisher's exact tests).

Results regarding the nature of the death wish are presented in **Table 3**. The characterization of the death wish differed significantly between the two groups (*P*=0.025 Fisher's exact test). In addition, respondents with a NL-PDW indicated a significantly stronger death wish in the past week (*P*=0.046 Kruskal–Wallis test). The groups did not differ significantly in terms of having made concrete plans or taken steps concerning the death wish, or in terms of having seriously considered attempting suicide. Of the respondents who ever considered attempting suicide, three (all from the NL-PDW group) attempted suicide in the past 12 months. With regard to communication about the death wish, the L-PDW group had significantly more often discussed the death wish than the NL-PDW group (24% vs 42% respectively had not discussed the death wish, *P*=0.024 Fisher's exact test).

TABLE 1. Background characteristics

	L-PDW (N=50) N (%)	**NL-PDW (N=217)** N (%)	**P-value**
Gender			
Female	33 (66)	116 (53)	0.117 (F)
Male	17 (34)	101 (47)	
Age (years)			
Median (Q1-Q3)	62 (58-68)	67 (61-75)	**0.000** (K)
55-59	19 (38)	39 (18)	
60-64	14 (28)	52 (24)	
65-69	7 (14)	39 (18)	
70-74	9 (18)	32 (15)	
75-79	0 (0)	32 (15)	
80+	1 (2)	23 (11)	
Educational attainment[a]			
Low	16 (32)	82 (38)	0.108 (K)
Middle	14 (28)	83 (38)	
High	19 (38)	50 (23)	
Worldview[b]			
Religious worldview	21 (40)	85 (37)	0.750 (F)
Non-religious worldview	15 (29)	66 (29)	1.000 (F)
No worldview	15 (29)	70 (30)	0.867 (F)
Worldview, religiousness unknown	1 (2)	10 (4)	0.695 (F)
(Step)Children[c]			
No	19 (38)	37 (17)	**0.001** (F)
Yes	19 (38)	131 (60)	
Household size			
Living alone	29 (58)	110 (51)	0.433 (F)
Living not alone	21 (42)	107 (49)	
Social class[d]			
Low	24 (48)	118 (54)	0.278 (K)
Middle	8 (16)	30 (14)	
High	18 (36)	69 (32)	
Urbanization[e]			
Very high	19 (38)	58 (27)	0.180 (K)
High	13 (26)	70 (32)	
Moderate	9 (18)	36 (17)	
Low/none	9 (18)	53 (24)	

Results are presented as N (%) unless "Median (Q1-Q3)" is reported.
Percentages may not add up to 100% because of rounding.
Medians are reported with 25th-75th percentiles.
Statistically significant results (p < 0.05) are in bold. P-values determined by Fisher's exact tests are indicated with (F) and P-values determined by Kruskal-Wallis tests with (K).

[a] Low= lower vocational education, lower secondary education, or lower. Middle= intermediate vocational education or higher secondary education. High= higher vocational education or university. N=1 and N=2 respectively selected "I do not know/want to answer". This category was not included in the test.

[b] Religious worldview= Protestant, Catholic, Muslim, Jewish, Hindu and Buddhist. Non-religious worldview= atheist, agnostic, "spiritual but not religious", humanist, anthroposophical and esoteric. Worldview, religiousness unknown= other worldview. Respondents could give more than one answer and may thus be counted in more than one category. Therefore, N=52 and N=231 respectively and percentages are based on these numbers. In group comparisons, worldview is tested with separate tests for each category (yes/no).

[c] N=12 and N=49 respectively are missing.

[d] Based upon the educational attainment and profession of the main breadwinner in the household.

[e] Very high= >2,500, high= 1,500-2,500, moderate= 1,000-1,500, low/none= <1,000 addresses per km^2.

TABLE 2. Health and illness

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Current health state VAS			
Median (Q1-Q3)	7 (6-7)	6 (5-7)	0.512 (K)
EQ-5D-5L sum score			
Median (Q1-Q3)	10 (8-12)	10 (8-13)	0.505 (K)
HADS depression subscale, sum score			
Median (Q1-Q3)	10 (4-12)	10 (7-12)	0.204 (K)
Life-threatening disease			
Never	40 (80)	159 (73)	0.472 (F)
Yes, but not anymore	9 (18)	43 (20)	
Yes, at this moment	1 (2)	15 (7)	
Number of current diseases[a]			
None	4 (8)	21 (10)	1.000 (F)
Median (Q1-Q3)	2 (1-3)	2 (1-3)	0.810 (K)
Burden of current diseases			
Median (Q1-Q3)	7 (5-8)	7 (5-8)	0.827 (K)
Number of current complaints[a]			
None	2 (4)	6 (3)	0.646 (F)
Median (Q1-Q3)	4 (2-6)	5 (3-7)	0.135 (K)
Burden of current complaints			
Median (Q1-Q3)	7 (5-7)	6 (5-7)	0.493 (K)
Number of medications[a]			
None	15 (30)	39 (18)	0.077 (F)
Median (Q1-Q3)	3 (2-4)	2 (1-4)	0.448 (K)

Results are presented as N (%) unless "Median (Q1-Q3)" is reported.
Percentages may not add up to 100% because of rounding.
Medians are reported with 25th-75th percentiles.
Statistically significant results (*p* < 0.05) are in bold. P-values determined by Fisher's exact tests are indicated with (F) and P-values determined by Kruskal-Wallis tests with (K).
[a] Listed in additional table 1.

TABLE 3. Nature of the death wish

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Characterization of the death wish			
A desire for a natural death that just happens	13 (26)	37 (17)	**0.025**
A desire to not wake up tomorrow and die in my sleep	20 (40)	118 (54)	
I feel my current situation is unlivable	1 (2)	10 (5)	
A wish to end my life myself	10 (20)	19 (9)	
A wish for someone to help me end my life[a]	1 (2)	21 (10)	
I do not know	5 (10)	12 (6)	

TABLE 3. Continued.

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Frequency of thinking about the death wish			
Rarely	11 (22)	19 (9)	0.111
Every month	5 (10)	21 (10)	
Every week	12 (24)	46 (21)	
Every day	3 (6)	31 (14)	
All the time	1 (2)	5 (2)	
It varies, sometimes frequently, sometimes not very often	18 (36)	95 (44)	
Strength of the death wish in the past week			
Median (Q1-Q3)	5 (2-6)	5 (3-7)	**0.046**
Strength of the wish to live in the past week			
Median (Q1-Q3)	5 (3-7)	5 (3-6)	0.938
Relative strength of the death wish and the wish to live in the past week			
The wish to live was stronger	21 (42)	74 (34)	0.467
About the same	19 (38)	102 (47)	
The death wish was stronger	10 (20)	41 (19)	
Alternation between the death wish and the wish to live			
In my case the death wish is always stronger	7 (14)	40 (18)	0.572
In my case the wish to live is always stronger	7 (14)	21 (10)	
Some periods my wish to live is stronger, at other times my death wish is dominant	36 (72)	156 (72)	
Having made concrete plans/taken steps concerning the death wish			
No	42 (84)	174 (80)	0.690
Yes	8 (16)	43 (20)	
Having seriously considered attempting suicide in the past 12 months[b]			
Never	23 (46)	90 (42)	0.749
Ever	25 (50)	110 (51)	
Having made a suicide attempt in the past 12 months[c]			
Yes	0 (0)	3 (1)	0.507
No	25 (50)	100 (46)	
Communication about the death wish			
No, I have not discussed it with anyone	12 (24)	91 (42)	**0.024**
Yes, with my spouse/partner	15 (30)	42 (19)	0.124
Yes, with (a) sibling(s)	4 (8)	18 (8)	1.000
Yes, with (a) friend(s)	13 (26)	34 (16)	0.099
Yes, with my child(ren) and grandchild(ren)	2 (4)	34 (16)	**0.036**
Yes, with my doctor and/or other healthcare professionals	11 (22)	66 (30)	0.299
Other	6 (12)	6 (3)	**0.012**

Results are presented as N (%) unless “Median (Q1-Q3)” is reported.
Percentages may not add up to 100% because of rounding. Percentages reported for the variable “Communication about the death wish” add up to more than 100% because respondents could select multiple ways of communication.
Medians are reported with 25th-75th percentiles.
Statistically significant results ($p < 0.05$) are in bold. All were determined by Fisher’s exact tests, except for the two variables “Strength of the death wish in the past week” and “Strength of the wish to live in the past week” (Kruskal-Wallis tests).

[a] Someone may include a doctor, another professional or someone close.

[b] N=2 and N=17 respectively selected “Not willing to answer”.

[c] N=0 and N=7 respectively selected “Not willing to answer”. Only the respondents who selected “Ever” on the item “Having seriously considered attempting suicide in the past 12 months” (N=25 and N=110 respectively) were asked whether they had actually attempted suicide in the past 12 months.

Table 4 presents the needs for help and support that were indicated by the respondents. The groups did not differ significantly in terms of their needs: both groups most often reported a need to have access to a suicide drug, followed by acknowledgment and appreciation of their feelings, assistance from a doctor to commit suicide, and more financial leeway.

Additional table 2 shows aspects strengthening the death wish or wish to live. The NL-PDW group significantly more often chose "Loss of my loved ones (e.g., through death, divorce)" as an aspect strengthening their death wishes and "Good memories (e.g., of the past)" as an aspect strengthening their wishes to live. The L-PDW group significantly more often chose "Sense that I am part of a larger whole" as an aspect strengthening their wishes to live.

Respondents' perspective on life, good memories, negative experiences or events, and life goals are presented in **Additional tables 3,4,5,6**. Concerning perspective on life, respondents with a NL-PDW significantly more strongly indicated having had a good life, being satisfied with their lives, having good memories, worrying about their partners' or (grand)children's future, preferring not to have to experience the future, and becoming increasingly dependent on others. Those with a L-PDW on the other hand significantly more strongly indicated being able to take care of themselves. As negative experiences or events, respondents in the L-PDW group significantly more often indicated a trauma and respondents in the NL-PDW group loss or bereavement.

TABLE 4. Needs for help and support

	L-PDW (N=50) N (%)	**NL-PDW (N=217)** N (%)	**P-value**
Needs concerning ending one's life			
Assistance from a doctor to commit suicide	8 (16)	60 (28)	0.106
Assistance from another professional or someone close to commit suicide	2 (4)	28 (13)	0.084
Access to a suicide drug	27 (54)	98 (45)	0.275
Information or support to stop eating and drinking	0 (0)	14 (7)	0.079
Social needs			
More social contacts	9 (18)	35 (16)	0.833
Better/more contact with my (grand)children/relatives	8 (16)	28 (13)	0.646
Acknowledgment and appreciation of my feelings	14 (28)	50 (23)	0.466
Good conversations with other older persons/others in the same situation	7 (14)	28 (13)	0.818
Good conversations with a professional (e.g., GP, psychologist, or spiritual counsellor)	8 (16)	41 (19)	0.839
Needs for activities			
Meaningful activities	4 (8)	27 (12)	0.469
Meaningful volunteer work	4 (8)	11 (5)	0.492
Opportunities to carry out my hobbies	3 (6)	11 (5)	0.730

TABLE 4. Continued.

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Needs for care and guidance			
Meditation or mindfulness training	4 (8)	14 (7)	0.754
More/better professional care and support (e.g., mental or physical)	7 (14)	28 (13)	0.818
Better fine-tuning of medications	4 (8)	28 (13)	0.470
Needs for practical or material things			
More financial leeway	11 (22)	40 (18)	0.554
Another place to live	4 (8)	18 (8)	1.000
Better access to transportation (e.g., public transportation, regional taxi, senior transportation service)	4 (8)	11 (5)	0.492
Other			
Other than above[a]	3 (6)	9 (4)	0.703
I do not know	3 (6)	10 (5)	0.715
No need for support or assistance	5 (10)	25 (12)	1.000

Results are presented as N (%).
Percentages add up to more than 100% because respondents could select multiple needs.
Statistically significant results ($p < 0.05$) are in bold. All were determined by Fisher's exact tests.
[a] Including being left alone, support in housekeeping, finding a life partner, overcome fears, and to be released of the pressure of providing informal care.

DISCUSSION

About one-fifth of the older adults with a persistent death wish without being severely ill, reported having had a death wish their whole lives. This study aimed to explore potential differences between older adults with a lifelong persistent death wish (L-PDW) and older adults who developed a persistent death wish later in life (NL-PDW). In general, the groups were largely similar. Both groups were heterogeneous and the nature of their death wishes was diverse. Some differences were found with regard to background characteristics, the nature of the death wish, physical complaints, aspects strengthening the death wish or wish to live, perspective on life, and negative experiences or events.

Those with a L-PDW were relatively younger older adults compared with those with a NL-PDW. The fact that they more often reported being able to take care of themselves and less frequently mentioned loss or bereavement as negative experience or event may be associated with this age difference. The age difference may be caused by more suicide deaths in the L-PDW group. After all, especially when the death wish developed at a young age, desire for death is an important risk factor for suicide attempts (22). However, no one in the L-PDW group attempted suicide in the past year, yet three older adults with a NL-PDW did. This may indicate more active death wishes in the NL-PDW group, though this was not represented in a significant difference. There were also no significant differences between both groups in terms of having made other concrete plans or having taken steps concerning the death wish and having seriously considered attempting suicide in the past year. Altogether, these findings suggest no difference between both groups in how active their death wishes are. In both groups the majority had not made concrete plans or taken steps concerning the death wish and approximately half had not seriously considered suicide in the past year, which points towards the existence of both passive and active death wishes in the two groups. Our results further indicate that a longer duration of the death wish does not necessarily result in a stronger death wish. In fact, the NL-PDW group reported a stronger death wish in the past week and a stronger preference not to have to experience the future.

Older adults with a L-PDW less often looked back on a good and satisfying life with many good memories than older adults with a NL-PDW. They more often reported trauma. Previous research describes links between trauma and adverse childhood experiences, developing a death wish, chronic suicidal thinking, a depressed affect, and mental disorders such as mood and anxiety disorders, posttraumatic stress disorder, and substance use disorders (27-32). In an interview study of Rurup et al. about wishes to die among older people, of the 31 included interviewees, four reported serious thoughts about death from a very early age. These four respondents related their death wish to traumatic experiences that happened at early age, such as (sexual) abuse or being imprisoned in a Japanese concentration camp. They reported that their death wish remained present throughout their lives, sometimes in the background, but could become more pronounced after experiencing negative life events, like the death of their spouses (31).

Despite these findings of a more troubled past and trauma among older adults with a L-PDW and the specific mental disorders associated with those (32-33), we did not find differences in terms of mental illness and associated medications between the groups L-PDW and NL-PDW. Approximately half of both groups reported mood or anxiety problems and depression or depressive feelings, and their HADS depression subscale sum scores were similar. Although just above the cutoff point for statistical significance, the L-PDW group more often used antidepressants (43%) than the NL-PDW group (29%), which may indicate differences in their mental health states.

The fact that we also found mood or anxiety problems and depression or depressive feelings among older adults with a NL-PDW may be related to their reports of loss and bereavement. Half of the older adults with a NL-PDW reported "Loss of my loved ones (e.g., through death, divorce)" as an aspect strengthening their death wishes and they more often indicated loss or bereavement as negative experience or event than older adults with a L-PDW. Bereavement is related to various psychological reactions, such as anxiety and depressive symptoms, and to an increased mortality risk from diverse causes, including suicide. While most people recover from loss over time, for others bereavement can be long-lasting and recovery may take months or even years (34). Death or divorce of one's partner can be a trigger for developing a death wish, for example, because life can be experienced as not worth living without one's partner (31).

Strengths and limitations with recommendations for future research

To our knowledge, this study is the first to describe many aspects of a L-PDW among older adults without severe illness. It provides explorative insight into the similarities and differences between older adults with a L-PDW and older adults with a NL-PDW. Future research into death wishes can build on this knowledge.

In this study, we focused on differences that were *statistically* significant. This does not necessarily mean that any of the other results which did not reach statistical significance do not differ in real world samples of older adults with L-PDW and NL-PDW. Despite the initial large total group of respondents (*N*=21,294), the group of 50 respondents with a L-PDW can be considered small for statistical analyses. This may have led to underreporting of differences; i.e., real-world differences that did not appear in this study. Second, differentiating L-PDW from NL-PDW was based upon respondents' self-reported response to the item "How long have you had a wish to be dead?". The response was not validated with an open answer option, so it was impossible to verify whether "lifelong" was in fact lifelong, or to provide a more meaningful estimate of the length of the respondents' death wish. Further research is needed to build on the explorative insight our study offers. Besides more larger-sampled quantitative studies, longitudinal methods and qualitative studies are advised to gain in-depth understanding of the experiences of people with lifelong death wishes, more knowledge of how these death wishes progressed during their lifetimes, and insight into associated risk factors.

Another limitation of this study concerns the findings regarding mental health. Respondents with an indication for severe depression were excluded from the study, which may have diminished differences in mental health factors between the groups. One of the groups may contain more respondents with a severe depression, however, since they were excluded, our study fails to demonstrate this. Second, besides mood or anxiety problems and depression or depressive feelings, no other mental disorders or complaints were assessed. It could be that one of the groups contains more respondents with mental illness we did not measure. Future studies are recommended to include more mental health parameters; this can yield important insights for the provision of adequate help and support to older adults with both L-PDW and NL-PDW.

Implications for (clinical) practice

Our study offers several relevant insights for (clinical) practice. First, the fact that even though the majority of both groups discussed their death wishes, only a small proportion shared it with a healthcare professional. Stigma is a commonly reported barrier for disclosing suicide related thoughts. A recent qualitative study described how participants experienced stigma in response to disclosing such thoughts. They, for instance, lost their jobs or the support of friends and family members. Healthcare was also a source of stigma where prejudice and discrimination occurred, including experiences of participants with healthcare professionals who did not want to treat them after disclosing previous suicidality (35).

Second, while only a small proportion of both groups discussed their death wishes with a healthcare professional, the large majority in both groups reported needs for help and support, among others, from healthcare professionals. Because studies have shown that patients are unlikely to disclose suicidal ideation to their healthcare providers unsolicitedly (36), healthcare professionals are advised to actively inquire about death wishes among older adults. Besides facilitating identification of older adults with a death wish, this can also serve as a first step towards an open conversation about the death wish and an exploration of its background and underlying needs. This may enable a personalized approach to help and support, which is recommended given the heterogeneity of both groups and the diverse nature of their death wishes.

Third, our study raises the question whether particularly older adults with a L-PDW may, in some cases, benefit from help and support directed towards coping with their past and trauma and whether particularly older adults with a NL-PDW may, in some cases, benefit from help and support directed towards coping with their loss and bereavement. Furthermore, in addition to the mental health problems described above, both groups reported physical health problems, such as joint problems, neck or back problems, overweight or obesity, chronic pain, and sleeping problems. Regarding physical health problems, the NL-PDW group more often reported hearing and vision problems than the L-PDW group, which may be related to their relatively older age. Providing help and support to, where possible, relieve (age-related) physical and mental health problems, may potentially also positively influences their death wishes. Specifically, because approximately half of both groups indicated diseases and physical or mental deterioration as aspects strengthening the death wish.

Lastly, almost nine out of ten respondents from both groups reported at least one need for help and support. They not only reported needs concerning the help and support of healthcare professionals. For example, the needs for acknowledgment and appreciation of their feelings and more financial leeway suggest that besides the formal care network, the social environment and society at large can play a role in meeting the needs of older adults with a death wish. The social environment of these older adults may be small though, since they frequently mentioned the loss of loved ones, not having enough good social contacts, and not having (step)children. Besides, also here, communication barriers may exist, as part of the older adults in our study did not communicate about their death wishes with anyone and indicated to feel like being a burden to others.

CONCLUSIONS

In conclusion, our study shows some differences between older adults with a lifelong persistent death wish and older adults who developed a persistent death wish later in life, with potential opportunities for providing them with adequate help and support. Overall the two groups are similar in terms of reporting a variety of characteristics, experiences, and needs. The heterogeneity of both groups and the diverse nature of their death wishes indicate that careful assessment of the death wish, its background, and underlying needs is required to provide personalized help and support. Besides the formal care network, the social environment and society at large can play a role in meeting the needs of older adults with a death wish, perhaps relieving their death wish.

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ADDITIONAL FILES

ADDITIONAL TABLE 1. Diseases, complaints, and medications

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Diseases			
Joint problems (e.g., arthritis, gout, rheumatism)	18 (36)	92 (42)	0.430
Neck or back problems	20 (40)	90 (42)	0.875
Bone decalcification (e.g., osteoporosis)	2 (4)	27 (12)	0.127
Diabetes	8 (16)	33 (15)	0.831
Tightness of the chest (e.g., COPD, asthma)	9 (18)	37 (17)	0.838
Crohn's disease	3 (6)	3 (1)	0.082
MS/ALS	1 (2)	3 (1)	0.566
Skin disease	4 (8)	11 (5)	0.492
Thyroid problems	5 (10)	22 (10)	1.000
Heart failure/heart disease	4 (8)	31 (14)	0.351
Consequences of a cerebral infarction/brain hemorrhage	2 (4)	11 (5)	1.000
Dementia	2 (4)	6 (3)	0.646
Parkinson's disease	1 (2)	2 (1)	0.465
Cancer	1 (2)	11 (5)	0.475
Psychological complaints (mood or anxiety problems, depression)	27 (54)	91 (42)	0.155
Other	9 (18)	29 (13)	0.377
None of these	4 (8)	21 (10)	1.000
Complaints			
Hearing problems or deafness, tinnitus	8 (16)	83 (38)	**0.003**
Eye problems and visual impairment	8 (16)	69 (32)	**0.025**
Memory problems	10 (20)	67 (31)	0.166
Difficulty speaking	2 (4)	5 (2)	0.619
Headache	13 (26)	53 (24)	0.856
Sleep problems	23 (46)	104 (48)	0.876
Falls (or fear of falling)	4 (8)	43 (20)	0.062
Problems walking	18 (36)	83 (38)	0.872
Dizziness	15 (30)	47 (22)	0.264
Problems with particular movements	13 (26)	77 (36)	0.246
Depression (depressive feelings)	28 (56)	125 (58)	0.875
Lack of appetite	5 (10)	26 (12)	0.810
Overweight, obesity	15 (30)	65 (30)	1.000
Incontinence (urinary or bowel)	4 (8)	19 (9)	1.000
Obstipation, hard/slow bowel movement	11 (22)	17 (8)	**0.008**
Impotence	3 (6)	28 (13)	0.223
Loss of sense of smell or taste	2 (4)	18 (8)	0.385
Chronic itching (for example due to dry skin)	5 (10)	24 (11)	1.000
Bedsores	1 (2)	2 (1)	0.465
Extreme/chronic fatigue	16 (32)	60 (28)	0.602
(Chronic) pain	16 (32)	74 (34)	0.869
Other	1 (2)	27 (12)	**0.037**
None of these	2 (4)	6 (3)	0.646

ADDITIONAL TABLE 1. Continued.

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Medications[a]			
Antidepressants	15 (43)	52 (29)	0.117
Tranquillizers	4 (11)	13 (7)	0.491
Sleeping pills	8 (23)	36 (20)	0.819
Pain killers	15 (43)	76 (43)	1.000
Blood thinners	9 (26)	61 (34)	0.431
Anti-hypertensives	15 (43)	81 (46)	0.853
Anti-inflammatories	5 (14)	31 (17)	0.807
Blood sugar medication	9 (26)	26 (15)	0.132
Thyroid medication	7 (20)	21 (12)	0.183
Lung medication	9 (26)	26 (15)	0.132
Prostate medication	1 (3)	7 (4)	1.000
Other	6 (17)	37 (21)	0.818
None of these medications	0 (0)	2 (1)	1.000

Results are presented as N (%).
Percentages add up to more than 100% because respondents could select multiple diseases, complaints, and medications.
Statistically significant results ($p < 0.05$) are in bold. All were determined by Fisher's exact tests.
[a] N=35 and N=178 because respondents who reported not using any medications were not asked to list their medications.

ADDITIONAL TABLE 2. Aspects strengthening the death wish or wish to live

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Aspects strengthening the death wish			
Diseases	22 (44)	108 (50)	0.128
Physical or mental deterioration	23 (46)	117 (54)	0.340
Increasing problems walking or with other movements	18 (36)	88 (41)	0.504
Limitation of my freedom	21 (42)	90 (42)	0.854
Being dependent on others	17 (34)	90 (42)	0.546
Sense of having little to no influence on my life	32 (64)	116 (54)	0.387
Feeling like I am a burden to others	19 (38)	86 (40)	0.970
Not enough good social contacts	22 (44)	97 (45)	0.247
Loss of my loved ones (e.g., through death, divorce)	12 (24)	109 (50)	**0.002**
Tension or arguments with people in my immediate environment	15 (30)	60 (28)	0.918
Loneliness	25 (50)	116 (54)	0.202
Not enough social activities	21 (42)	92 (42)	0.709
Loss (or lack) of status	5 (10)	29 (13)	0.365
Loss (or lack) of self-respect	26 (52)	73 (34)	0.062
No (or limited) future perspective	32 (64)	147 (68)	0.614
Boredom	11 (22)	53 (24)	0.627
Worrying	30 (60)	143 (66)	0.623
Bad memories (e.g., of traumatic experiences)	17 (34)	85 (39)	0.139

ADDITIONAL TABLE 2. Continued.

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Move that is disappointing/turns out badly	5 (10)	18 (8)	0.810
Financial problems	16 (32)	54 (25)	0.596
Time of year	12 (24)	46 (21)	0.427
Something else	13 (26)	33 (15)	0.174
Aspects strengthening the wish to live			
Independence	31 (62)	144 (66)	0.760
Sense of freedom	33 (66)	118 (54)	0.382
Good social contacts, friendship	21 (42)	108 (50)	0.478
Sense of being connected to other people	22 (44)	99 (46)	0.899
Comfortable living conditions (nice house, nice neighborhood)	33 (66)	146 (67)	0.217
Meaningful social activities	21 (42)	81 (37)	0.852
Volunteer work	10 (20)	56 (26)	0.332
Social engagement	17 (34)	72 (33)	0.910
Taking care of others	26 (52)	102 (47)	0.690
Making a difference for others	31 (62)	124 (57)	0.788
Feeling that I mean as much to the people around me as they do to me	18 (36)	91 (42)	0.412
Feeling useful	26 (52)	95 (44)	0.539
Sense of self-worth	25 (50)	100 (46)	0.843
Sense of self-respect	22 (44)	96 (44)	1.000
Being respected and appreciated by others	23 (46)	110 (51)	0.829
Good care	15 (30)	79 (36)	0.673
Good memories (e.g., of the past)	14 (28)	114 (53)	**0.005**
Humor, fun	34 (68)	115 (53)	0.168
Playing or watching sports	10 (20)	47 (22)	0.719
Sense that I am a part of a community	13 (26)	55 (25)	0.781
Sense that I am part of a larger whole	15 (30)	44 (20)	**0.029**
My worldview	12 (24)	53 (24)	0.919
My faith in God	5 (10)	36 (17)	0.534
The time of year/the season	17 (34)	64 (30)	0.113
Peace	31 (62)	136 (63)	0.425
Something else	8 (16)	25 (12)	0.204

Results are presented as N (%).
Percentages add up to more than 100% because respondents could select multiple aspects.
Statistically significant results (p < 0.05) are in bold. All were determined by Fisher's exact tests.

ADDITIONAL TABLE 3. Perspective on life

	L-PDW (N=50) N (%)	NL-PDW (N=217) N (%)	P-value
Looking back			
I have had a good life	4 (3-6)	5 (4-6)	**0.001**
I have been mostly satisfied with my life	4 (2-6)	5 (4-6)	**0.002**
I have many good memories	4 (3-6)	5 (4-7)	**0.000**
I remember many negative experiences/events	5 (4-6)	5 (4-6)	0.762
Current situation			
Finding life worthwhile at this moment			
Yes	29 (58)	102 (47)	0.209
No	21 (42)	115 (53)	
I often feel lonely	4 (2-6)	5 (3-6)	0.154
People close to me need me	3 (2-5)	4 (3-5)	0.071
I am happy with my social contacts	4 (3-5)	4 (3-5)	0.837
I am attached to my pet(s)	6 (3-5)	5 (2-7)	0.068
I experience support from God/a higher power	1 (1-4)	1 (1-4)	0.971
There are plenty of things that make my life worthwhile	3 (2-5)	4 (3-5)	0.583
I contribute to society	4 (2-5)	4 (2-5)	0.455
As I grow older, I am appreciated less	4 (3-6)	4 (3-6)	0.501
I have sufficient opportunities to develop myself	4 (3-6)	4 (3-5)	0.120
I am able to do what suits me	4 (3-6)	4 (3-6)	0.913
I enjoy the everyday things	4 (3-5)	4 (3-5)	0.482
I am often bored	2 (1-4)	3 (2-5)	0.371
The burden of life weighs me down	5 (3-6)	5 (4-6)	0.387
I am afraid I will forget more and more	4 (2-6)	4 (2-6)	0.259
I regret things I did or neglected to do	4 (2-6)	4 (3-6)	0.155
I can take care of myself	6 (5-7)	5 (4-6)	**0.016**
I am becoming increasingly dependent on others	2 (1-5)	4 (2-5)	**0.013**
I have increasing doubts about my intellectual abilities	2 (1-4)	2 (1-4)	0.194
Care provided by others is an invasion of my privacy	4 (2-6)	4 (3-5)	0.768
In my life many things have happened that I had no say in	5 (4-7)	5 (4-6)	0.788
As I grow older, I feel I can be myself more and more	4 (3-6)	4 (3-5)	0.305
Looking at the future			
I worry about my own future	4 (3-6)	5 (3-6)	0.053
I worry about my partner's or (grand)children's future	3 (1-6)	5 (3-6)	**0.002**
I am curious to see what the future holds for me	3 (1-5)	3 (2-5)	0.086
I would prefer not to have to experience the future	5 (3-6)	5 (4-6)	**0.039**
Things can only go downhill as I grow older	5 (4-6)	6 (5-7)	0.086
I live by the day and I do not think about the future	5 (3-6)	5 (4-6)	0.727

Results are presented as Median (Q1-Q3) except for the variable
"Finding life worthwhile at this moment", which is presented as N (%).
Medians are reported with 25th-75th percentiles.
Statistically significant results ($p < 0.05$) are in bold. All were determined by Kruskal-Wallis tests, except for the variable "Current situation" (Fisher's exact test).
Except for the variable "Finding life worthwhile at this moment" respondents gave answers about their perspectives on life on a 7-point Likert scale. For the variable "Looking back" this scale ranged from 1 ("Totally disagree") to 7 ("Strongly agree") and for the other variables from 1 ("Not at all") to 7 ("Very strong"). Respondents also had the option to answer "I do not know" (this answer is left out of the presentation of Medians (Q1-Q3) and not included in the tests).

ADDITIONAL TABLE 4. Good memories

	L-PDW (N=17)[a] N (%)	**NL-PDW (N=154)[a]** N (%)	**P-value**
Happy memories with loved ones (like a birth, wedding day, family Christmas)	9 (53)	98 (64)	0.434
Successful moments (like graduation, promotion, being decorated, retirement, an anniversary)	3 (18)	18 (12)	0.443
A happy marriage/a happy relationship	9 (53)	77 (50)	1.000
Important achievements in my work	1 (6)	30 (19)	0.316
Moments that I was of significance to others	7 (41)	48 (31)	0.420
Sport achievements	0 (0)	8 (5)	1.000
Great vacations or travels	9 (53)	86 (56)	1.000
Healing/recovery from severe illness	1 (6)	23 (15)	0.473
Other	3 (18)	7 (5)	0.063

Results are presented as N (%).
Percentages add up to more than 100% because respondents could select multiple good memories.
Statistically significant results (*p* < 0.05) are in bold. All were determined by Fisher's exact tests.
[a] N=17 instead of 50 and N=154 instead of 217 respectively because only the respondents who had a score of 5 or higher on "I have many good memories" in table S3 were asked to list their good memories. Percentages in table S4 are based on N=17 and N=154.

ADDITIONAL TABLE 5. Negative experiences or events

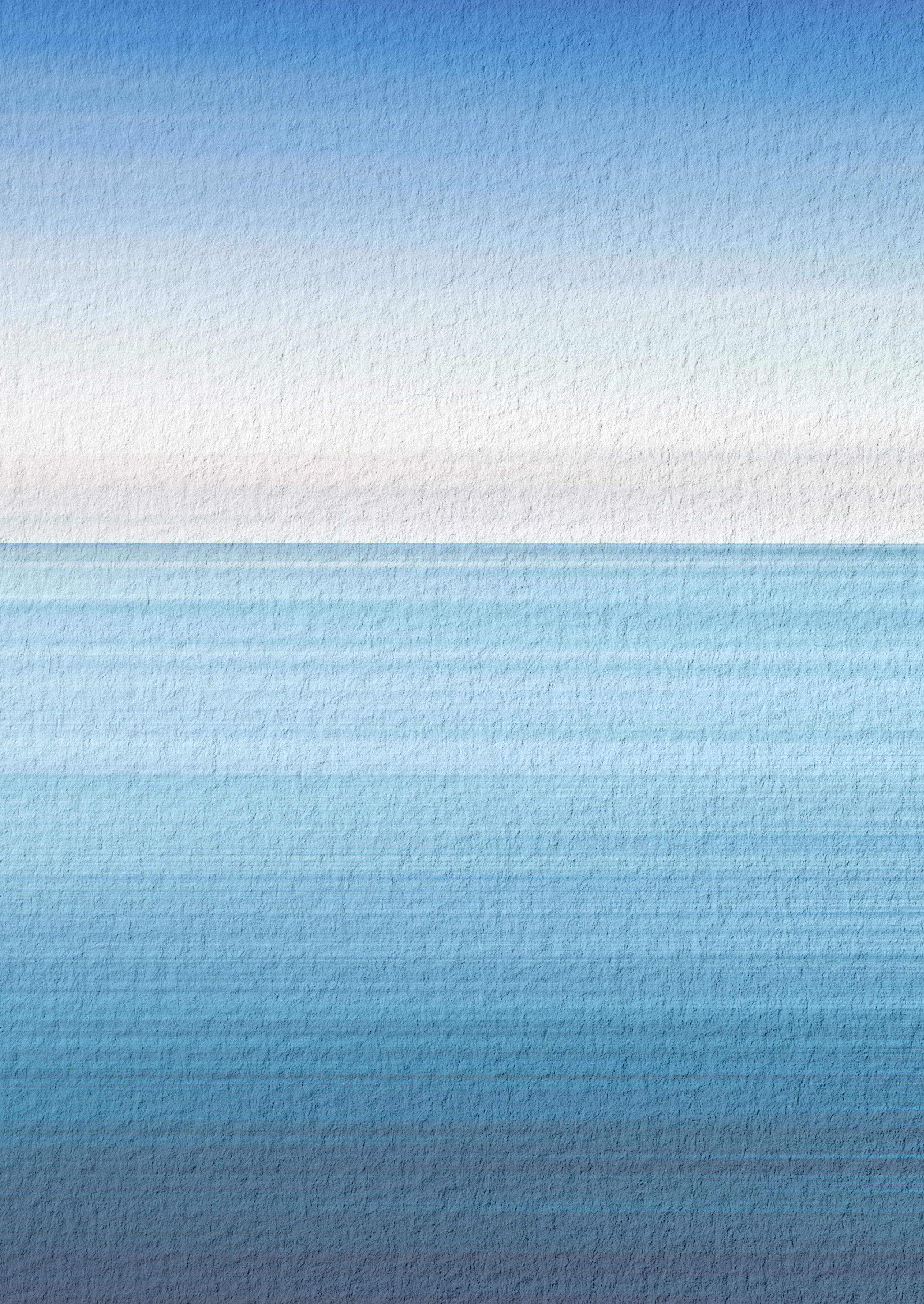
	L-PDW (N=30)[a] N (%)	**NL-PDW (N=138)[a]** N (%)	**P-value**
Dismissal or unemployment	3 (10)	11 (8)	0.718
Failed career	4 (13)	8 (6)	0.230
Tensions or conflicts with my loved ones (e.g., spouse/partner, children, friends)	9 (30)	38 (28)	0.824
Broken contact with relative or friend	5 (17)	23 (17)	1.000
(Forced) move	0 (0)	5 (4)	0.587
Divorce	7 (23)	25 (18)	0.608
Illness	5 (17)	39 (28)	0.253
Childlessness	3 (10)	3 (2)	0.071
Death of a loved one	5 (17)	42 (30)	0.178
Attempted suicide of a loved one	0 (0)	5 (4)	0.587
Memories of war	0 (0)	3 (2)	1.000
Bad memories from my childhood	18 (60)	57 (41)	0.071
A trauma	10 (33)	21 (15)	**0.035**
Loss or bereavement	4 (13)	50 (36)	**0.017**
Financial problems	7 (23)	31 (22)	1.000
Other	3 (10)	10 (7)	0.705

Results are presented as N (%).
Percentages add up to more than 100% because respondents could select multiple negative experiences or events. Statistically significant results (*p* < 0.05) are in bold. All were determined by Fisher's exact tests.
[a] N=30 instead of 50 and N=138 instead of 217 respectively because only the respondents who had a score of 5 or higher on "I remember many negative experiences/events" in table S3 were asked to list their negative experiences or events. Percentages in table S5 are based on N=30 and N=138.

ADDITIONAL TABLE 6. Life goals

	L-PDW (N=50) N (%)	**NL-PDW (N=217)** N (%)	**P-value**
Importance of each life goal			
Live a healthy life	5 (4-6)	5 (4-6)	0.591
Be independent/self-reliant	6 (5-7)	6 (5-7)	0.816
Be able to decide how I live my life	7 (6-7)	6 (6-7)	0.491
Be involved in the community	5 (4-6)	5 (4-6)	0.848
Be of significance to others	5 (4-6)	5 (4-6)	0.206
Achieve something in life	4 (3-5)	4 (3-5)	0.827
Take care of others	5 (3-6)	5 (4-6)	0.137
Have/maintain friendships	5 (4-6)	6 (4-6)	0.211
Do what is right for me	6 (5-7)	6 (5-7)	0.311
Self development	5 (3-6)	4 (3-6)	0.463
Be appreciated, acknowledged	5 (4-6)	5 (4-6)	0.939
Enjoy life	5 (4-7)	6 (4-7)	0.641

Results are presented as Median (Q1-Q3).
Medians are reported with 25th-75th percentiles.
Statistically significant results ($p < 0.05$) are in bold. All were determined by Kruskal-Wallis tests.
7-point Likert scale ranging from 1 (“Very unimportant”) to 7 (“Very important”).



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Requests for euthanasia or assisted suicide of people without (severe) illness

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Contribution of the author of this dissertation:
I participated in the data collection and together with VvdB I took the lead in the data analysis and the interpretation of the findings. VvdB and I collaborated in writing the first draft of the article and revising several versions based on feedback of the co-authors.

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ABSTRACT

Background

Some people request euthanasia or assisted suicide (EAS) even though they are not (severely) ill. In the Netherlands the presence of sufficient medical ground for the suffering is a strict prerequisite for EAS. The desirability of this ‘medical ground’-boundary is currently questioned. Legislation has been proposed to facilitate EAS for older persons with “completed life” or “tiredness of life” in the absence of (severe) illness.

Objectives

To describe the characteristics and motivations of persons whose requests for EAS in the absence of (severe) illness did not result in EAS and the decision-making process of medical professionals in these types of requests.

Methods

Analysis of 237 applicant records of the Dutch Euthanasia Expertise Center. We studied both the perspectives of applicants and medical professionals.

Findings

The majority of the applicants were women (73%) aged 75 years and older (79%). Applicants most often indicated physical suffering as element of suffering and reason for the request. Medical professionals indicated in 40% of the cases no or insufficient medical ground for the suffering.

Conclusions

Physical suffering plays an important role in requests for EAS even for persons who are not (severely) ill. From the presence of physical suffering it does not necessarily follow that for medical professionals there is sufficient medical ground to comply with the ‘medical ground’-boundary.

INTRODUCTION

The Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (WTL) came into force in 2002 (1). This Act holds legislation on the voluntary termination of life (euthanasia; the physician administers the lethal substances to the patient) and assisted suicide (the patient himself takes the lethal substances provided by the physician) (2). According to the WTL, a physician has to comply with six due care criteria for euthanasia or assisted suicide (EAS) to be legally permissible. One of the due care criteria is that the physician should "be satisfied that the patient's suffering is unbearable, with no prospect of improvement" (2). A specification of this due care criterion resulted from a Dutch Supreme Court ruling stating that the patient's suffering has to predominantly stem from one or more medically classifiable somatic or psychiatric diseases or conditions (2-3). Since then, case law determines that the presence of sufficient medical ground for the suffering is a strict prerequisite for EAS (2, 4).

The vast majority of requests for EAS are based on suffering from cancer or other medical diseases or conditions (5-6). Research among physicians from 2016 shows that the nature of the suffering associated with - granted or not granted - requests for EAS was cancer in 67% of the cases, another somatic illness (21%), a psychiatric illness (4%), or dementia (3%) (5). However, there are also people who wish help from a physician to end their lives while they are not (severely) ill. For instance, persons with an accumulation of health problems associated with aging (multiple geriatric syndromes) (5, 7-8) and persons who are relatively healthy but consider their lives to be "completed" or are "tired of life" (9-13).

Requests for EAS based on "completed life" or "tiredness of life" alone are in principle not granted, while a number of requests for EAS of persons who suffer from multiple geriatric syndromes are granted every year (5-8, 11-12, 14). From 2013 to 2020 between 172 and 293 cases of EAS for multiple geriatric syndromes were notified to regional review committees each year (172 was 2.7% of the total number of 6,361 notifications in 2019 and 293 was 4.4% of the total number of 6,585 notifications in 2017) (6-7). This is in line with the assumption that multiple geriatric syndromes can involve unbearable suffering without prospect of improvement based on sufficient medical ground, whereas "completed life" or "tiredness of life" in relatively healthy persons cannot (2). At the same time, far from all requests for EAS based on multiple geriatric syndromes are granted (5, 8, 14-15). This corresponds with research showing that physicians consider it less likely to grant EAS to persons with multiple geriatric syndromes compared to persons with severe illness (8, 16-17).

Currently, the desirability of the 'medical ground'-boundary is questioned (18). This is not only reflected in the establishment of a citizens' initiative and organizations that plea for widening EAS legislation but also in the highly political debate. In an effort to expand the possibility for assisted dying, a bill concerning a new legal framework, that will operate next to the existing law, has been proposed in Dutch parliament to facilitate EAS for older persons with "completed life" or "tiredness of life" who are not (severely) ill (19). The possible implications and ethical considerations of this proposal have been addressed by Florijn (4).

A well-informed debate about the 'medical ground'-boundary has been hampered by the fact that arguments for and against are mainly ideological and theoretical in nature (20-21). After all, there are only a few empirical studies available about the characteristics and motivations of specifically those persons without (severe) illness whose requests did not result in EAS and the decision-making process on these requests (8, 11-12). The studies that are available are all written from the physician's perspective only.

Hence, debate about the 'medical ground'-boundary could benefit from a study into the perspective of persons without (severe) illness who are not eligible for EAS in the current situation. In this way, arguments and future policy could be more in line with the realities of the people in question instead of being based on ideological and theoretical views only. Furthermore, the reports of medical professionals who bear the responsibility for the decision-making process on EAS in these cases are relevant for the debate. For instance, because they may point out existing difficulties and hesitations in their assessments of requests for EAS of persons without (severe) illness. It is important to take these into account since future policy also requires actors (such as medical professionals) for whom it needs to be feasible and acceptable to carry out the policy. Therefore, this paper includes both the perspectives of persons without (severe) illness who are not eligible for EAS in the current situation and medical professionals to answer the questions: what are the characteristics and motivations of persons without (severe) illness whose requests did not result in EAS? And how are these types of requests for EAS currently decided upon by medical professionals in the Netherlands?

An answer to these questions is not only relevant in the Dutch context, as also more widely in the Western world, death wishes associated with "completed life" or "tiredness of life" are increasingly encountered by medical professionals, publicly discussed, and debated in law, academia, and politics as a social issue (22-25). Moreover, there are studies suggesting the occurrence of death wishes of older persons who are not (severely) ill outside the Western world as well (26-29). Our study may provide insights relevant for other countries that wish to carefully reflect on and develop (their existing) legal options for EAS.

METHODS

We performed an analysis of applicant records of the Dutch Euthanasia Expertise Center (EEC) (30). This organization comprises a network of 140 physicians and nurses.

It originated from Right-to-Die Netherlands and its guiding principle is that everyone with a request for EAS should have the opportunity to get an assessment of their case in light of the law. This assessment is done by a team consisting of a physician and a nurse. Requests are only declined when EAS is not legally permissible. In all other cases, the physicians of EEC are willing to grant EAS. This is in contrast to other physicians who might have personal considerations to decline requests for EAS (5, 16, 31). Furthermore, EEC typically receives complex, less common requests for EAS, in which many physicians outside EEC have reservations, such as requests for EAS from persons with multiple geriatric syndromes and persons with "completed life" or "tiredness of life" who are relatively healthy (5-6, 14, 32). Because of these differences between EEC and other physicians, EEC not only seems to be a suitable place to gain insight into how limitations of law and case law are carried out in practice but also to trace specifically those cases of persons who request EAS while they are not (severely) ill.

On receipt of the request for EAS at EEC all applicant records are categorized by a medical manager and a physician based on the grounds for the request. In our study we included all requests in the category "multiple geriatric syndromes" that did not result in EAS and all requests in the category "no medical ground" from 01-01-2016 up to 28-09-2020. We only included these specific requests because of our aim to study cases of persons without (severe) illness who are currently excluded from EAS.

Data collection

The applicant records of EEC generally include an application form completed by the applicants themselves or their representative, the medical record of the applicant, and, if applicable, minutes of contact moments between the applicant and EEC, minutes of contact moments between EEC and medical professionals from outside EEC, and a letter explaining the reasons for declining the request. From these documents we extracted characteristics of the applicants and information about the motivations behind their requests. With regard to motivations, one question in the application form concerned elements of suffering. In the majority of the application forms (approximately 90%) this was a closed-ended question with a prescribed list of answer options, sometimes including the open field: "other, namely:...". In approximately 10% of the application forms this was an open-ended question. Also with regard to motivations, a second question in the application form concerned reasons for the request. This was an open-ended question in all application forms. Furthermore, with regard to the decision-making process of EEC, we gathered information concerning (number of) contacts as well as the reasons for the request not resulting in EAS. A format to arrange this information was developed by EW and GT. It consisted of the four fields general characteristics, application form, process, and decision-making. These fields were subdivided in line with the variables that are displayed in the Tables in the results section to target our search for information. Data were collected by GT, SM, SW, VB and MZ.

Data analysis

This study is an example of a document analysis in which elements of content analysis and thematic analysis are combined (33). We (VB and MZ) used inductive coding to organize the data in categories. As the content analysis part of the document analysis allowed to quantify the data, we entered the categorization of each applicant record in SPSS Statistics 26.0.0.1 (34). For the thematic analysis part of the document analysis, we carefully re-read and reviewed the data to recognize patterns (themes) within the data (33, 35).

During analysis, four files in the category "multiple geriatric syndromes" were excluded: one because the applicant concerned did not suffer from an accumulation of health problems associated with aging, one because the application did result in EAS, and two because the decision-making process of EEC was not yet completed. Besides, two files in the category "no medical ground" were excluded: one because there was no application form and one because it was a duplicate.

Ethics approval

As a standard procedure at EEC, applicants are asked to give their written informed consent for the use of their records for scientific purposes.

RESULTS

A total of 237 files of requests that did not result in EAS were analyzed; 167 in the category "multiple geriatric syndromes" and 70 in the category "no medical ground".

Characteristics

Table 1 shows the characteristics of the applicants at EEC. Nearly three-quarters of the applicants were women. Age ranged from 28 to 101 and more than half of the applicants were 85 years or older. More than four-fifths of the applicants lived without a partner. Most applicants had children (71%) and three-quarters of the applicants lived independently.

Motivations

Table 2 provides insight into what motivations underlie the applicant's request for EAS at EEC. One question in the application form concerned elements of suffering. Physical decline/loss of strength was listed most often (73%). Among the most listed elements of suffering were also tiredness (61%) and loss of autonomy/loss of control over own life/dependence (60%). Besides, approximately half of the applicants listed: loneliness, no prospect of improvement, psychological suffering (long lasting), pain, and/or loss of capacity to maintain social contacts.

A second question concerned reasons for the request. Physical problems/suffering was described most often (56%) and followed by poor quality of life/life is a burden/being done with life (36%), “completed life”/”tiredness of life” (25%), and psychological problems/suffering (20%). Of all applicants, 11% referred to old age when they were asked for the reason for their request. Only a few applicants expressed their reasons for the request in a positive way e.g., having had a good life and wanting a good death. In general, applicants motivated their request for EAS with negative expressions e.g., having enough of life and being sick of life. The answers to reasons for the request contained both elaborations of and additions to the listed elements of suffering.

In most cases, relatives/close ones were informed about the application (72%). The applicant’s reason for not informing relatives/close ones was in most cases: having no or few relatives/close ones (anymore) or having no or little contact with them.

TABLE 1. Characteristics of the selected applicants at EEC

Characteristics	N = 237 (%)
Gender	
Female	173 (73)
Male	64 (27)
Age (years)	
Median (Q1-Q3)	85 (78-91)
Younger than 55	13 (6)
55-74	37 (16)
75-84	56 (24)
85 or older	131 (55)
Marital status	
Widow(er)	131 (55)
Single	67 (28)
Married	37 (16)
Living together	2 (1)
Children	
One or more	168 (71)
None	59 (25)
Unknown	10 (4)
Living conditions	
Independent house	179 (76)
Healthcare institution/protected residence	49 (21)
Other[1]	9 (4)

Results are presented as N (%) unless “Median (Q1-Q3)” is reported. The median is reported with 25th-75th percentiles. Percentages may not add up to 100% because of rounding.

Information in this table is derived from the application form completed by the applicants themselves or their representative. Sporadically, if a certain question in the application form was not present or not answered by the applicant, we extracted the required information - if available - from the other documents in the applicant’s record.

[1] Namely: homeless; temporary place to stay; temporary place to rehabilitate; penitentiary institution; residence for disabled people; retirement home; detention center; no right to residence without ‘assistance’.

TABLE 2. Motivations of the selected applicants at EEC

Motivations	N = 237 (%)
Elements of suffering[1]	
Physical decline/loss of strength	173 (73)
Tiredness	145 (61)
Loss of autonomy/loss of control over own life/dependence	142 (60)
Loneliness[2]	131 (55)
No prospect of improvement	128 (54)
Psychological suffering (long lasting)	127 (54)
Pain	115 (49)
Loss of capacity to maintain social contacts	112 (47)
Loss of dignity	90 (38)
Loss of sensory functions (e.g., deaf- or blindness)	85 (36)
Shortness of breath	56 (24)
Loss of mental capacities	55 (23)
Confusion	52 (22)
Bedriddenness	43 (18)
Nausea	38 (16)
Disconnectedness	32 (14)
Reasons for the request[3]	
Physical problems/suffering	133 (56)
Poor quality of life/life is a burden/being done with life	85 (36)
"Completed life"/ "tiredness of life"[4]	58 (25)
Psychological problems/suffering	48 (20)
(Fearing) loss of independence/dignity[5]	43 (18)
Loneliness[2]	43 (18)
No prospect of improvement	29 (12)
Old age	26 (11)
Spouse/closed ones are deceased/will die soon	23 (10)
Meaninglessness/lack of purpose	22 (9)
Not answered	5 (2)
Relatives/close ones informed about application	
Yes	171 (72)
No	47 (20)
Unknown	19 (8)
Desired moment for granting the request	
In the short term[6]	159 (67)
Not in the short term	23 (10)
Other[7]	32 (14)
Unknown	23 (10)

Results are presented as N (%). Percentages may not add up to 100% because of rounding. Percentages below "Elements of suffering" and "Reasons for the request" do not add up to 100% because applicants could name more than one of the categories. Information in this table is derived from the application form completed by the applicants themselves or their representative. Sporadically, if a certain question in the application form was not present or not answered by the applicant, we extracted the required information - if available - from the other documents in the applicant's record. This was, however, never the case for Elements of suffering and Reasons for the request.

[1] We included all answer options that occurred in the application forms as categories. We also added some categories in order to classify all given answers as specific as possible. Elements of suffering that were mentioned by 20 applicants or less are in order of frequency (from most frequently to least frequently mentioned): Other/undefined physical problems e.g., tinnitus; Mourning; Incontinence; Anticipated wish to end one's life/fearing or dreading the future; Poor quality of life/life is a burden/being done with life; Meaninglessness/lack of purpose; Limited capabilities/limited range of motion;

"Completed life"/"tiredness of life" (literally described with these words). Elements of suffering that were mentioned by 5 applicants or less were not categorized.

[2] Statements about having limited social contact or feeling alone were also classified as loneliness.

[3] Reasons for the request that were mentioned by 20 applicants or less are in order of frequency (from most frequently to least frequently mentioned): Lack of lust/zest for life; General practitioner not willing to grant EAS/not willing or able to do it myself; Aspiring a good death; Not wanting to receive help/not wanting to move (to a healthcare institution); Looking back on a long/satisfied life; Anticipated wish to end one's life/fearing or dreading the future; Limited capabilities/limited range of motion; Self-determination is important for me; Negative events in the past. Reasons for the request that were mentioned by 5 applicants or less were not categorized.

[4] Literally described with these words.

[5] Those who described current or threatening loss of independence/dignity as well as those who feared this loss.

[6] The answer "as soon as possible" and terms within approximately one year were also categorized as in the short term.

[7] Such as: when the applicant named a specific date or when the applicant answered that it depended on, for instance, a specific expected situation, the development of one's physical and psychological health, or something that needs to be done first.

Decision-making process

Table 3 describes features of the decision-making process of EEC. Approximately three-quarters of the applicants had between one to three contact moments with EEC. In nearly four-fifths of the cases the decision-making process of EEC did not include an extra consultation with a medical professional from outside their organization. If another medical professional was consulted, this was most often a geriatrician/geriatric specialist or psychiatrist.

The most often mentioned reason for the request not resulting in EAS was "Not meeting one or more of the due care criteria for EAS" (165 cases; 70%). Thereafter followed "No or insufficient medical ground for the suffering" (95 cases; 40%) and "No (current) request for EAS" (61 cases; 26%). Remarks about no or insufficient medical ground for the suffering were frequently accompanied by remarks about the absence of unbearable suffering and/or the absence of no prospect of improvement.

Twenty-nine (one out of eight) cases were reopened at a later moment in time. For instance, when the applicant's situation had changed and he or she reapplied at EEC. In 10 of these 29 cases, reopening of the case resulted in a granted request.

DISCUSSION

Most applicants without (severe) illness at EEC whose requests for EAS did not result in EAS were women (73%) aged 75 years and older (79%). Over the last years an increasing part of the requests for EAS in general was requested by persons of 75 years or older (36). Moreover, most records we studied (167 out of 237) concerned those of applicants within the category "multiple geriatric syndromes", a category in which it is logical to find older persons. Yet, the thirteen cases of persons younger than 55 years, indicate that requesting EAS without being (severely) ill is not strictly reserved for older persons.

TABLE 3. Decision-making process of EEC

Decision-making process	N = 237 (%)
Number of contact moments between applicant and EEC	
None[1]	32 (14)
One to three	173 (73)
Four to six	22 (9)
Seven or more	3 (1)
Unknown	7 (3)
Extra consultation with medical professional from outside EEC	
None	188 (79)
Geriatrician/geriatric specialist	19 (8)
Psychiatrist	15 (6)
SCEN-physician[2]	4 (2)
Other medical specialist	1 (<1)
Psychologist	1 (<1)
Combination of two or three from above	3 (1)
Unknown	6 (3)
Reasons for the request not resulting in EAS[3]	
Solely no or insufficient medical ground for the suffering[4]	19 (8)
Solely not meeting one or more of the due care criteria for EAS[5]	71 (30)
Solely no (current) request for EAS[6]	28 (12)
Both no or insufficient medical ground for the suffering and not meeting one or more of the due care criteria for EAS	64 (27)
Both no or insufficient medical ground for the suffering and no (current) request for EAS	3 (1)
Both not meeting one or more of the due care criteria for EAS and no (current) request for EAS	21 (9)
Combination of all three reasons mentioned above	9 (4)
Authorization of applicant to request medical record is lacking	11 (5)
Contact information is lacking	1 (<1)
Natural death	1 (<1)
Unknown	9 (4)
Decision made by	
Physician	79 (33)
Team	70 (30)
Triage	45 (19)
Nurse	13 (6)
Other[7]	24 (10)
Unknown	6 (3)
Reopening of case at a later moment in time	
No	208 (88)
Yes	29 (12)
Not resulting in EAS	14
Resulting in EAS	10
Unknown if reopening resulted in EAS	5

Results are presented as N (%). Percentages may not add up to 100% because of rounding.
Information in this table is derived from the documents written by the medical professionals at EEC.

[1] For example, because the applicant did not deliver the needed information or authorization to further process the application, or on receipt of the request for EAS the delivered documents clearly indicated no current request for EAS.

[2] According to the WTL, before performing EAS, the physician must consult at least one other, independent physician who must see the patient and assess whether the statutory due care criteria are met. The independent physician

consulted is often a SCEN-physician. SCEN-physicians are trained by the Royal Dutch Medical Association (RDMA, or in Dutch KNMG) and are available to make an independent, expert assessment of a request for EAS.

[3] How many times the reasons "No or insufficient medical ground for the suffering", "Not meeting one or more of the due care criteria for EAS", and "No (current) request for EAS" were mentioned in total is described in the text.

[4] Reasons were classified into this category if it was literally stated that there was no or insufficient medical ground for the suffering or if there were doubts about sufficient medical ground for the suffering. Also more implicit references to (unclarity about) no or insufficient medical ground for the suffering were included, such as: "completed life", "tiredness of life", without (severe) illness, or suffering that was not in the first place or predominantly related to something somatic or psychiatric.

[5] Also doubts about meeting the due care criteria were included in this category. There were remarks about the following due care criteria: "be satisfied that the patient's request is voluntary and well considered"; "be satisfied that the patient's suffering is unbearable, with no prospect of improvement"; "have informed the patient about his situation and prognosis"; "have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation" [2].

[6] Reasons were classified into this category if it turned out there was in fact no death wish but need for other help than EAS, if there was no current request for EAS anymore, or if the request for EAS was anticipatory from the beginning. Also doubts about these issues were included in this category.

[7] Such as: by the applicant or by the system (if record status had been more than six months on hold).

The overrepresentation of women older than 75 years is in line with previous studies into requests for EAS in the categories "tired of living, no severe disease" (12) and "multiple geriatric syndromes" (7). The question arises why women outnumber men in these types of requests for EAS, while an almost 50-50 distribution is seen in requests for EAS in general (37). The fact that women generally tend to live longer than men, although relatively more years with deficits and functional limitations is probably part of the answer to this question (38-39).

Our study supports studies indicating that loneliness and both the subjective feeling and objective condition of being alone are related to having death wishes and suicidal outcomes (40-43). For example, the majority of the applicants lived without a partner (84%) in an independent house (76%). Furthermore, despite the fact that the majority of the applicants had children (71%), part of them indicated feelings of loneliness, having limited social contact, or feeling alone. The finding that one-fifth of the applicants did not inform their relatives/close ones about their application at EEC suggests that for some the eventual step towards requesting end of life may be a lonely experience.

Only a few applicants expressed their reasons for the request in a positive way e.g., having had a good life and wanting a good death. In most cases, existential suffering came to the fore though. Of the applicants, about one third referred to poor quality of life/life is a burden/being done with life and one quarter to "completed life"/"tiredness of life". In general, applicants motivated their request for EAS with negative expressions e.g., having enough of life and being sick of life. Different types of loss were mentioned as elements of suffering and part of the applicants referred to old age as reason for their request for EAS. These findings point to experiences of meaninglessness in the daily lives of older people as a result of the process of aging and age-related losses such as loss of loved ones, health, and social roles (4).

All dimensions of suffering, the physical, psychological, social, and existential, were clearly present (45). This finding corresponds with previous research showing that suffering leading to a request for EAS relates to various aspects of personhood (7, 46). Physical suffering was indicated most often by the applicants not only as element of suffering but also as reason for the request (the latter was an open-ended question and therefore completely open for applicants to express the key point of their suffering in their own wording). Thus, even in the absence of (severe) illness, physical suffering played an important role in requests for EAS. This finding is remarkable, as previous research indicates that people requesting EAS predominantly associate psychosocial, psycho-emotional, and existential problems with their unbearable suffering (46-47). Even patients with (severe) diseases and illnesses mainly evoke non-physical suffering when they describe their suffering (46).

This finding is also remarkable because, from the medical professional's perspective, in a significant part (40%) of the cases there was no or insufficient medical ground for the suffering. This reveals that medical professionals may not associate the physical suffering of applicants with suffering that predominantly stems from one or more medically classifiable somatic or psychiatric conditions. Hence, from the presence of physical suffering it does not necessarily follow that for medical professionals there is sufficient medical ground to comply with the 'medical ground'-boundary.

Previous research indicates that physicians relate unbearable suffering to physical suffering (46). In line with this, we noted in the files of medical professionals at EEC that remarks about no or insufficient medical ground for the suffering were frequently accompanied by remarks about the absence of unbearable suffering. Besides, there were accompanying remarks about the absence of no prospect of improvement. These findings underline the fact that the 'medical ground'-boundary is a specification of the due care criterion "be satisfied that the patient's suffering is unbearable, with no prospect of improvement" (2). In practice, reflection upon this due care criterion and the 'medical ground'-boundary seems to be intertwined. Moreover, the fact that also other reasons for the request not resulting in EAS were found in combinations, suggests that intertwining factors play a role in the decision-making process.

Comparison with granted requests for EAS in cases of multiple geriatric syndromes might shed light on why some persons with multiple geriatric syndromes are eligible for EAS and others are not. If our study is compared to a study into granted requests for EAS in cases of multiple geriatric syndromes, similar findings are found concerning an overrepresentation of older women with physical suffering but also suffering in the psychological, social, and existential dimensions (7). Dependence, fears, social isolation, and loss of meaning in daily life were found in both studies as elements of suffering. There are also differences between both studies though. Loss of mobility, the occurrence of falls, and the presence of a tipping point played an important role in the results of the study into granted requests for EAS, while these factors do not specifically come to the fore in this study. These factors may, therefore, hint towards causes for medical professionals to consider granting EAS. However, we cannot exclude that these factors are also implicit in the physical suffering as shown in our present study.

In the absence of (severe) illness, it might be difficult to exactly point out why some persons with physical suffering are eligible for EAS and others are not. For multiple geriatric syndromes is described: "These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement" (2). Hence, differences in eligibility might be a matter of individual context-dependent nuances.

Strengths and limitations

This study is to our knowledge the first to examine cases of persons without (severe) illness whose requests for EAS did not result in EAS and in which both the perspectives of applicants and medical professionals were taken into account. A limitation of this study is that we did not study our research questions in cases outside EEC. We are aware that an examination of applicant records of EEC does not provide a complete overview of all requests for EAS of people who are not (severely) ill. It is likely though that our study provides insight into a great part of such requests, since EEC typically receives complex, less common requests for EAS (6, 14). Another limitation is related to the fact that the studied documents had a different original purpose than scientific research. The application forms and letters of decline from which we extracted information about characteristics, motivations, and the decision-making process slightly changed over the years. For example, the prescribed list of answer options to identify elements of suffering. This may have impact on the frequencies of some answers. Yet, as we also included and thoroughly studied open fields and open-ended questions, we believe these slight changes have only small impact on the results as a whole. Further, our study is partly based on closed-ended questions. This may be considered as a limitation. Since we were aware of the fact that closed-ended questions might direct persons in their answers and leave no room for specification, we drew only careful conclusions and took the added value of open fields and open-ended questions into account. A final limitation could be that some applicants may have been aware of what factors could increase their chances of being eligible for EAS under the current jurisprudence and law, which might have influenced their answers (48). For instance, they may have emphasized their physical suffering or may have chosen to express their reasons for the request in a negative way. Nonetheless, while this possibility is described in literature, to our knowledge there is no evidence of its actual (frequent) occurrence in practice.

CONCLUSIONS AND RECOMMENDATIONS

In the absence of (severe) illness, suffering manifests itself in physical, psychological, social, and existential dimensions. Motivations behind the request for EAS are mostly expressed in a negative way and point to experiences of meaninglessness in the daily lives of older people as a result of the process of aging and age-related losses. Even in the absence of (severe)illness, physical suffering plays an important role in requests for EAS. However, from the presence of physical suffering it does not necessarily follow that for medical professionals there is sufficient medical ground to comply with the 'medical ground'-boundary. The 'medical ground'-boundary is reflected upon and applied as a reason to decline requests for EAS by medical professionals at EEC. Reflection upon this boundary and the due care criterion of unbearable suffering, with no prospect of improvement seems to be intertwined.

In the absence of (severe) illness, it might be difficult to exactly point out why some persons with physical suffering are eligible for EAS and others are not. Differences in eligibility might be a matter of individual context-dependent nuances. Future research might provide some more insight into these differences though. For instance, by means of a qualitative interview study with medical professionals who assess requests for EAS of people without (severe) illness. Or by means of a comparison study in which the reasons of medical professionals to grant requests for EAS in some cases of persons with multiple geriatric syndromes are analyzed together with their reasons to decline such requests in other cases.

Our study provides a picture of the group, except for those below the age of 75 years, for whom the proposed bill without 'medical ground'-boundary is intended (19). Based on the multidimensional suffering our study unraveled, it seems important that in future policy there is also attention for the help and support the people in question might need. Are there perhaps ways in which their suffering could be relieved other than by EAS? Future research could focus on what help and support would be needed and welcomed by persons with a death wish without (severe) illness, and who could provide this.

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SUPPLEMENTARY MATERIAL

SUPPLEMENTARY TABLE 1. Characteristics of the selected applicants at EEC

Characteristics	MGS + NMG N = 237 (%)	MGS N = 167 (%)	NMG N = 70 (%)
Gender			
Female	173 (73)	129 (77)	44 (63)
Male	64 (27)	38 (23)	26 (37)
Age (years)			
Median (Q1-Q3)	85 (78-91)	87 (83-91)	74 (58-86)
Younger than 55	13 (6)	1 (1)	12 (17)
55-74	37 (16)	12 (7)	25 (36)
75-84	56 (24)	42 (25)	14 (20)
85 or older	131 (55)	112 (67)	19 (27)
Marital status			
Widow(er)	131 (55)	109 (65)	22 (31)
Single	67 (28)	31 (19)	36 (51)
Married	37 (16)	25 (15)	12 (17)
Living together	2 (1)	2 (1)	0 (0)
Children			
One or more	168 (71)	125 (75)	43 (61)
None	59 (25)	36 (22)	23 (33)
Unknown	10 (4)	6 (4)	4 (6)
Living conditions			
Independent house	179 (76)	122 (73)	57 (81)
Healthcare institution/protected residence	49 (21)	39 (23)	10 (14)
Other[1]	9 (4)	6 (4)	3 (4)

MGS = “multiple geriatric syndromes” and NMG = “no medical ground”.
Results are presented as N (%) unless “Median (Q1-Q3)” is reported. The median is reported with 25th-75th percentiles. Percentages may not add up to 100% because of rounding.
Information in this table is derived from the application form completed by the applicants themselves or their representative. Sporadically, if a certain question in the application form was not present or not answered by the applicant, we extracted the required information - if available - from the other documents in the applicant’s record.

[1] Namely: homeless; temporary place to stay; temporary place to rehabilitate; penitentiary institution; residence for disabled people; retirement home; detention center; no right to residence without ‘assistance’.

SUPPLEMENTARY TABLE 2. Motivations of the selected applicants at EEC

Motivations	MGS + NMG N = 237 (%)	MGS N = 167 (%)	NMG N = 70 (%)
Elements of suffering[1]			
Physical decline/loss of strength	173 (73)	138 (83)	35 (50)
Tiredness	145 (61)	110 (66)	35 (50)
Loss of autonomy/loss of control over own life/dependence	142 (60)	118 (71)	24 (34)
Loneliness[2]	131 (55)	97 (58)	34 (49)
No prospect of improvement	128 (54)	99 (59)	29 (41)
Psychological suffering (long lasting)	127 (54)	94 (56)	33 (47)
Pain	115 (49)	93 (56)	22 (31)
Loss of capacity to maintain social contacts	112 (47)	88 (53)	24 (34)
Loss of dignity	90 (38)	71 (43)	19 (27)
Loss of sensory functions (e.g., deaf- or blindness)	85 (36)	73 (44)	12 (17)

SUPPLEMENTARY TABLE 2. Continued.

Motivations	MGS + NMG N = 237 (%)	MGS N = 167 (%)	NMG N = 70 (%)
Shortness of breath	56 (24)	45 (27)	11 (16)
Loss of mental capacities	55 (23)	47 (28)	8 (11)
Confusion	52 (22)	46 (28)	6 (9)
Bedriddenness	43 (18)	36 (22)	7 (10)
Nausea	38 (16)	34 (20)	4 (6)
Disconnectedness	32 (14)	23 (14)	9 (13)
Reasons for the request[3]			
Physical problems/suffering	133 (56)	112 (67)	21 (30)
Poor quality of life/life is a burden/being done with life	85 (36)	58 (35)	27 (39)
"Completed life"/"tiredness of life"[4]	58 (25)	36 (22)	22 (31)
Psychological problems/suffering	48 (20)	37 (22)	11 (16)
(Fearing) loss of independence/dignity[5]	43 (18)	38 (23)	5 (7)
Loneliness[2]	43 (18)	36 (22)	7 (10)
No prospect of improvement	29 (12)	24 (14)	5 (7)
Old age	26 (11)	19 (11)	7 (10)
Spouse/closed ones are deceased/will die soon	23 (10)	15 (9)	8 (11)
Meaninglessness/lack of purpose	22 (9)	13 (8)	9 (13)
Not answered	5 (2)	5 (3)	0 (0)
Relatives/close ones informed about application			
Yes	171 (72)	132 (79)	39 (56)
No	47 (20)	23 (14)	24 (34)
Unknown	19 (8)	12 (7)	7 (10)
Desired moment for granting the request			
In the short term[6]	159 (67)	112 (67)	47 (67)
Not in the short term	23 (10)	14 (8)	9 (13)
Other[7]	32 (14)	21 (13)	11 (16)
Unknown	23 (10)	20 (12)	3 (4)

MGS = "multiple geriatric syndromes" and NMG = "no medical ground".
Results are presented as N (%). Percentages may not add up to 100% because of rounding. Percentages below "Elements of suffering" and "Reasons for the request" do not add up to 100% because applicants could name more than one of the categories.
Information in this table is derived from the application form completed by the applicants themselves or their representative. Sporadically, if a certain question in the application form was not present or not answered by the applicant, we extracted the required information - if available - from the other documents in the applicant's record. This was, however, never the case for Elements of suffering and Reasons for the request.

[1] We included all answer options that occurred in the application forms as categories. We also added some categories in order to classify all given answers as specific as possible. Elements of suffering that were mentioned by 20 applicants or less are in order of frequency (from most frequently to least frequently mentioned): Other/undefined physical problems e.g., tinnitus; Mourning; Incontinence; Anticipated wish to end one's life/fearing or dreading the future; Poor quality of life/life is a burden/being done with life; Meaninglessness/lack of purpose; Limited capabilities/limited range of motion; "Completed life"/"tiredness of life" (literally described with these words). Elements of suffering that were mentioned by 5 applicants or less were not categorized.

[2] Statements about having limited social contact or feeling alone were also classified as loneliness.

[3] Reasons for the request that were mentioned by 20 applicants or less are in order of frequency (from most frequently to least frequently mentioned): Lack of lust/zest for life; General practitioner not willing to grant EAS/not willing or able to do it myself; Aspiring a good death; Not wanting to receive help/not wanting to move (to a healthcare institution); Looking back on a long/satisfied life; Anticipated wish to end one's life/fearing or dreading the future; Limited capabilities/limited range of motion; Self-determination is important for me; Negative events in the past. Reasons for the request that were mentioned by 5 applicants or less were not categorized.

[4] Literally described with these words.

[5] Those who described current or threatening loss of independence/dignity as well as those who feared this loss.

[6] The answer "as soon as possible" and terms within approximately one year were also categorized as in the short term.

[7] Such as: when the applicant named a specific date or when the applicant answered that it depended on, for instance, a specific expected situation, the development of one's physical and psychological health, or something that needs to be done first.

SUPPLEMENTARY TABLE 3. Decision-making process of EEC

Decision-making process	MGS + NMG N = 237 (%)	MGS N = 167 (%)	NMG N = 70 (%)
Number of contact moments between applicant and EEC			
None[1]	32 (14)	9 (5)	23 (33)
One to three	173 (73)	130 (78)	43 (61)
Four to six	22 (9)	19 (11)	3 (4)
Seven or more	3 (1)	2 (1)	1 (1)
Unknown	7 (3)	7 (4)	0 (0)
Extra consultation with medical professional from outside EEC			
None	188 (79)	126 (75)	62 (89)
Geriatrician/geriatric specialist	19 (8)	16 (10)	3 (4)
Psychiatrist	15 (6)	12 (7)	3 (4)
SCEN-physician[2]	4 (2)	4 (2)	0 (0)
Other medical specialist	1 (<1)	1 (1)	0 (0)
Psychologist	1 (<1)	0 (0)	1 (1)
Combination of two or three from above	3 (1)	2 (1)	1 (1)
Unknown	6 (3)	6 (4)	0 (0)
Reasons for the request not resulting in EAS[3]			
Solely no or insufficient medical ground for the suffering[4]	19 (8)	15 (9)	4 (6)
Solely not meeting one or more of the due care criteria for EAS[5]	71 (30)	49 (29)	22 (31)
Solely no (current) request for EAS[6]	28 (12)	18 (11)	10 (14)
Both no or insufficient medical ground for the suffering and not meeting one or more of the due care criteria for EAS	64 (27)	46 (28)	18 (26)
Both no or insufficient medical ground for the suffering and no (current) request for EAS	3 (1)	2 (1)	1 (1)
Both not meeting one or more of the due care criteria for EAS and no (current) request for EAS	21 (9)	20 (12)	1 (1)
Combination of all three reasons mentioned above	9 (4)	7 (4)	2 (3)
Authorization of applicant to request medical record is lacking	11 (5)	2 (1)	9 (13)
Contact information is lacking	1 (<1)	0 (0)	1 (1)
Natural death	1 (<1)	1 (1)	0 (0)
Unknown	9 (4)	7 (4)	2 (3)
Decision made by			
Physician	79 (33)	62 (37)	17 (24)
Team	70 (30)	62 (37)	8 (11)
Triage	45 (19)	11 (7)	34 (49)
Nurse	13 (6)	10 (6)	3 (4)
Other[7]	24 (10)	16 (10)	8 (11)
Unknown	6 (3)	6 (4)	0 (0)
Reopening of case at a later moment in time			
No	208 (88)	143 (86)	65 (93)
Yes	29 (12)	24 (14)	5 (7)
Not resulting in EAS	14	10	4
Resulting in EAS	10	9	1
Unknown if reopening resulted in EAS	5	5	0

MGS = “multiple geriatric syndromes” and NMG = “no medical ground”.

Results are presented as N (%). Percentages may not add up to 100% because of rounding.

Information in this table is derived from the documents written by the medical professionals at EEC.

[1] For example, because the applicant did not deliver the needed information or authorization to further process the

application, or on receipt of the request for EAS the delivered documents clearly indicated no current request for EAS.

[2] According to the WTL, before performing EAS, the physician must consult at least one other, independent physician who must see the patient and assess whether the statutory due care criteria are met. The independent physician consulted is often a SCEN-physician. SCEN-physicians are trained by the Royal Dutch Medical Association (RDMA, or in Dutch KNMG) and are available to make an independent, expert assessment of a request for EAS.

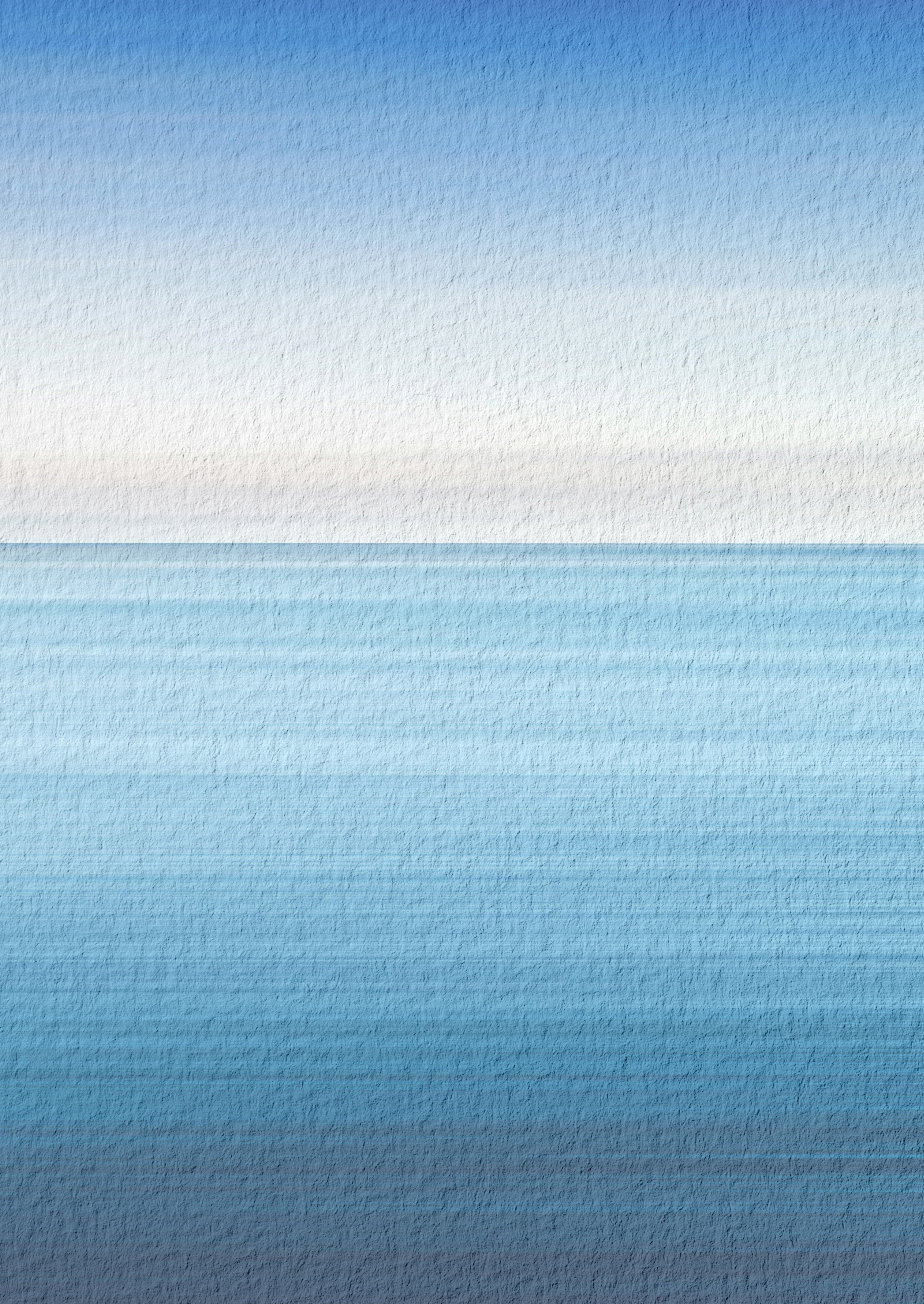
[3] How many times the reasons “No or insufficient medical ground for the suffering”, “Not meeting one or more of the due care criteria for EAS”, and “No (current) request for EAS” were mentioned in total is described in the text.

[4] Reasons were classified into this category if it was literally stated that there was no or insufficient medical ground for the suffering or if there were doubts about sufficient medical ground for the suffering. Also more implicit references to (unclarity about) no or insufficient medical ground for the suffering were included, such as: “completed life”, “tiredness of life”, without (severe) illness, or suffering that was not in the first place or predominantly related to something somatic or psychiatric.

[5] Also doubts about meeting the due care criteria were included in this category. There were remarks about the following due care criteria: “be satisfied that the patient’s request is voluntary and well considered”; “be satisfied that the patient’s suffering is unbearable, with no prospect of improvement”; “have informed the patient about his situation and prognosis”; “have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation” [2].

[6] Reasons were classified into this category if it turned out there was in fact no death wish but need for other help than EAS, if there was no current request for EAS anymore, or if the request for EAS was anticipatory from the beginning. Also doubts about these issues were included in this category.

[7] Such as: by the applicant or by the system (if record status had been more than six months on hold).



7|

Euthanasia and physician-assisted suicide in patients with multiple geriatric syndromes

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I participated in the interpretation of the findings and provided feedback on the manuscript during several revision rounds.

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ABSTRACT

Importance

The Dutch Regional Euthanasia Review Committees (RTEs) reviewed and reported an increasing number of cases of euthanasia and physician-assisted suicide (EAS) requested by older people with multiple geriatric syndromes (MGS). Knowledge of the characteristics of cases of EAS for MGS is important to facilitate societal debate and to monitor EAS practice.

Objective

To examine the accumulation of patient characteristics, geriatric syndromes, and other circumstances as reported in the case summaries of the RTEs that led to unbearable suffering associated with a request for EAS and to analyze the RTEs' assessments of these cases of EAS.

Design, setting, and participants

A qualitative content analysis was conducted of all case summaries filed from January 1, 2013, to December 31, 2019, under the category MGS and published in a national open access database. These case summaries were selected by the RTEs from the total of 1,605 reported cases of EAS in the category MGS.

Results

The RTEs published 53 cases (41 [77%] female) under the category MGS. A total of 28 patients (53%) had always perceived themselves as independent, active, and socially involved. None of the patients suffered from life-threatening conditions. Multiple geriatric syndromes, such as visual impairment (34 cases [64%]), hearing loss (28 cases [53%]), pain (25 cases [47%]), and chronic tiredness (22 cases [42%]), were common. The request for EAS was often preceded by a sequence of events, especially recurrent falls (33 cases [62%]). Although physical suffering could be determined in all cases, the case descriptions found that suffering occurred on multiple dimensions, such as the loss of mobility (44 [83%]), fears (21 [40%]), dependence (23 [43%]), and social isolation (19 [36%]).

Conclusions and relevance

This qualitative study suggests that an accumulation of geriatric syndromes leading to a request for EAS is often intertwined with the social and existential dimension of suffering. This leads to a complex interplay of physical, psychological, and existential suffering that changes over time.

INTRODUCTION

Since 2002, Dutch physicians are allowed to perform euthanasia and physician-assisted suicide (EAS) when the due care criteria laid down in the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (hereafter referred to as the Dutch euthanasia law) are met (1). One of the 6 criteria for legally permissible EAS is that "the physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement." (For the other criteria, see **Box 1**.) Each case of EAS is reported to the Dutch Regional Euthanasia Review Committees (RTEs). These committees assess and determine whether the physician acted in accordance with the due care criteria in the Dutch euthanasia law (2). (See the **Supplement** for information about the RTEs' review procedure.)

BOX 1. Criteria for due care in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002) (1)

Requirements physician must satisfy:

A. Must be satisfied that the patient's request is voluntary and well considered.
B. Must be satisfied that the patient's suffering is unbearable, with no prospect of improvement.
C. Must have informed the patient about the situation and prognosis.
D. Must have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation.
E. Must have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled.
F. Must have exercised due medical care and attention in terminating the patient's life or assisting in suicide.

Most Dutch EAS cases involve patients who suffer unbearably because of cancer in the last phase of life. In recent years, however, an increase has been reported in EAS performed in patients with dementia, psychiatric disorders, or multiple geriatric syndromes (MGS) (3-4). Following the Euthanasia Code 2018, a geriatric syndrome is defined as degenerative in nature, often occurring in older patients. With regard to MGS, such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems, or cognitive deterioration, the Dutch RTE guidance for physicians states that these geriatric syndromes may cause unbearable suffering without the prospect of improvement "in conjunction with the patient's medical history, life history, personality, values and stamina" (5). Although acceptance of EAS in cases of MGS is increasing in Dutch society, a majority of Dutch physicians are reluctant to grant a request for EAS on these grounds (6). Such requests are considered to be much more complex than those made by patients with a terminal disease, not only in ethical terms but also in legal and medical terms. For example, when does an accumulation of geriatric syndromes cause unbearable suffering without prospect of improvement?

Are physicians sufficiently equipped to assess this suffering? Are these requests caused by a trend of people increasingly regarding normal decline as a disease?

This study aims to contribute to the further debate on dealing with requests for EAS from older persons with MGS. To this end, we (1) describe the patient characteristics, including the geriatric syndromes, that are associated with the request for EAS in cases of MGS; (2) explore which accumulation of syndromes and circumstances are associated with unbearable suffering in cases of MGS; and (3) attempt to gain a better understanding of the RTEs' assessment practice.

METHODS

We studied all 53 anonymized case summaries filed under the category MGS from an open access database on the RTE website (1). These cases are selected by the RTEs from all 1,605 reported EAS cases in the category MGS from January 1, 2013, to December 31, 2019 (2). An overview of total numbers of deaths, EAS cases, and EAS cases of MGS per year is given in **Table 1** (7-9). The Medical Research Ethics Committee Utrecht confirmed that our study was exempt from further ethical review, so no informed consent was required. All patient data were deidentified. This study followed the Standards for Reporting Qualitative Research (SRQR) reporting guideline. The selection of cases for publication on the website is guided by the aim to give an overview of the spectrum of cases reviewed and to contribute to the understanding of complex or controversial cases among physicians and the general public. In a meeting with a member and the chairman of the RTEs, we discussed the question of which cases are to be published in the national database. They confirmed that not only cases that address questions and dilemmas were selected but also cases representing situations that often occurred and were therefore considered common (oral communication, February 28, 2019). The length of the case summaries varies from 567 to 3,130 words (approximately 2-6 pages), with a median of 1,132 words. Among the more extensive case reports are the ones in which the RTE asked the physician (and sometimes also the consultant) for additional information. In these cases, the RTE had a face-to-face discussion with the physician (and consultant).

We conducted a directed qualitative content analysis (10) of the cases using the analysis program ATLAS.ti, version 8.4.15 (ATLAS.ti Scientific Software Development GmbH). One author (V.v.d.B.) read all 53 documents completely to acquire an overall picture of the nature of the cases, repeatedly comparing variables of interest in light of the main research question of the study. The coding scheme was developed by 2 authors (V.v.d.B. and E.v.W.) and discussed with another (G.v.T.). All documents were coded by 1 author (V.v.d.B.) based on the predetermined codes. New findings beyond the scheme and discrepancies were discussed and resolved among 4 authors (V.v.d.B., E.v.W., G.v.T., and M.Z.) and assessed by the whole team. Given the descriptive goals of this study, the emphasis was on frequency tabulation.

TABLE 1. Numbers of deaths, EAS cases, and EAS for MGS cases per year[a]

Year	Total No. of deaths	No. of deaths per age category	Total No. of deaths by EAS[b]	No. of deaths by EAS per age category	Total No. of EAS deaths for MGS
2013	141,245	80-89 years of age: 49,583; ≥90 years of age: 25,229	4,829	NA	251
2014	139,223	80-89 years of age: 48,182; ≥90 years of age: 25,676	5,306	NA	257
2015	147,134	80-89 years of age: 51,283; ≥90 years of age: 27,962	5,516	NA	183
2016	148,973	80-89 years of age: 51,665; ≥90 years of age: 28,649	6,091	80-89 years of age: 1,487; ≥90 years of age: 522	244
2017	150,027	80-89 years of age: 52,397; ≥90 years of age: 29,640	6,585	80-89 years of age: 1,634; ≥90 years of age: 653	293
2018	153,328	80-89 years of age: 53,203; ≥90 years of age: 30,401	6,126	80-89 years of age: 1,442; ≥90 years of age: 512	205
2019	151,793	80-89 years of age: 52,810; ≥90 years of age: 30,089	6,361	80-89 years of age: 1,628; ≥90 years of age: 504	172

Abbreviations: EAS, euthanasia and physician-assisted suicide; MGS, multiple geriatric syndromes; NA, not available.

[a] Data are based on information from the Dutch Central Bureau of Statistics (7) and the Dutch Regional Euthanasia Review Committees (http://www.euthanasiecommissie.nl) (8).

[b] According to the Third Evaluation of the Euthanasia Law (9), 55% of the expressed requests for euthanasia are honored. It is not known how many of these cases are associated with MGS.

RESULTS

The RTEs published 53 cases (41 [77%] female) under the category MGS, which were reported between 2013 and 2019. In **Box 2**, we first present 3 of the analyzed cases to illustrate how the combination of medical conditions and other characteristics accumulate to create a situation in which the physician became convinced that the patient was suffering unbearably without prospect of improvement.

Patient characteristics

Patient characteristics and circumstances are given in **Table 2**. All 53 patients were 80 years of age or older and 41 (77%) were 90 years of age or older. In 28 cases (53%), it was reported that patients had always perceived themselves as independent, active, and socially involved persons.

BOX 2. Descriptions of cases of multiple geriatric syndromes[a]

Case 1
A woman in the age range of 90 to 100 years had progressive vision loss and hearing impairment. She also experienced chronic pain in her legs, loss of mobility, and balance problems. A few weeks before the euthanasia and physician-assisted suicide, she fell out of bed and suffered several fractures. Since that moment, her 20fear of a repeated fall made it difficult for her to sleep. Because of her condition, she felt lonely and cut off from her social environment. She was not able to read or watch television and was not up to any activities anymore.

Case 2
A woman in her 90s had been suffering from the consequences of osteoporosis for several years. Recurrent falls caused multiple fractures. A month before her death, she underwent surgery for a hip fracture. Her recovery did not go well, and the prognosis was bleak. Loss of mobility and pain prevented her from sitting comfortably. The lack of any prospect of improvement, the loss of autonomy, being completely dependent, and the fear of losing clarity of mind together caused the unbearable suffering that was the medical grounds for euthanasia and physician-assisted suicide.

Case 3
A woman older than 90 years whose physical health was deteriorating was dealing with hearing loss, severe fatigue, uncontrollable headaches, restless legs, and incontinence. All her life she had been a very independent, active, and engaged person. She hated accepting help from others, and because of her worsening hearing impairment, she was not able to participate in social activities. She felt excluded from society. She feared further physical decline, with her greatest fear being forced to move to a nursing home environment.

[a] These case descriptions illustrate the most important findings of this study: (1) that falls often occur and can be a tipping point that leads to a request for euthanasia; (2) that the consequences of a single geriatric syndrome can, in some cases, be sufficient to grant a request for euthanasia; and (3) that suffering has multiple intertwined dimensions.

Geriatric syndromes

All but 1 patient had more than 1 medical condition that caused multiple symptoms. In none of the cases were the health problems caused by a life-threatening disease. Visual impairment was the most reported symptom (34 cases[64%]), followed by hearing loss (28 cases[53%]) and chronic pain (25 cases[47%]).

Sequence of events and falls as recurrent themes

In most cases, 2 types of circumstances were reported to be important for the patient's wish to receive EAS. First, in 39 cases (74%), there was a sequence of events set off by an incident (the tipping point). The older patients in these cases had been dealing with multiple health problems for several years. The patients judged their suffering to be sufficient to request EAS after a decline in physical health because of the incident (e.g., a fall, an infection, a hospitalization, or the loss of a close relative). Second, partly overlapping the first circumstance, in 33 cases (62%), falls and their consequences were reported. Recurrent falls caused complicated fractures in 7 cases (13%) and fear of falling in 11 cases (21%), which contributed to the experience of unbearable suffering.

TABLE 2. Patient characteristics and circumstances

Characteristic	No. (%) of cases (N = 53)
Age group, years	
80-89	12 (23)
90-100	41 (77)
Sex	
Male	12 (23)
Female	41 (77)
Geriatric syndrome[a,b]	
Visual impairment	34 (64)
(Chronic) pain	25 (47)
Hearing loss	28 (53)
(Chronic) tiredness or fatigue	22 (42)
Osteoporosis	17 (32)
Arthrosis	16 (30)
Incontinence	14 (26)
Decubitus	10 (19)
Other characteristics	
Gloomy feelings	2 (4)
Depressive feelings[c]	4 (8)
Always independent	18 (34)
Always active	10 (19)
Refuses medical examination or medical treatment	7 (13)
Recurrent falls	33 (62)
Sequence of events	39 (74)

[a] Numbers in this category do not total 53 because most patients had more than 1 health problem.

[b] Geriatric syndromes that occurred in at least 10 cases are presented in this table. Other medical syndromes or diseases included chronic obstructive pulmonary disease, dizziness, heart failure, constipation, and fractures.

[c] In some of these cases, additional psychological examination was conducted because of the depressive feelings. In these cases, depression was not diagnosed.

Description of elements of suffering

Each case summary contained a characterization of the patient's suffering caused by MGS. These characterizations show an association between medical conditions and losses in several dimensions of life (i.e., physical, psychological, social, and existential) (**Table 3**). In 44 cases (83%), loss of mobility was an element in the suffering of the patient. The loss of mobility ranged from not being able to go outside for a walk to being bedridden and inactive. Different kinds of fears were also an element in the experience of suffering. In addition, patients experienced social isolation and loneliness (19 [36%]). Not being able to read, watch television, or undertake meaningful activities was also an element of suffering in 19 cases (36%).

Conjunction of symptoms and events

The cases reported under the category MGS all described patients whose suffering was caused by a combination of symptoms attributable to an accumulation of syndromes. There was 1 exception, which demonstrates that a singular syndrome in combination with related experiences can be accepted by the RTEs as sufficient to meet the due care criterion of unbearable suffering without prospect of improvement.

TABLE 3. Elements of suffering[a]

Element	No. (%) of cases (N = 53)
Loss of mobility	44 (83)
Decline of mobility	16 (30)
All day sitting in a chair	12 (23)
Bedridden	9 (17)
Unable to do anything	8 (15)
Fears	21 (40)
Fear of further physical decline	20 (38)
Fear of losing independence	11 (21)
Fear of falling	11 (21)
Fear of having to move to a foster care home	10 (19)
Dependence	23 (43)
Becoming more dependent	19 (36)
Completely dependent on others	8 (15)
Social isolation	19 (36)
Loss of meaning in daily life	19 (36)
Unable to read or watch television	15 (28)
No meaningful activities	12 (23)
Loss of quality of life	9 (17)
Loss of control	5 (9)
Loss of dignity	6 (11)

[a] Numbers do not total 53 because patients could list multiple elements of suffering.

Practical and procedural aspects

All case summaries, in line with the standard procedure and the due care criteria stipulated in the Dutch law, stated that the physicians were convinced that the request was voluntary, which means that the patients made their wishes known without pressure or undue influence from others, such as family members. In addition, all published cases reflect that the physician saw no alternatives for improvement. In a number of cases, the physician had consulted a geriatric psychiatrist to rule out a reversible depression. With the exception of 1 person who received assisted suicide, all patients received euthanasia. In 32 cases (60%), a general practitioner performed the EAS; in the other 21 cases (40%), a physician from Euthanasia Expertise Center (3) (formerly the End-of-Life Clinic) was involved.

During the review process of 9 cases (17%), the RTEs had additional questions (25 in total) concerning the physician's justification. Five questions were whether the patient's unbearable suffering originated in a medically classifiable disease. The question regarding additional information at the request of the patient was asked by the RTE in 5 cases. Three times the RTE wanted additional information on possible alternatives for the EAS, and 3 times they requested information on how the physician came to be satisfied that the patient's suffering was unbearable. Two times the RTE wanted to know more about the psychological aspect of the patient's suffering, including the question regarding whether the patient was suffering from depression. Examples of other questions were whether consultation of an independent expert had been necessary and whether due medical care was exercised in the performance of the EAS.

After obtaining additional information from the physician who performed the EAS, the independent consultant, and other involved medical specialists, the RTEs concluded that the EAS was in accordance with the due care criteria in all but 1 case. In the case that was not approved, several due care criteria were not met. The physician was not prosecuted in court. Compared with EAS in cancer cases, cases of MGS had a greater chance of generating more questions during the review procedures of the RTEs. Physicians of Euthanasia Expertise Center were 5 times more likely to be questioned (4).

DISCUSSION

The patients who received EAS because of MGS were the oldest old. Most (77%) of the patients were women. None of them had a life-threatening condition, and all except 1 patient with a single geriatric condition had MGS, such as visual impairment and hearing loss. Pain and chronic tiredness were also common.

This study is the first, to our knowledge, to describe case reports of EAS for MGS. Two studies (11-12) have analyzed cases of EAS for patients with psychiatric illnesses. Additional literature on the experiences concerning end-of-life decisions for the oldest old is scarce. Available studies (13-14) reveal that fear of suffering, the wish to remain living at home, and the need for control are important elements in end-of-life decision-making. Although a medical condition associated with old age with symptoms could be determined in all 53 cases analyzed in this study, the case descriptions show that suffering occurred on multiple dimensions besides the medical one. This finding corresponds with the influential view of Cassell (15) that the interconnectedness and the interplay among physical, psychological, social, and existential experiences are crucial for a deeper understanding of suffering (16). Suffering not only is a matter of pain and other physical symptoms but also has psychological, social, and existential dimensions (15). In addition, suffering has a temporal dimension: it can be triggered by becoming aware of what the future holds (17). The present analysis shows that fearing the future, fearing further physical decline, becoming more dependent, or losing control over the situation are important aspects of suffering. This finding is in line with previous research (18) into requests for EAS by patients with end-stage cancer. In patients with MGS, these fears seem to emerge after a sequence of events. Furthermore, in 74% of the cases, an incident was reported as a decisive factor in the request for EAS. These incidents did not merely add to the accumulation of health problems. It has been observed that such incidents can be seen as a “tipping point, a warning of functional decline, dependence and isolation” (19). In 33 of the 39 cases with incidents, this point concerned a fall that negatively affected different life dimensions. This finding confirms previous studies in which falls were interpreted as a starting point for reflection on life (20) and a factor associated with the development of a wish to die (21).

Strengths and limitations

This study has strengths and limitations. Its primary strength is its exploration of the case summaries of the RTEs in the category of MGS. These summaries describe real EAS cases and are the only accessible source to study EAS in patients suffering from MGS. Nevertheless, this study is limited by the fact that the published cases are a selection of a larger number of dossiers. For example, in 2018, the RTEs reviewed a total of 205 cases of EAS for patients with MGS. In addition, data were extracted from secondary official state documents. Such documents represent a shortened and specific version of realities, suitable for publication on an open access website (22) and therefore containing little social history. Occasionally, a spouse or children are mentioned, but neither a person’s family structure nor living arrangement could be reconstructed.

In addition, there is a risk of underreporting cases of euthanasia. Two partly overlapping sources of underreporting exist. First, physicians sometimes misclassify their actions. Second, physicians who perform euthanasia do not always report this action to the RTEs. With regard to reporting to the RTEs, 81% of all cases of euthanasia were reported in 2015 (4). Conclusions about the numbers and characteristics of patients with MGS among these misclassified and/or unreported cases cannot be drawn because specific data are not available.

CONCLUSIONS

According to these findings, an accumulation of geriatric syndromes alone is insufficient to explain the unbearableness of suffering that leads to a request for EAS in older persons with MGS. In this study, all cases referred to patients who had been suffering from MGS for several years. At a certain moment in time, the suffering resulted in a request for EAS. Given that patients were already suffering from the geriatric syndromes for a long time, the findings suggest that it is not only the total number of these geriatric syndromes that is associated with unbearable suffering (and a granted request) but also the sum of these problems (often in combination with a tipping point incident) in conjunction with the patient's medical history, life history, personality, and values that gives rise to suffering that the patient in question experiences as unbearable and without prospect of improvement. This finding also may also explain why, in some exceptional cases, the medical dimension of the suffering can also be based on only 1 geriatric syndrome that, in combination with social and existential problems associated with that syndrome, may result in unbearable suffering. In summary, in most cases, experiences in the social and existential dimensions are intertwined with the medical dimension of suffering. The variety of relevant elements in these complex cases raises the question of what the role of these different elements should be in the assessment of requests for EAS and which expertise is needed for optimal care for these older persons.

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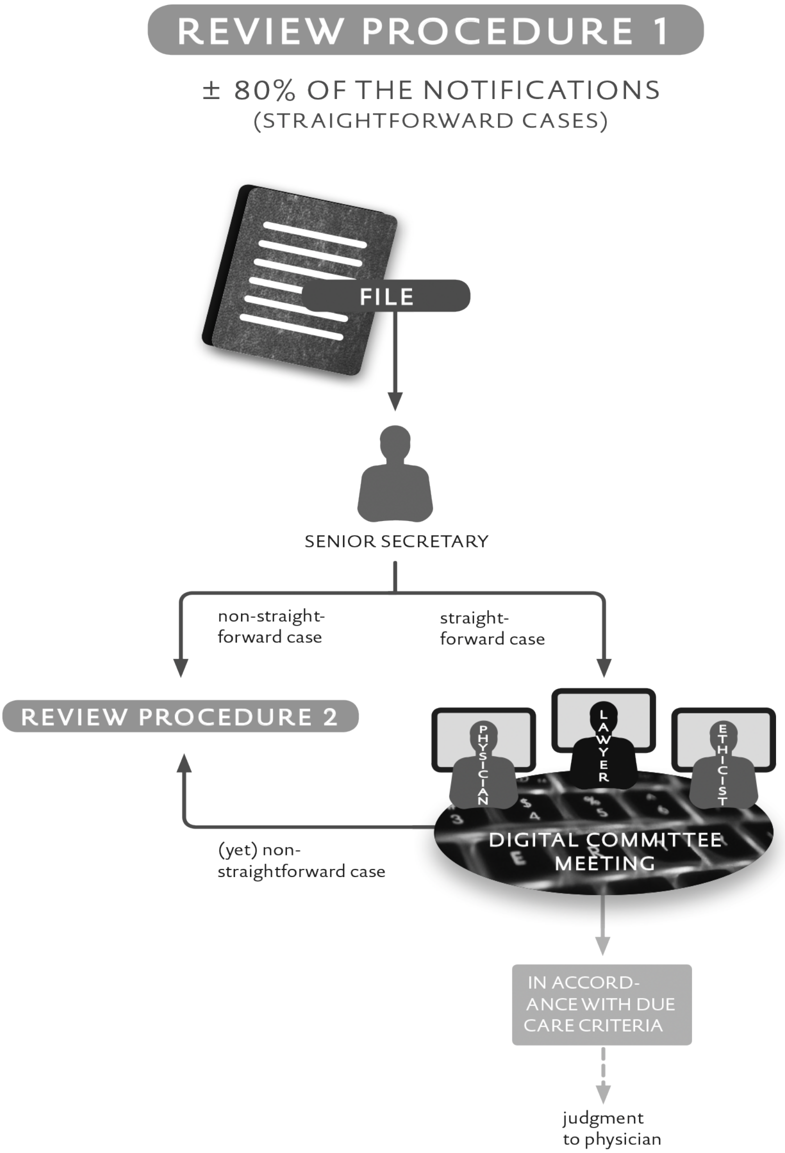
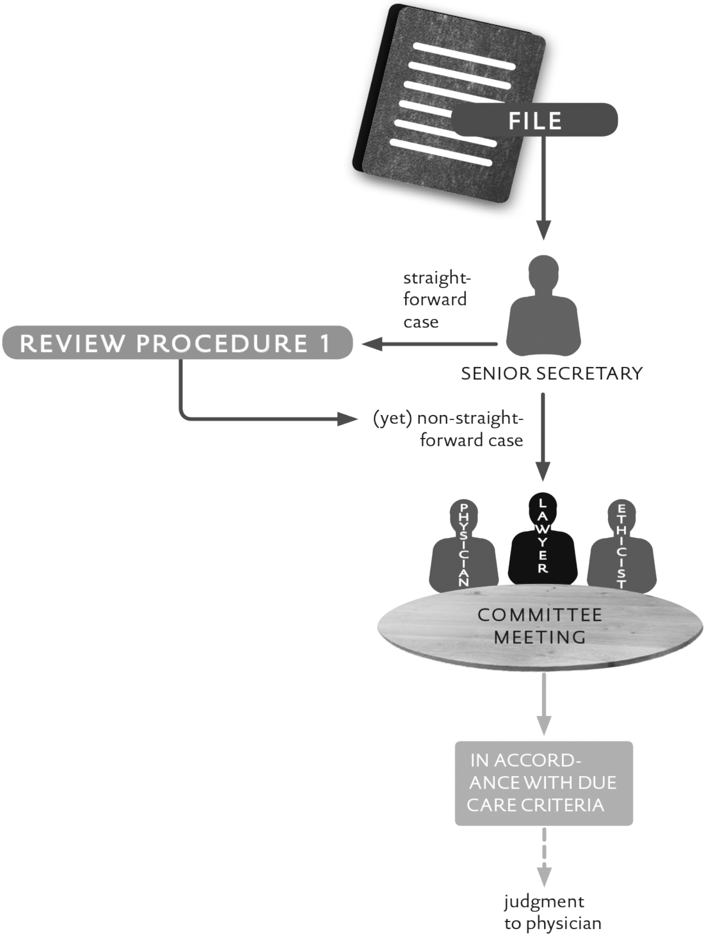
SUPPLEMENTAL MATERIAL

SUPPLEMENT. Review procedures of the Dutch Regional Review Committees



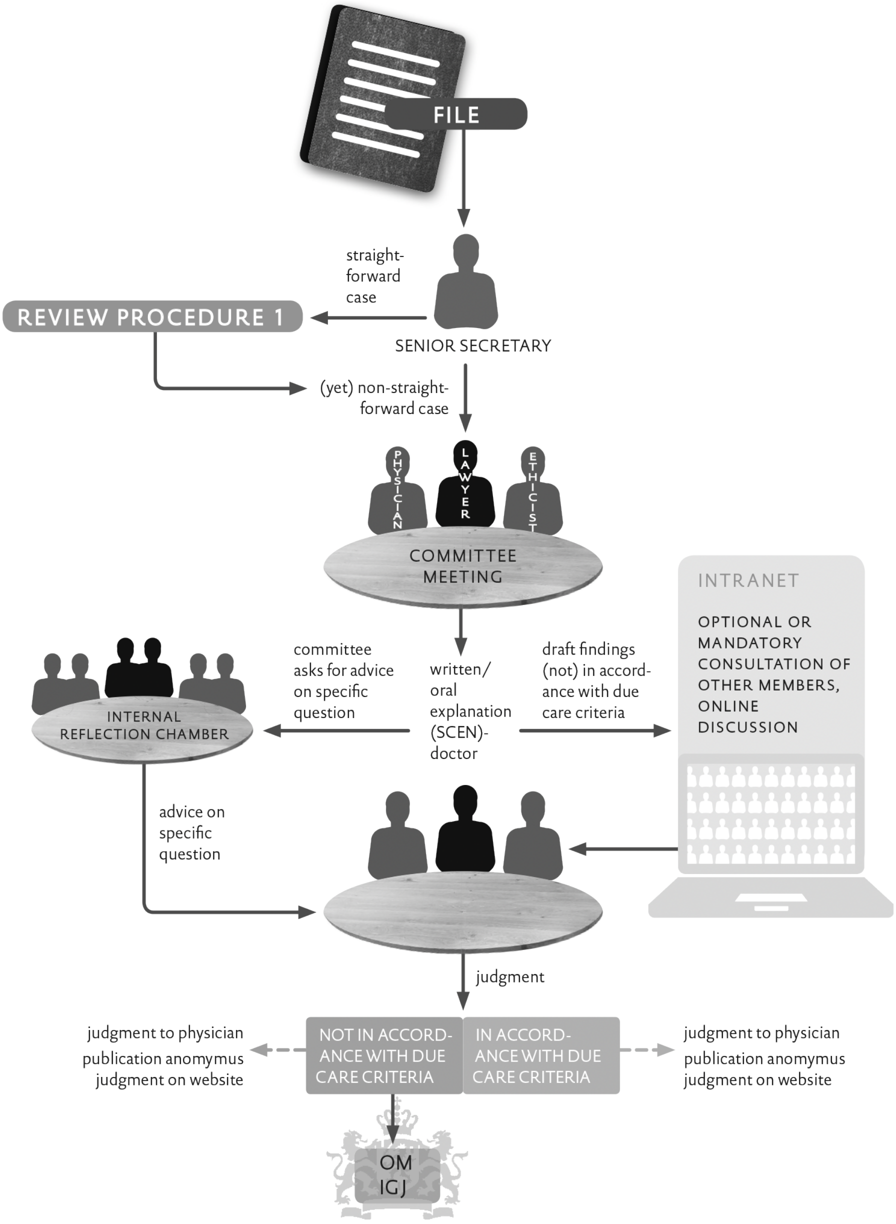
REVIEW PROCEDURE 2

± 19% OF THE NOTIFICATIONS
(NON-STRAIGHTFORWARD CASES)



REVIEW PROCEDURE 3

±1% OF THE NOTIFICATIONS (NON-STRAIGHTFORWARD CASES)



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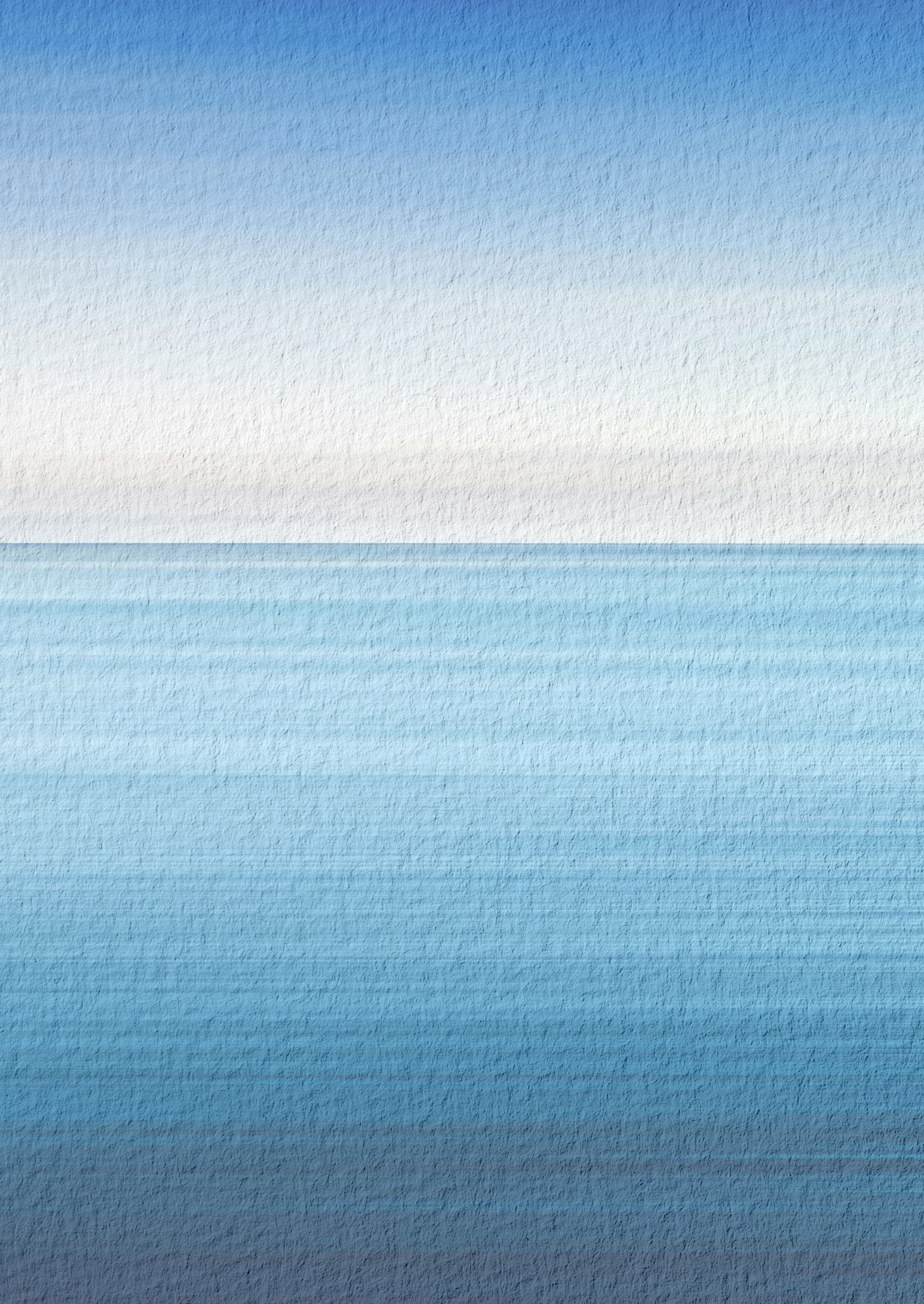

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Meaningful respect for the autonomy of persons with "completed life": an analysis in light of empirical research

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Contribution of the author of this dissertation:
After discussing the points we could address in this open peer commentary with the co-authors, I studied several sources and wrote the article. I revised the article based on feedback of the co-authors.

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OPEN PEER COMMENTARY

In the Netherlands, the legalization of assisted suicide for persons with a death wish without severe illness, often referred to as persons with "completed life" or "tiredness of life," is intensely debated. Florijn's analysis touches upon an important aspect of this debate, namely the role of respect for autonomy and the different ways in which autonomy can be interpreted (1). In what follows, we provide an analysis based on data from our empirical research to elaborate on how respect for the autonomy of persons with "completed life" could best be expressed.

Empirical research into the experiences of persons with "completed life" indicates that these persons are dealing with physical, psychological, social, and existential distress (2-6). For example, even though they are not severely ill, they report physical and mental health problems and decline. They also report loneliness, having little to no influence on their lives, limitation of their freedom, worrying, dependence on other people, difficulty with adjusting to old age, a sense of uselessness and meaninglessness, not being able to express themselves, being a burden to other people, tiredness, loss of dignity, loss of status, and financial problems. In conversations with persons with "completed life" it turns out that their experience of "completed life" is multi-layered and among each person multiple forms of distress are intertwined (3-4, 6).

Moreover, their experience of "completed life" is full of ambivalences and ambiguities (2-6). This means that persons with "completed life" live with mixed feelings about their death wish (6). For example, many of them report that they have a death wish and that they find life worthwhile at the same time (2). Also many of them report that in the same moment the death wish can be as strong as the wish to live (5). Hence, they may simultaneously feel detached from and attached to life (4). This corresponds with the finding that having a death wish does not necessarily signify a wish to actually end one's life here and now (2). Further ambivalences and ambiguities are indicated by the fact that the death wish of persons with "completed life" may be driven by both rational considerations and non-rational bodily and emotional compulsions (4). They may experience being in control while also being uncertain and worried about the dying process. More importantly, they may on the one hand resist interference and on the other hand long for support. Lastly, their death wish may feel both legitimate and illegitimate.

Furthermore, the pattern of physical, psychological, social, and existential distress of persons with "completed life" fluctuates (6). This results in a dynamic, unpredictable death wish that is subject to change over time. In many cases, the death wish and the wish to live alternate; some periods the death wish is dominant, at other times the wish to live is stronger (5). Over the long-term, a death wish may become realized, intensify, diminish, or vanish (6). These changes are often impacted by external circumstances. For example, a death wish that diminishes or vanishes is often associated with an establishment or reestablishment of connections with other people, society, or themselves. This highlights the situational and relational context in which the death wish emerges.

Finally, with regard to needs, persons with "completed life" mostly express their need for access to a suicide drug and assistance from a physician to commit suicide (5). With regard to needs that are not directly related to ending one's life, they mostly express their need for acknowledgment and appreciation of their feelings. Next to that, they express the following needs most often: more financial leeway, good conversations with a professional, more social contacts, better and more contact with (grand)children and other relatives, good conversations with other older adults and other people in the same situation, better and more professional care and support, meaningful activities, and better fine-tuning of medications.

Altogether, these findings show the complexity of a "completed life" experience. There may be multiple forms of distress and needs underlying the death wish. The meaning of a death wish based on "completed life" may vary from person to person and moment to moment, among others due to (fluctuating) external circumstances. Moreover, persons with "completed life" may themselves be confused about and struggle with their death wish.

In much of the debate about legalization of assisted suicide for persons with "completed life," this complexity has not been sufficiently acknowledged. Instead, a "completed life" experience has been presented as clear-cut, and the death wish as well-considered and stable. Based on this simplified view, it might seem a logical step to provide assisted suicide if a person with "completed life" asks for it. But what if this person is lonely yet dependent on other people, has financial problems, and is, therefore, deprived of adequate care and support? Or what if this person non-autonomously decides to end his or her life, i.e., the decision to end one's life is not a well-considered, voluntary decision made in a mentally competent state? This could, for example, happen if one has mixed feelings about one's death wish and longs for but has no access good conversations and information to find out what one truly wishes, what possible responses to the death wish could be, and how certain distress can be taken away or needs can be fulfilled to relieve the death wish in other ways than by ending one's life. Besides, it may be questioned whether one can autonomously decide to end one's life if one is led by pressure from non-rational bodily and emotional compulsions or if one suffers from mental health problems or decline.

Denying the complexity and providing assisted suicide does not seem a desirable step in these cases, as it does not take into account the vulnerabilities of persons with "completed life" related to the complexity of their experience. While persons with "completed life" are not vulnerable per se, as if it were a fixed label on these persons, particular situations may make them vulnerable. These particular situations may be seen as several different and sometimes overlapping layers of vulnerability

(7-8). If we recognize the layers of the vulnerability of other people, then this brings about obligations, duties, or at least opportunities to—whenever possible—avoid exacerbating, eradicate, or minimize these layers. After all, our common vulnerability, i.e., vulnerability as an ontological condition of human beings, encourages us to respond to the vulnerabilities of other people on the basis of a sense of solidarity (9). Therefore, the right approach seems to acknowledge the complexity of a "completed life" experience and to explore together with the person with "completed life" how could best be responded to his or her accompanying vulnerabilities.

Responding to the vulnerabilities of persons with "completed life" might seem inconsistent with respect for their autonomy. That might seem the case if autonomy is interpreted as a right to self-determination and freedom, sometimes referred to as "negative" autonomy (10). This interpretation of autonomy holds that input from other people may be seen as threat rather than as helpful. Complementary to this interpretation of autonomy, there is another interpretation of autonomy, which can be referred to as "positive" autonomy. This complementary interpretation of autonomy views autonomy as an ideal that can be pursued in interaction with other people. Because ultimately, "autonomy is a socially constituted capacity, which is developed, sustained, and exercised only with extensive social scaffolding and support" and important to lead a flourishing life (9). According to this complementary interpretation of autonomy, responding to the vulnerabilities of persons with "completed life" is not at all inconsistent with respect for their autonomy. Rather, it holds that the moral demands arising from vulnerability extend beyond strategies such as the provision of protections and safeguards to prevent harm, to strategies such as the provision of social support to promote autonomy (8-9).

In sum, empirical research has demonstrated that a "completed life" experience is highly complex. By denying this complexity and providing assisted suicide, the vulnerabilities of persons with "completed life" are overlooked. This is undesirable as it may, for example, result in someone deciding non-autonomously to end his or her life, or in someone wishing to end his or her life while being deprived of adequate care and support. Therefore, respecting the autonomy of persons with "completed life" in terms of "negative" autonomy is not a meaningful way and may even cause harm. Instead, in line with the "positive" interpretation of autonomy, we might position ourselves next to persons with "completed life" to explore together how could best be responded to their vulnerabilities. That is not to say that providing assisted suicide to persons with "completed life" may never be considered a possibility. It is to say though that it would be good to postpone this consideration until particular situations that may make these persons vulnerable are adequately addressed. We need to face that a "completed life" experience simply is not clear-cut. For this reason, it does not allow for quick answers. On the contrary, it calls for care. This call for care creates room to consider attentively, in a shared exploration, how the death wish can best be taken care of.

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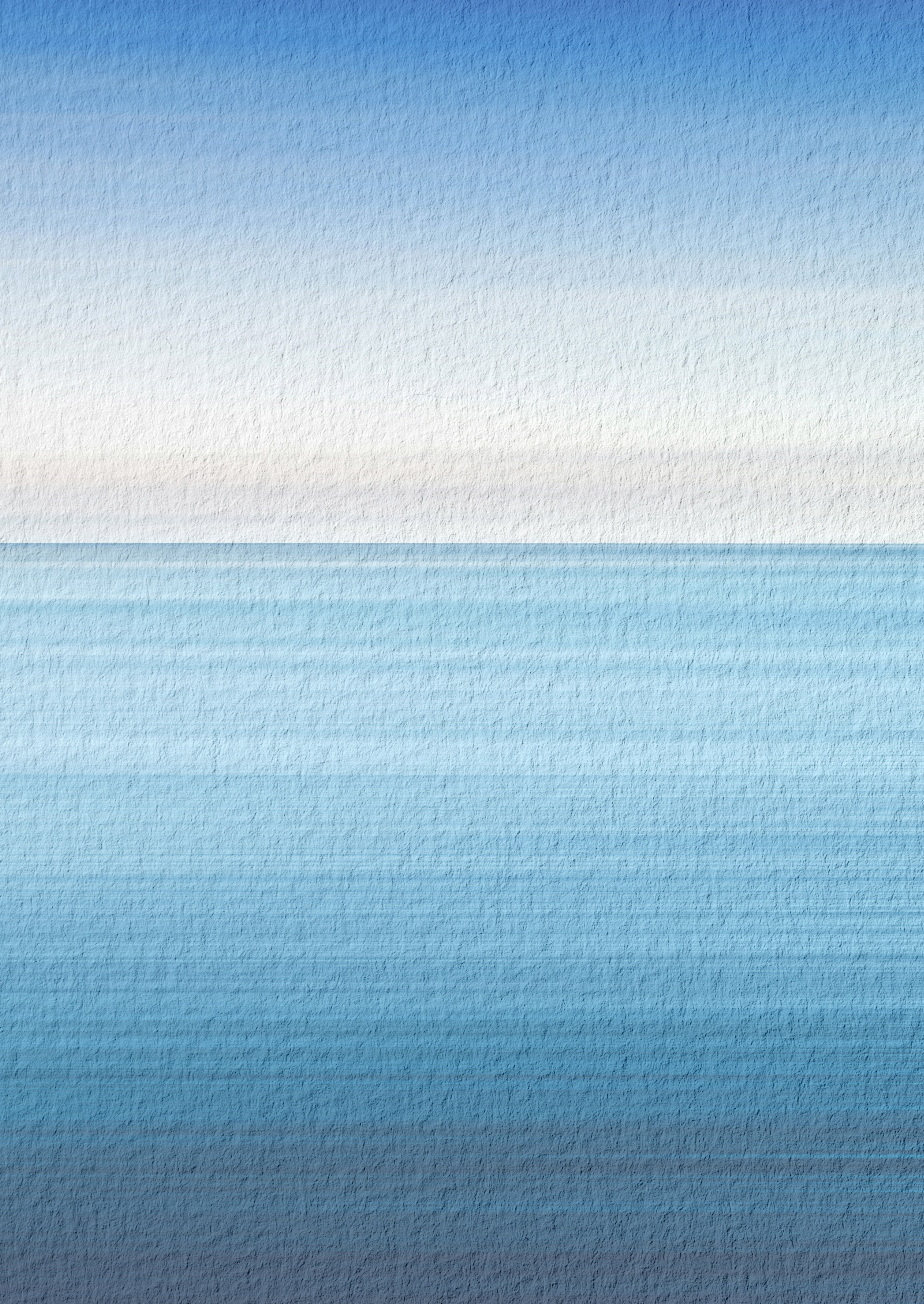

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General discussion

Contribution of the author of this dissertation:
I designed and wrote the general discussion and revised it based on two feedback rounds with my supervisory team.

AN ARCH OVER ALL CHAPTERS: OUR MAIN FINDINGS

As described in the general introduction of this dissertation, various sources were used to answer the research questions in this dissertation. In the previous chapters, these sources one by one came to the fore: a review of the literature; a cross-sectional survey among a representative sample of 32,477 Dutch citizens aged 55+; the record at EEC of requests for EAS that did not result in EAS in the categories “multiple geriatric syndromes” and “no medical ground”; and the national open access database of the RTEs with granted requests for EAS in the category “multiple geriatric syndromes”. Now the research questions will be answered one by one based on our findings in these sources.

1. What is the prevalence of older adults with a death wish without severe illness?
Our review of the literature and previous reviews of the literature show a limited amount of national and international quantitative data sources on the prevalence of older adults with a death wish without severe illness. (Chapter 2) In the period between January 1, 2012 and July 12, 2021, we only found four studies with such data. The identified prevalence in these studies ranged from 0.38% to 7.7% and was difficult to compare among the studies due to several important differences between the studies, such as the way in which the absence of severe illness was interpreted and operationalized.

Our large cross-sectional survey among Dutch older adults aged 55+ indicates that a small group of older adults have a persistent death wish in the absence of severe illness. (Chapter 3) The percentage, weighted according to the composition of the Dutch population, represents 1.34% (95% CI: 1.20-1.51) of all older adults aged 55+ in the Netherlands. In the subgroup of older adults aged 75+ the weighted percentage of having a persistent death wish in the absence of severe illness was slightly higher, namely 2.07% (95% CI: 1.63-2.63). (Chapter 4)

Only part of all older adults with a persistent death wish without severe illness reported an active persistent death wish, which means that only part has made concrete plans or has taken steps and/or has seriously considered attempting suicide in the past 12 months. (Chapters 3 and 4) In the total group of respondents aged 55+ the weighted percentage of having an active persistent death wish was 0.77% (95% CI: 0.66-0.90) and in the subgroup of older adults aged 75+ this weighted percentage was 1.10% (95% CI: 0.79-1.53). Of those who reported to have made concrete plans or have taken steps, a large part mentioned plans or steps that did not necessarily signify a wish to end one’s life here and now. (Chapter 3) They, for example, stated that they became member of an interest group regarding voluntary end of life or that they wrote down their wishes regarding refraining from medical treatment (such as “do not resuscitate”), end-of-life care (such as a wish for euthanasia in due time), or their testament.

Of the older adults with an active persistent death wish, only part reported that their death wishes – according to themselves – can best be described as a wish to end their lives. (Chapters 3 and 4) In the total group of respondents aged 55+ this weighted percentage was 0.18% (95% CI: 0.13-0.25). (Chapter 3) Most of them indicated a wish to end their lives themselves instead of a wish for help from a caregiver or someone close to end their lives. In the subgroup of older adults aged 75+ this was the other way around. (Chapter 4)

The majority of both the total group of respondents aged 55+ and the subgroup of respondents aged 75+ with a persistent death wish without severe illness, indicated that their death wishes – according to themselves – can best be described as a desire to not wake up tomorrow and die in their sleep or as a desire for a natural death that just happens. (Chapters 3 and 4)

2. How can older adults with a death wish without severe illness be described in terms of characteristics and circumstances?

Our large cross-sectional survey among Dutch older adults aged 55+ shows that a persistent death wish without severe illness occurs among older adults with all kinds of characteristics and circumstances: men and women, ages between 55 and 95 years, low to high educational attainment and social class, with or without (religious) worldview, living alone or together, with or without (step)children, and living inside or outside highly urbanized regions. (Chapter 3) Chapters 6 and 7, in which requests for EAS of persons in the categories "multiple geriatric syndromes" and "no medical ground" were studied, show that the characteristics and circumstances of these persons also vary in terms of gender, age, marital status, having children, and living conditions.

If older adults aged 55+ with a persistent death wish without severe illness are compared with older adults aged 55+ who did not recognize themselves in the description 'seeing no future for oneself, longing for death, while not being severely ill', the first group more often lived alone and more often had no or less (step)children. (Chapter 3) Besides, they were of lower social class, lived in highly urbanized areas more often, and a smaller percentage had a religious worldview. These differences were statistically significant. We found no statistically significant differences for gender, age, and educational attainment. In the subgroup of older adults aged 75+ some similar differences were found such as more often living alone, being of lower social class, and a smaller percentage with a religious worldview (not tested on statistical significance). (Chapter 4)

We found that a persistent death wish without severe illness occurs not only in the oldest old. (Chapter 3) In the total group of respondents aged 55+ the majority were under the age of 75. In comparison with those who did not recognize themselves in the description ‘seeing no future for oneself, longing for death, while not being severely ill’, there was no statistically significant overall difference in age distribution. This finding suggests that there is not an increase of death wishes with age. On the other hand, our finding that among the subgroup of older adults aged 75+ there was a slightly higher prevalence of persistent death wishes without severe illness (2.07%) compared to the total group of respondents aged 55+ (1.34%), suggests an increase of death wishes with age. (Chapter 4)

In our study at EEC into requests for EAS in the categories “multiple geriatric syndromes” and “no medical ground” that did not result in EAS, we found that most applicants were women (73%) aged 75 years and older (79%). (Chapter 6) Also in our study at the RTEs into requests for EAS in the category “multiple geriatric syndromes” that did result in EAS, we found that most applicants were women (77%). (Chapter 7) They were all between 80 and 100 years old, and 77% was oldest old; between 90 and 100 years old.

In our study of older adults with a lifelong death wish, we found that they were statistically significantly younger and more often had no (step)children compared to older adults with a persistent death wish that was not lifelong. (Chapter 5) We found no statistically significant differences with regard to gender, educational attainment, worldview, household size, social class, and urbanization between these two groups. Overall, both groups appeared to be similar in terms of characteristics and circumstances.

3. What is the background of the death wish of older adults without severe illness considering the nature of the death wish, motivations and needs behind the death wish, and communication about the death wish?

Our large cross-sectional survey among Dutch older adults aged 55+ shows that persistent death wishes of older adults without severe illness are diverse in nature and often experienced in a dynamic way. (Chapters 3-5) The diversity is shown by the different ways in which the death wish was characterized by respondents and the duration, which ranged from one year to lifelong. A dynamic experience of the death wish is indicated by the fact that most respondents answered that some periods the wish to live is stronger and at other times the death wish is dominant. (Chapters 4 and 5) Besides, for most, the frequency of thinking about the death wish varies; sometimes frequently, sometimes not very often.

Older adults with a persistent death wish without severe illness reported all kinds of aspects strengthening the death wish, covering physical, psychological, social, and existential dimensions of suffering. (Chapters 4 and 5) They, among others, mentioned: no (or limited) future perspective, worrying, the sense of having little to no influence on one’s life, loneliness, physical or mental deterioration, diseases, not enough good social contacts, loss of one’s loved ones (e.g., through death, divorce), limitation of one's freedom, not enough social activities, being dependent on others, having increasing problems with walking or with other movements, feeling like being a burden to others, bad memories (e.g., of traumatic experiences), loss (or lack) of self-respect, tension or arguments with people in one's immediate environment, and financial problems (in order from most to least frequently mentioned and all mentioned by more than a quarter). (Chapter 5) Also in our review of the literature and in our studies in which requests for EAS of persons in the categories "multiple geriatric syndromes" and "no medical ground" were studied, physical, psychological, social, and existential dimensions of suffering were described. (Chapters 2, 6 and 7) Health problems came to the fore as aspect strengthening the death wish, element of suffering, and reason to request EAS. (Chapters 4, 5, 6 and 7) Our results indicate that the group we identified as having a persistent death wish without being severely ill cannot be characterized as a group of healthy older persons. (Chapter 3)

Older adults with a persistent death wish without severe illness also reported all kinds of aspects strengthening the wish to live, among others: comfortable living conditions (nice house, nice neighborhood), independence, peace, making a difference for others, sense of freedom, good memories (e.g., of the past), being respected and appreciated by others, good social contacts and friendship, taking care of others, sense of being connected to other people, feeling useful, sense of self-respect, being meaningful to people around, meaningful social activities, good care, social engagement, the time of the year or the season, and the sense of being part of a community (in order from most to least frequently mentioned and all mentioned by more than a quarter). (Chapter 5) These aspects are in part similar to the aspects strengthening the death wish but positively formulated. This finding suggests that some aspects can strengthen either the wish to live or the death wish depending on the extent to which the aspect is satisfied or not.

Needs that were mostly expressed by older adults with a persistent death wish without severe illness were access to a suicide drug (47%) and assistance from a doctor to commit suicide (25%). (Chapter 5) Not all respondents expressed needs concerning ending one's life though. Besides, also other needs were expressed; social needs, needs for activities, needs for care and guidance, and needs for practical or material things. With regard to other needs, older adults with a persistent death wish without severe illness mostly expressed their need for acknowledgment and appreciation of their feelings (24%). In addition, more than 10% expressed the following needs: more financial leeway, good conversations with a professional (e.g., GP, psychologist, or spiritual counsellor), more social contacts, better or more contact with (grand)children or other relatives, good conversations with other older persons or others in the same situation, better or more professional care and support, meaningful activities, and better fine-tuning of medications (in order from most to least frequently mentioned). Less than 10% expressed the need for another place to live, meditation or mindfulness training, meaningful volunteer work, better access to transportation (e.g., public transportation, regional taxi, senior transportation service), and opportunities to carry out hobbies. Of all older adults with a persistent death wish without severe illness, 11% indicated no need for support or assistance.

Of the older adults with a persistent death wish without severe illness, nearly two-fifths did not discuss the death wish with anyone. (Chapter 5) This finding suggests that active inquiry of others might be required to identify that someone is living with a death wish and to explore how this person might be helped and supported with regard to the death wish. Of the approximately three-fifths who did communicate about the death wish, most discussed it with their doctor and/or other healthcare professionals (more than a quarter of all older adults with a persistent death wish without severe illness). Less than a quarter discussed it with their spouse/partner (21%), their friend(s) (18%), their child(ren) and grandchild(ren) (13%), and/or with their sibling(s) (8%).

The expression of having a death wish is characterized by ambivalences and ambiguities, as there may be mixed feelings about and different meanings of the death wish, respectively. For example, almost half of the older adults with a persistent death wish without severe illness, reported finding life worthwhile at the same time. (Chapter 3) Also nearly half of them indicated that in the same moment the death wish can be as strong as the wish to live, which implies that someone can simultaneously feel detached from and attached to life. (Chapter 5) Older adults with a persistent death wish without severe illness did not always report a strong preference *not* to witness the future. (Chapter 3) The different meanings of the death wish, are for instance shown by the fact that the expression of having a death wish for some means that they will wait for death to come, for some that they wish to end their lives, and for others that they consider their current situation unlivable. (Chapters 3-5) For some the expression of having a death wish includes having made concrete plans or having taken steps, having seriously considered attempting suicide, or having actually attempted suicide. However, for most respondents the expression of having a death wish did not necessarily signify a wish to end one's life here and now. (Chapter 3)

In our study of older adults with a lifelong death wish, we found that they statistically significantly less often looked back on a good and satisfying life with many good memories than older adults with a persistent death wish that was not lifelong. (Chapter 5) They more often reported trauma. On the contrary, older adults with a persistent death wish that was not lifelong more often indicated loss or bereavement as negative experience or event and more often reported the loss of loved ones, for instance through death or divorce, as an aspect strengthening their death wishes. As described in chapter 5, these differences might be relevant for the provision of adequate help and support to both groups. The two groups further showed a lot of similarities with regard to the background of their death wishes. For example, they both reported a death wish diverse in nature and a variety of needs for help and support.

4. How are requests for euthanasia and assisted suicide (EAS) of older adults with a death wish without severe illness decided upon by Euthanasia Expertise Center (EEC) and assessed by the Regional Euthanasia Review Committees (RTEs)? Our study at EEC included 237 requests for EAS that did not result in EAS from 01-01-2016 up to 28-09-2020; 167 in the category "multiple geriatric syndromes" and 70 in the category "no medical ground". (Chapter 6) Approximately three-quarters of the applicants had between one to three contact moments with EEC. In nearly four-fifths of the cases the decision-making process of EEC did not include an extra consultation with a medical professional from outside their organization.

From the physician's perspective, in a significant part of the cases (40%) there was no or insufficient medical ground for the suffering to grant EAS. (Chapter 6) Yet, by the applicants themselves, physical suffering was indicated most often as element of suffering and as reason for the request. This finding reveals that physicians may not associate the physical suffering of applicants with suffering that predominantly stems from one or more medically classifiable somatic or psychiatric diseases or conditions. Hence, from the presence of physical suffering it does not necessarily follow that for physicians there is sufficient medical ground to comply with the 'medical ground'-boundary of EAS. Or it could be that some applicants may have been aware of what factors could increase their chances of being eligible for EAS. They might have emphasized physical suffering in the application form to indicate sufficient medical ground for their suffering, while closer examination might have shown that there was in fact not so much physical suffering.

With regard to the 'medical ground'-boundary of EAS, our study at EEC further shows that in 19 cases (8%) no or insufficient medical ground for the suffering was the sole reason for the request not resulting in EAS. (Chapter 6) Based on this finding it seems that there are people whose requests for EAS actually fall outside the scope of the WTL solely because of no or insufficient medical ground for the suffering. Besides, the judgment no or insufficient medical ground for the suffering was also assigned to part of the requests for EAS in the category "multiple geriatric syndromes". This finding indicates that, even though suffering from multiple geriatric syndromes can be judged as suffering mainly based on medical ground, requests for EAS related to multiple geriatric syndromes can also be declined because of the 'medical ground'-boundary of EAS. In addition, our study at EEC shows that the 'medical ground'-boundary is reflected upon and applied as a reason to decline requests for EAS by physicians at EEC. However, the judgment no or insufficient medical ground for the suffering was not assigned to all requests for EAS in the category "no medical ground". This finding might mean that not all medical professionals at EEC reflect upon and apply the 'medical ground'-boundary as reason to decline requests for EAS, or that they all do but that it is not documented as such by all.

The fact that reasons for the request not resulting in EAS were found in combinations, suggests that intertwining factors play a role in the decision-making process. (Chapter 6) Remarks about no or insufficient medical ground for the suffering were frequently accompanied by remarks about the absence of unbearable suffering. Besides, there were accompanying remarks about the absence of no prospect of improvement. These findings underline the fact that the 'medical ground'-boundary is a specification of the due care criterion b ("the physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement"). In practice, reflection upon this due care criterion and the 'medical ground'-boundary seems to be intertwined.

Our study at the RTEs included 53 granted requests for EAS from 01-01-2013 up to 31-12-2019 in the category "multiple geriatric syndromes". (Chapter 7) According to the RTEs, these cases provide an overview of the spectrum of cases reviewed within this category and contribute to the understanding of complex or controversial cases among physicians and the general public. Our study at the RTEs shows that next to a sum of geriatric syndromes, the presence of one single geriatric syndrome can be judged as sufficient medical ground for the suffering to grant EAS, both by the physician who performs EAS and the RTEs that assess EAS afterwards.

The RTEs concluded in all but one case that EAS was performed in accordance with the due care criteria of the WTL. (Chapter 7) In the case that was not approved, several due care criteria were not met. During the review process, in 9 cases (17%) the RTEs had additional questions (25 in total) concerning the physician's justification for performing EAS. Approximately one-third concerned questions regarding due care criterion b ("the physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement") of which the 'medical ground'-boundary is a specification. The RTEs asked how the physician became convinced that the patient's suffering was unbearable and whether the patient's unbearable suffering originated from a medically classifiable disease. In other cases they asked additional information on the request of the patient, possible alternatives for EAS, the psychological aspect of the patient's suffering such as an indication for depression, the option of consulting an independent expert, and the exercise of due medical care in the performance of EAS.

Comparison of the findings in chapters 6 and 7 might shed light on why some persons with multiple geriatric syndromes are eligible for EAS and others are not. Similar findings were found concerning an overrepresentation of older women with physical suffering but also suffering in the psychological, social, and existential dimensions. Some elements such as dependence and fears were found in both studies as elements of suffering. A difference between both studies was that loss of mobility, the occurrence of falls, and the presence of a tipping point played an important role in the results of the study into granted requests for EAS, while these factors do not specifically come to the fore in the study into request for EAS that did not result in EAS. These factors may, therefore, hint towards causes for physicians to consider granting EAS. (chapter 7) However, we cannot exclude that these factors are also implicit in the physical suffering as shown in chapter 6.

5. In what ways can be appropriately responded to the death wish of older adults without severe illness in light of empirical findings?

The beginning of the answer to research question 5 can be found in chapter 8. This chapter described the complexity of a "completed life" experience and introduced the concept of vulnerability in relation to empirical findings about older adults with a death wish without severe illness. It also linked responding to vulnerability to respect for the autonomy of older adults with a death wish without severe illness. Those points will be addressed below and further elaborated in several steps to answer research question 5.

<u>The complexity of a "completed life" experience</u>

The main point with regard to empirical findings about older adults with a death wish without severe illness, that is brought to the fore in chapter 8, is the fact that a "completed life" experience is highly complex. This complexity has not been sufficiently acknowledged in much of the debate about the question whether older adults with "completed life" who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. A "completed life" experience has been presented as the experience of people mostly at an old age without illness who look back on a good life in which most of what they wished for has been achieved (1). Now there is little to no future perspective they wish to end their lives. Their death wish has been presented as well-considered, voluntary, consistent, stable, and durable (2-4). However, based on empirical findings in this dissertation and other studies, a more complex picture emerges.

First, although those who requested EAS were mostly 75 years and older (Chapters 6 and 7), the majority of the older adults with a persistent death wish without severe illness were relatively younger older adults under the age of 75. (Chapter 3) Besides, health problems came to the fore as aspect strengthening the death wish, element of suffering, and reason to request EAS. (Chapters 4, 5, 6 and 7) Our results indicate that the group we identified as having a persistent death wish without being severely ill cannot be characterized as a group of healthy older persons. (Chapter 3) Further, almost one in five respondents with a persistent death wish without severe illness reported having had a death wish their whole lives. (Chapters 3 and 5) In our study of specifically these lifelong death wishes, we found that certainly not all older adults with a persistent death wish without severe illness look back on a good and satisfying life; part reported trauma and not having many good memories. (Chapter 5) Also the mostly negative way in which requests for EAS were motivated by applicants at EEC (e.g., having enough of life and being sick of life) does not suggest that they all look back on a good and satisfying life. (Chapter 6) Only a few applicants expressed their reasons for the request in a positive way (e.g., having had a good life and wanting a good death). Finally, while no (or limited) future perspective was most frequently mentioned as aspect strengthening the death wish by older adults with a persistent death wish without severe illness (67%) they mentioned much more aspects, such as worrying, loneliness, not enough good social contacts and activities, feeling like being a burden to others, and financial problems. (Chapter 5) Our results indicate that death wishes of older adults without severe illness can be accompanied by multiple forms of distress, suffering, and needs. (Chapters 2-7)

Second, the expression of having a death wish is characterized by ambivalences and ambiguities. For example, the expression of having a death wish can have different meanings. For some the death wish can indeed best be described as a wish to end their lives but for others the death wish is an expression of waiting for death to come or an expression of considering their current situation unlivable. (Chapters 3-5) The findings in this dissertation underline in a robust quantitative way what is also indicated in several interview studies about ambivalences and ambiguities (5-7). The older adults concerned live with mixed feelings about the death wish; on the one hand there can be the longing for a self-chosen death and on the other hand there can be the wish to live (7). They live fluctuating patterns of distress and relief, and may themselves be confused about and struggle with their death wishes (6-7). They may simultaneously feel detached from and attached to life (6). Their death wish may be driven by both rational considerations and non-rational bodily and emotional compulsions. They may experience being in control while also being uncertain and worried about the dying process. Their death wish may feel both legitimate and illegitimate. Lastly, they may on the one hand resist interference and on the other hand long for support. While they wish to run their own affairs without being interfered by others, findings at the same time indicate that the older adults concerned are highly dependent on others for their well-being and desire to be valued, recognized, wanted, depended upon, needed, or attended by others (5). Besides, while the death wish is driven by the great value that is attached to autonomy and independence, it is strongly influenced by loneliness, sadness, and fears.

Third, the death wish is often experienced in a dynamic way. For example, some periods the wish to live is stronger and at other times the death wish is dominant. (Chapters 4 and 5) Interview studies found fluid and potentially shifting wishes as well (6-7). Over the long-term, the death wish was unpredictable and subject to change over time (7). It may become realized, intensify, diminish, or vanish. These changes are often impacted by external circumstances. For example, a death wish that diminishes or vanishes is often associated with an establishment or reestablishment of connections with other people, society, or oneself. This highlights the relational and situational context in which the death wish emerges. That connections with other people, society or oneself are important for the older adults concerned is now also shown in a robust quantitative way. Not only the needs they express but also various aspects strengthening the wish to live point towards the importance of such connections; making a difference for others, being respected and appreciated by others, good social contacts and friendship, taking care of others, sense of being connected to other people, being meaningful to people around, social engagement, sense of being part of a community, meaningful social activities, feeling useful, and the sense of self-respect. (Chapter 5) Part of these aspects can, if not satisfied, also be aspects strengthening the death wish.

Potential vulnerabilities of older adults with "completed life"

If the complexity of a "completed life" experience is not sufficiently acknowledged, potential vulnerabilities of older adults with "completed life" might not be taken into account. Empirical findings suggest that there are particular situations which could make older adults with a death wish without severe illness vulnerable to non-autonomously deciding to end their lives. It is common to regard a decision as autonomous if one is able to make a well-informed, voluntary decision in a mentally competent state (8-9). The latter means that one has the decision-making capacity to communicate a choice, understand relevant information, appreciate (consequences of) the current situation, and reason about information rationally (10). Besides, there are particular situations which could make older adults with a death wish without severe illness vulnerable to remain out of sight of care providers and others who might provide them with adequate help and support to relieve sources of distress and suffering, and to fulfill needs.

For instance the following -according to empirical findings realistic- situations might be the case: not discussing the death wish with anyone; being driven by non-rational bodily and emotional compulsions or the feeling like being a burden to others; suffering from mental health problems or decline; being confused about and struggling with the death wish due to mixed and unstable feelings; longing for better and more social contact and professional care and support; longing for good conversations with a professional, other older persons, or others in the same situation; being restrained in terms of, for instance, financial resources, mobility, access to transportation, and dependence on others.

Older adults in such situations may not be able to make an autonomous decision to end life when they are driven by involuntary pressures. Or when they cannot make the decision in a mentally competent state due to suffering from mental health problems or decline. Besides, when they are confused about and struggle with the death wish but do not have access to good conversations or other care and support, they may not find out what they truly wish, what possible responses to the death wish could be, and how sources of distress and suffering can be relieved or needs can be fulfilled. If one does not find out about possible, reasonable other ways to respond to the death wish than by ending one's life, this hampers a well-informed decision to end life. Further, older adults in such situations may be vulnerable to being deprived of adequate help and support when they do not discuss the death wish with anyone. Or when they are dependent on others but have social, practical, and material restraints to receive care and fulfill needs.

Different accounts of the concept of vulnerability

These potential vulnerabilities in terms of particular situations that could make one vulnerable to non-autonomously deciding to end one's life and to being deprived of adequate help and support, can be linked to bioethical literature on the concept of vulnerability. Concern for vulnerability appears to be at the heart of bioethics because bioethics is occupied with, among others, respect for autonomy and risk of harm (11). Bioethical literature links vulnerability to a limited capacity for autonomy and an increased risk of harm.

The concept of vulnerability has been interpreted in different ways. One of the accounts holds that vulnerability is an ontological condition of human beings (11). Because we are embodied beings we are all susceptible to illness, disability, injury, death, and dependence on care of others; because we are social and affective beings we are all susceptible to grief and loss, neglect, abuse, rejection, a lack of care, humiliation, and ostracism; and because we are sociopolitical beings, we are all susceptible to oppression, exploitation, manipulation, rights abuses, and political violence (12). Finally, we all live in an environment that may affect us. It has been argued that this account of vulnerability has the disadvantage that if everyone can be considered vulnerable, then the concept of vulnerability potentially becomes too broad, vacuous, and of limited practical use (12-13).

Another account of vulnerability does not stress our common vulnerability, but focuses on specific persons or groups that are susceptible to specific threat or harm (12). Vulnerable are those persons with less capacity, control, or power to protect their interests relative to other persons. A disadvantage of this account of vulnerability is that there are dangers involved with labeling specific persons or groups as vulnerable, such as the danger of stereotyping and discriminating certain persons or groups (12-14).

There is also the layered notion of vulnerability, which indicates that people might have several different and sometimes overlapping layers of vulnerability (14-15). It takes into account that within a certain group, each person may be burdened with other layers of vulnerability related to their own characteristics and circumstances (14). This layered notion of vulnerability aims to avoid the dangers of labeling specific persons or groups as vulnerable. It understands vulnerability in a relational and dynamic way and holds that it is not the case that a person *is* vulnerable, as if it were a fixed label on this person or a permanent and categorical condition. Instead, what is the case is that there are particular situations which could *make* a person vulnerable. The layered notion of vulnerability pays attention to the relation between persons and their circumstances or context, and recognizes that if these circumstances or context change, the person may no longer be rendered vulnerable.

This latter account of the concept of vulnerability seems suitable to apply to the potential vulnerabilities of older adults with "completed life". The idea that within a certain group, each person may be burdened with other layers of vulnerability related to their own characteristics and circumstances, seems to be well-applicable to the heterogeneous group of older adults with a death wish without severe illness. Besides, the relational and dynamic ideas of the layered notion of vulnerability seem to fit well with the relational and situational context in which the death wish of older adults without severe illness emerges.

Moral obligations arising from vulnerability

With concern for vulnerability at the heart, bioethics is also occupied with the kind of moral response that is required by the identification of vulnerability (11). Vulnerability itself can be viewed as a source of moral obligation, but vulnerability can also be viewed as the signal that there may be harm or need from which moral obligations arise (12). From an ontological perspective it can be said that there is no need to protect some people from vulnerability because vulnerability is a "natural fact" that is shared by everyone (15). On the other hand, it has been argued that our common vulnerability encourages us to respond to "more than ordinary vulnerability" on the basis of a sense of solidarity (11-12). Moral obligations that are involved in responding to vulnerability are, among others, protection from harm, giving care, and meeting needs but also promoting autonomy and capabilities of the persons concerned (12).

Luna, who proposed the layered notion of vulnerability, argues as well that obligations are attached to the identification of layers of vulnerability of other people, and that these obligations can be expressed by means of protections and safeguards but also by the generation of autonomy and empowerment (15). She describes we should avoid exacerbating, eradicate, or minimize the layers of vulnerability of other people. The several different and sometimes overlapping layers may be unfolded and removed layer by layer through multiple approaches (14).

Responding to vulnerability and respect for autonomy

There are accounts of vulnerability that focus on the obligation of protection from harm and not on the obligation to promote autonomy and capabilities (12, 16). This opens the door to unwarranted paternalistic interventions (12). Therefore, there is sought for a way to reconcile the obligation of protection from harm with respect for autonomy: "If human persons are both ontologically vulnerable but also autonomous agents, then we need an account of autonomy that is premised on recognition of vulnerability and an analysis of vulnerability that explains why we have obligations not only to protect vulnerable persons from harm but also to do so in ways that promote, whenever possible, their capacities for autonomy” (11-12).

Responding to vulnerability might seem inconsistent with respect for autonomy. That might seem the case if autonomy is interpreted as a right to self-determination and freedom, sometimes referred to as “negative” autonomy (17). This interpretation of autonomy holds that input from other people may be seen as threat rather than as helpful. Complementary to the “negative” interpretation of autonomy, there is another interpretation of autonomy, which can be referred to as “positive” autonomy. This complementary interpretation of autonomy views autonomy as an ideal that can be pursued in interaction with other people. Relational theories of autonomy consider autonomy as “a socially constituted capacity, which is developed, sustained, and exercised only with extensive social scaffolding and support” and important to lead a flourishing life (11). According to this complementary interpretation of autonomy, responding to vulnerability is not at all inconsistent with respect for autonomy. Rather, it holds that the moral demands arising from vulnerability extend beyond strategies such as the provision of protections and safeguards to prevent harm, to strategies such as the provision of social support to promote autonomy (11, 15).

Identifying layers of vulnerability which could make older adults with a death wish without severe illness vulnerable to non-autonomously deciding to end their lives and to being deprived of adequate help and support, asks for a response in which autonomy is promoted and harm is prevented. Interaction with other people might promote autonomy and the receipt of adequate help and support. For instance, good conversations or other care and support might enable someone to find out what one truly wishes, what possible responses to the death wish could be, and how sources of distress and suffering can be relieved or needs can be fulfilled. It is in line with the “positive” interpretation of autonomy to position ourselves next to persons with “completed life” to explore together how potential vulnerabilities and the death wish can best be taken care of.

IMPLICATIONS OF OUR MAIN FINDINGS FOR POLICYMAKING ON “COMPLETED LIFE”

The public and political debate about “completed life” is highly focused on the question whether older adults with “completed life” who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. Our findings show that policymaking only targeted at legal options for assisted dying would be too narrow-focused. Having a persistent death wish without severe illness is not necessarily accompanied by a wish for a self-directed death. (Chapters 3 and 4) In fact, the majority of older adults with a persistent death wish without severe illness report a death wish that can best be described as a desire to not wake up tomorrow and die in their sleep or as a desire for a natural death that just happens. Far from all older adults with a persistent death wish without severe illness actively act upon their death wishes; a considerable part does not make concrete plans or take steps and/or does not seriously consider attempting suicide. Besides, not all older adults with a persistent death wish without severe illness express needs concerning ending their lives. (Chapter 5) These older adults may currently not, and perhaps never, aim for a self-directed death. They may have other, such as social, practical, and material needs.

At the same time, among others, chapters 6 and 7 show that there actually are older adults with a death wish without severe illness who actively act upon their death wishes. Moreover, our findings in chapter 6 suggest that there is an actual group among those who wish to end their lives by means of EAS, which falls outside the scope of the WTL because of the 'medical ground'-boundary. The needs that are most frequently expressed by older adults with a persistent death wish without severe illness show the wish for access to a suicide drug and the wish for assistance from a doctor to commit suicide. (Chapter 5) While this does not necessarily mean that all older adults who express such needs would, if available, actually choose to use these options, for the majority of the older adults with a persistent death wish without severe illness, legal options for assisted dying seem to be important.

Both assistance in living and assistance in dying can thus be needed by older adults with a death wish without severe illness. With regard to assistance in living, policymaking might be directed towards tackling the challenges faced by older adults with a death wish without severe illness. This policy direction seems logical given the physical, psychological, social, and existential dimensions of suffering that came forward in our studies. (Chapters 2-7) Besides, older adults with a persistent death wish without severe illness report all kinds of needs, suggesting that they face challenges for which they wish help and support. (Chapters 4 and 5)

Nevertheless, whereas for instance social, practical, and material challenges can sometimes be tackled, not all challenges faced by older adults with a persistent death wish without severe illness can be tackled. For example, physical or mental deterioration, diseases, loss of one's loved ones (e.g., through death, divorce), and dependence on others cannot (always) be remedied. Further, it may be that the aim to tackle challenges is for some older adults and for some challenges not the best way to provide help and support. For instance, social interventions that aim to tackle loneliness could actually worsen feelings of loneliness, as these interventions may not give room to live through one's inner experience and may simplify a deep sense of separation to a solvable problem (18).

Therefore, it seems desirable that next to being directed towards tackling certain challenges, policymaking is directed towards assigning sense and meaning to other challenges. The latter policy direction is not occupied with the desire to control and solve suffering but with the existential question: what does it mean to get older and how can we relate ourselves to the inevitable challenges that accompany getting older (18)? It centers around a learning process on how to cope with loss, powerlessness, failure, diminishing possibilities, and suffering (19). Assigning sense and meaning to challenges is consistent with the recovery model in which the focus lies on regaining a meaningful life despite challenges (20). The recovery model is not about 'getting rid' of problems but about seeing beyond problems to develop relationships, activities, and goals that give one's life meaning. Assigning sense and meaning to challenges is also consistent with the model of positive health in which "the ability to adapt and self manage in the face of social, physical, and emotional challenges" is emphasized instead of viewing health as complete wellbeing (21). If one is able to cope with life's ever changing social, physical, and emotional challenges, one may live a fulfilling life and foster a feeling of wellbeing despite those challenges. Existential treatment may help to promote such coping (22). Components of existential treatment are working in a relational way, showing empathy, fostering conditions for co-creation and cooperation, getting involved and engaged with the person concerned, and trying to create perspective, for example, through an appreciative inquiry of positive elements in life.

In order to assist older adults with a death wish without severe illness in living by means of tackling or assigning sense and meaning to challenges, it seems important to carefully assess the context of the person concerned. The group of older adults with a death wish without severe illness is heterogeneous and the background of their death wishes is diverse. For different persons different characteristics and circumstances, aspects strengthening the death wish or wish to live, elements of suffering, and needs may play a role. Therefore, personalized help and support, attuned to what makes sense and meaning to the person involved and to his or her personal preferences, values, and wishes, seems vital.

But what if help and support to tackle challenges or to assign sense and meaning to challenges is rejected by the older person and the wish to end life continues? Or what if despite such help and support the wish to end life continues? Should policymakers provide legal options for assisted dying for such cases? On the one hand, it might in some cases be desirable to help those with a continuing wish to end life, who might eventually nonetheless realize this wish, to end life in a peaceful, non-violent way, if existing options (23) such as voluntarily stopping with eating and drinking under supervision do not sufficiently provide for this. Longitudinal research has shown that in some cases the death wish intensifies and becomes realized over the long-term (7). On the other hand, there are many counterarguments with regard to the provision of a legal option for assisted dying to older adults with "completed life" who are not eligible for EAS but wish for a self-directed death. For example, the negative message it may convey about getting older, the choice it may impose on older adults who consider their lives “completed”, the danger it may create by potential easier access to lethal substances, and the undermining it may cause of the well-functioning and careful EAS legislation and practice (23). In their report on “completed life”, committee Schnabel discusses pros and cons of various possibilities.

Perhaps, expanding the current EAS legislation and practice is the most promising option to reconcile the call for legal options for assisted dying with counterarguments. This option prevents the danger of easier access to lethal substances and the emergence of two routes (i.e., the existing route and a new route with less due care) by which the current EAS legislation and practice might be undermined. Besides, compared to some other possibilities, this option may have less negative impact on the perception of getting older and on potential pressure on older adults, since an expanded version of the current EAS legislation and practice would approach the death wish of older adults without severe illness with all kinds of safeguards. However, as the current EAS legislation and practice are medicalized, there are obstacles for the realization of this option (23). In addition, this option will probably not satisfy all proponents because it requires the assessment of due care criteria by physicians. Some proponents express the preference of no interference and wish, for example, for a “Drion pill” or “last-will-pill” which can be taken at a self-chosen moment without the approval of someone else (24).

Yet, no interference is undesirable. If future developments would at some point result in legal options for assisted dying for older adults with “completed life” who wish for a self-directed death, due care is required. Among others, to verify that the decision to end life is an autonomous decision, which includes being able to make a well-informed decision by being aware of possible, reasonable other ways to respond to the death wish than by ending one’s life. Just like all other cases of assisted dying, this due care is important to prevent the situation that the irreversible decision is made to end the life of someone who actually does not want to die. There is no reason to omit such due care in cases of older adults with a death wish without severe illness, especially considering the potential vulnerabilities of these older adults.

STRENGTHS AND LIMITATIONS OF THIS DISSERTATION

A strength of this dissertation is the fact that it contains the first internationally published robust quantitative insights into the prevalence, characteristics, and circumstances of older adults with a death wish without severe illness and the background of their death wishes. These insights, combined with findings from other studies inside and outside this dissertation, were used to come to empirically funded ideas about what is important to take into account for policymaking on “completed life”.

That the findings in this dissertation are valued and have impact is shown by the fact that, among others, the Council of State, a prominent advisory body in the Netherlands, has used these findings to advise on a new legal framework that was proposed to facilitate assisted dying for older adults who are not severely ill (25-26). Based on our findings, the Council of State mentions several aspects that indicate the complexity of the experience of older adults with a death wish without severe illness (25). It raises objections to the due care criteria as proposed in the new legal framework, since these are, according to the Council of State, insufficient to verify that the wish to end life is voluntary and representing one's true wish, that it is stable and coherent, and that it is not related to medical problems or other problems that may be solvable, such as financial problems. These objections of the Council of State align with concerns that were pointed out in chapter 8 and further elaborated in the discussion of this dissertation.

A limitation of this dissertation is the fact that we had to work with several illusive concepts, which are open to more than one interpretation. First and foremost, "completed life", which has repeatedly been labeled as an umbrella term that does not have an unequivocal meaning (23, 26). Second, our operationalization of "completed life" as older adults with a death wish without severe illness, contains concepts that are difficult to define as well. Who are older adults, what exactly is a death wish, and when is someone severely ill or not? As a team we had to make choices in how to operationalize the illusive concepts we had to work with. The operationalization of concepts affects the measurements and therefore the results. Nevertheless, because we based our operationalizations where possible on literature and on the views of a multidisciplinary panel of experts, we believe the choices we made correspond with the interpretation of a relatively large group of people with knowledge on the issue of concern.

Another limitation of this dissertation is that it does not provide a complete overview of all requests for EAS of older adults with a death wish without severe illness that currently fall outside the scope of the WTL because of the 'medical ground'-boundary. We studied these requests at a logical place because EEC typically receives complex, less common requests for EAS in which many physicians outside EEC have reservations (27-30). Nevertheless, EEC is not the only place where older adults with a death wish without severe illness may request EAS. In our study at EEC, we found that in 19 cases (8%), no or insufficient medical ground for the suffering was the sole reason for the request not resulting in EAS. While this suggests that there is an actual group among those who wish to end their lives by means of EAS, which falls outside the scope of the WTL because of the 'medical ground'-boundary, this dissertation does not provide insight into the number of such cases. Insight into this number would be interesting to gain more knowledge on the extent to which the WTL offers sufficient scope to mitigate the majority of "completed life" (23). After all, the public and political debate focuses on the group of people with "completed life" for whom the by committee Schnabel mentioned broad interpretation and practice of the WTL does not offer sufficient solace.

FINAL SHORT OUTLOOK ON THE FUTURE

The recently published integral care agreement describes the ambition of a broad range of parties in several sectors for future-proof healthcare (31). In this agreement, health is viewed as a broad concept that is not only related to physical and mental wellbeing, but also to people's social, living, educational, working, and financial circumstances. Health is influenced by the extent to which someone is able to participate in society. The integral care agreement strives for a healthy society in which all these health aspects are promoted not only by care parties, but also by governmental, business, and other parties. It is committed to reduce health inequalities, to reinforce collective resilience, and prevention.

This future ambition sounds promising for the issue of "completed life". If promoting the described broad range of health aspects succeeds, this could foster a resilient society in which people are connected and able to participate. In such a society, also those who face the inevitable challenges of getting older may live a meaningful life. And if older adults without severe illness would develop a death wish, the promotion of aspects such as good social contacts and connections with other people, comfortable living conditions, meaningful activities, financial leeway, social engagement, and the sense of being part of a community may fulfill their needs and strengthen their wish to live. (Chapter 5)

How we respond to the issue of "completed life" reveals something about the society we are. On the one hand, there is the call for assistance in dying and there seem to be people whose requests for EAS actually fall outside the scope of the WTL because of the 'medical ground'-boundary. The needs that are most frequently expressed by older adults with a persistent death wish without severe illness show the wish for access to a suicide drug and the wish for assistance from a doctor to commit suicide. (Chapter 5) On the other hand, the empirical findings in this dissertation indicate that there can be much more answers to the issue of "completed life" than assistance in dying. Assistance in living can also be needed by older adults with a death wish without severe illness. Moreover, a "completed life" experience can be accompanied by particular situations that could make older adults with a death wish without severe illness vulnerable to non-autonomously deciding to end their lives and to being deprived of adequate help and support. Taking these empirical findings seriously, means that we cannot deny that both needs for assistance in dying and assistance in living exist and that the death wish of older adults without severe illness should be approached with care. It is worth pursuing to be a society in which we care about each other, recognize each other's needs, and try to find a middle-ground to reconcile different needs of different people.

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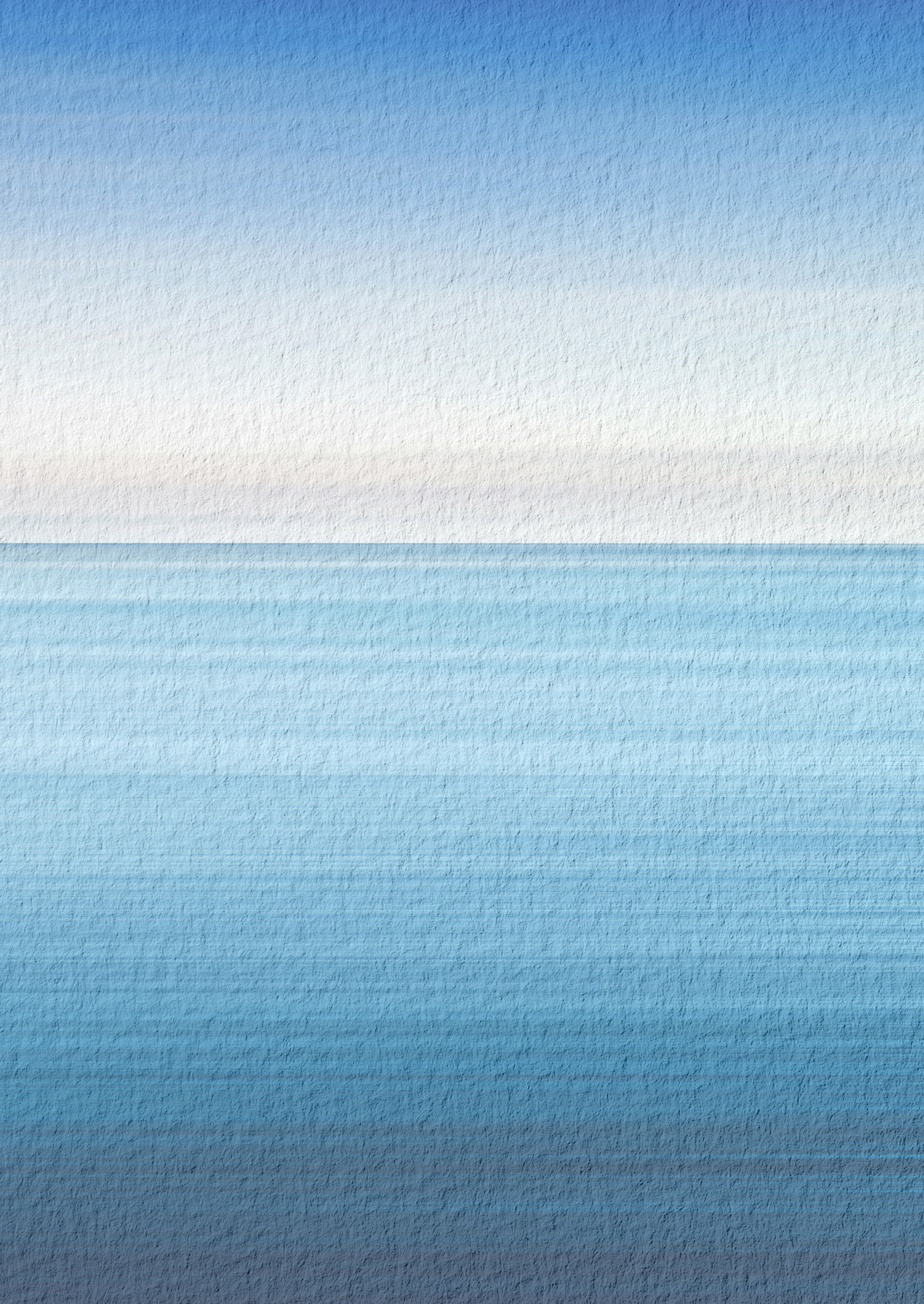

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Summary
Nederlandstalige samenvatting
Dankwoord
Curriculum vitae
List of publications
List of abbreviations

SUMMARY

This dissertation is about older adults who have a death wish without being severely ill. Some older adults may come to the conclusion that even though they are not severely ill, the quality and the meaning of their life has deteriorated to such extent that they do no longer see a future for themselves and prefer death over life, leading to a death wish and sometimes also to a wish for a self-directed death. One commonly used expression for this experience is “completed life”.

To be eligible for euthanasia and assisted suicide (EAS) in the Netherlands, it is, among others, required that the patient’s suffering is mainly based on medical ground. This means that patients who do not have one or more medically classifiable somatic or psychiatric diseases or conditions, or whose suffering does not mainly originate from those, are not eligible for EAS.

Strictly speaking, “completed life” may occur both in cases with and cases without suffering mainly based on medical ground. Therefore, it has been described that “completed life” may fall both inside and outside the scope of the current EAS legislation. It may fall inside the scope, because cases of “completed life” are considered to be cases that are closely related to cases of multiple geriatric syndromes. Suffering from multiple geriatric syndromes can be judged as suffering mainly based on medical ground.

However, the public and political debate focuses on older adults with “completed life” without a medical ground that predominantly accounts for their suffering and who are therefore not eligible for EAS under the current EAS legislation. There are people who hold the view that the current EAS legislation should be expanded or otherwise legal options for assisted dying should be provided for these older adults.

In the beginning of 2019 when the work for this dissertation started, there was an ongoing public and political debate about “completed life”. The debate centered around the question whether older adults with “completed life” who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. At the same time, due to the limited empirical knowledge that was available, arguments for and against offering such legal options were mainly ideological and theoretical in nature. For well-informed policymaking on how the death wish of older adults with “completed life” can be appropriately responded to, more empirical knowledge was required. There was insufficient empirical knowledge on how many older adults have a death wish without being severely ill, who these older adults are, what the background of their death wishes is, and how their requests for EAS are handled by medical professionals. This dissertation aimed to address this knowledge gap by answering the following research questions:

1. What is the prevalence of older adults with a death wish without severe illness?
2. How can older adults with a death wish without severe illness be described in terms of characteristics and circumstances?

3. What is the background of the death wish of older adults without severe illness considering the nature of the death wish, motivations and needs behind the death wish, and communication about the death wish?
4. How are requests for euthanasia and assisted suicide (EAS) of older adults with a death wish without severe illness decided upon by Euthanasia Expertise Center (EEC) and assessed by the Regional Euthanasia Review Committees (RTEs)?
5. In what ways can be appropriately responded to the death wish of older adults without severe illness in light of empirical findings?

Various sources were used to answer the research questions in this dissertation. First, a review of the literature was conducted to study the state of affairs of international scientific knowledge on older adults with a death wish without severe illness. (**Chapter 2**) Second, a survey among a representative sample of over thirty-two thousand Dutch citizens aged 55+ was executed for insight into older adults with a death wish without severe illness in the Dutch general population. (**Chapter 3**) Two sub studies of this survey were performed. One studied the subgroup of older adults aged 75+ because this group was targeted by a new legal framework that was proposed to facilitate assisted dying for older adults who are not severely ill. (**Chapter 4**) The other studied the relatively large subgroup of older adults with a lifelong death wish that emerged from the main study, as differentiating this group from older adults who developed a death wish later in life can be relevant for the provision of adequate help and support. (**Chapter 5**)

Also two other sources were consulted that particularly focused on active acting upon the death wish by means of requesting EAS. The third source was the record at Euthanasia Expertise Center (EEC) of requests for EAS that did not result in EAS. (**Chapter 6**) By means of this source, actual requests for EAS in the categories "multiple geriatric syndromes" and "no medical ground", and the decision-making process of EEC in these types of requests could be studied. Lastly, the fourth source was the national open access database of the Regional Euthanasia Review Committees (RTEs). (**Chapter 7**) In this database, case summaries of granted requests for EAS in, among others, the category "multiple geriatric syndromes" are published. Besides studying actual requests for EAS that were granted in the category "multiple geriatric syndromes", the database of the RTEs provided the opportunity to study the assessment of the RTEs in these types of requests.

Chapter 8 brings empirical findings from this dissertation and from other studies together to start with an answer to research question 5. This beginning of the answer to research question 5 is further elaborated in the general discussion of this dissertation. The general discussion also contains an arch over all chapters, stating our main findings. Summarized versions of answers to the research questions are presented below:

Answer to research question 1 - Our survey indicates that 1.34% of all older adults aged

55+ in the Netherlands have a persistent death wish in the absence of severe illness (± 76,000 persons, estimated based on CBS data from 2019). This percentage was 2.07% in the subgroup of older adults aged 75+ (± 29,000 persons, estimated based on CBS data from 2019). Only part of them has made concrete plans or has taken steps and/or has seriously considered attempting suicide in the past 12 months. Of those who did and thus have an active persistent death wish, only part reported that their death wishes – according to themselves – can best be described as a wish to end their lives.

Our review of the literature and previous reviews of the literature show a limited amount of national and international quantitative data sources on the prevalence of older adults with a death wish without severe illness. In the four studies we found, the identified prevalence ranged from 0.38% to 7.7%. The prevalence was difficult to compare among the studies, for example, due to different ways in which the absence of severe illness was interpreted and operationalized.

Answer to research question 2 - Several chapters in this dissertation show that the characteristics and circumstances of older adults with a (persistent) death wish without severe illness vary, e.g., in terms of gender, age, educational attainment, social class, worldview, marital status, having (step)children, and living conditions. Our survey suggests that some characteristics and circumstances occur more often among older adults with a persistent death wish without severe illness if compared with older adults who did not recognize themselves in the description ‘seeing no future for oneself, longing for death, while not being severely ill’, namely, living alone, having no or less (step)children, being of lower social class, living in highly urbanized areas, and not having a religious worldview. We found no statistically significant differences for gender, age, and educational attainment. With regard to age, our survey indicates that a persistent death wish without severe illness occurs not only in the oldest old. In the total group aged 55+, the majority with this wish were under the age of 75.

In our study at EEC, we found that most applicants were 75 years and older and in our study at the RTEs we found that most applicants were oldest old; between 90 and 100 years old. Both studies showed that approximately three-quarters of the applicants were women.

In our study of older adults with a lifelong death wish, we found that they were statistically significantly younger and more often had no (step)children compared to older adults with a persistent death wish that was not lifelong. Overall, both groups appeared to be similar in terms of characteristics and circumstances.

Answer to research question 3 - Our survey shows that persistent death wishes of older adults without severe illness are diverse in nature (e.g., different ways in which the death wish is characterized and durations ranging from one year to lifelong). Besides, the death wish is often experienced in a dynamic way (e.g., some periods the wish to live is stronger and at other times the death wish is dominant).

Older adults with a (persistent) death wish without severe illness report motivations indicating physical, psychological, social, and existential dimensions of suffering. Health problems came to the fore as aspect strengthening the death wish, element of suffering, and reason to request EAS. Needs that were mostly expressed by older adults with a persistent death wish without severe illness were access to a suicide drug and assistance from a doctor to commit suicide. Not all expressed needs concerning ending one's life though. Besides, also other needs were expressed; social needs, needs for activities, needs for care and guidance, and needs for practical or material things. These latter needs seem to be in line with aspects that strengthened the death wish, such as loneliness, not enough good social contacts and activities, physical or mental deterioration, diseases, being dependent on others, and financial problems.

Of the older adults with a persistent death wish without severe illness, nearly 40% did not discuss the death wish with anyone. Of the approximately 60% who did communicate about the death wish, most discussed it with their doctor and/or other healthcare professionals. The expression of having a death wish is characterized by ambivalence and ambiguity, as there may be mixed feelings about and different meanings of the death wish, respectively.

In our study of older adults with a lifelong death wish, we found that they statistically significantly less often looked back on a good and satisfying life with many good memories than older adults with a persistent death wish that was not lifelong. They more often reported trauma. On the contrary, older adults with a persistent death wish that was not lifelong more often reported the loss of loved ones as an aspect strengthening their death wishes.

Answer to research question 4 - Our study at EEC shows that the 'medical ground'-boundary is reflected upon and applied as a reason to decline requests for EAS by physicians at EEC. Applicants indicated physical problems most often as element of suffering and as reason for the request for EAS. However, from the physician's perspective, in a significant part of the cases there was no or insufficient medical ground for the suffering to grant EAS. Based on the findings in this study it seems that there are people whose requests for EAS actually fall outside the scope of the current EAS legislation solely because of no or insufficient medical ground for the suffering. Also several requests for EAS related to multiple geriatric syndromes were declined because of the 'medical ground'-boundary.

Our study at the RTEs shows that next to a sum of geriatric syndromes, the presence of one single geriatric syndrome can be judged as sufficient medical ground for the suffering to grant EAS, both by the physician who performs EAS and the RTEs that assess EAS afterwards. During the review process, the RTEs had additional questions concerning the physician's justification for performing EAS in some cases.

Approximately one-third concerned questions regarding the unbearableness of the patient's suffering and whether this suffering originated from a medically classifiable disease. The 'medical ground'-boundary is thus addressed in the assessment of the RTEs. The RTEs concluded in all but one case that EAS was performed in accordance with the due care criteria of the EAS legislation. In the case that was not approved, several due care criteria were not met.

Answer to research question 5 - Based on empirical findings in this dissertation and other studies, a more complex picture of "completed life" emerges than how this experience has been presented in the public and political debate. It has been presented as the experience of people mostly at an old age without illness who look back on a good life in which most of what they wished for has been achieved. Now there is little to no future perspective they wish to end their lives. Their death wish has been presented as well-considered, voluntary, consistent, stable, and durable. However, empirical findings indicate that this view is too simplified. Our findings show that the majority of the older adults with a persistent death wish without severe illness are relatively younger older adults. They cannot be characterized as a group of healthy older persons. Besides, certainly not all these older adults look back on a good and satisfying life. Next to limited or no future perspective, also other aspects strengthen the death wish, such as worrying, loneliness, not enough good social contacts and activities, feeling like being a burden to others, and financial problems. Further, they express also other needs than needs concerning ending one's life. Finally, the death wish is often experienced in a dynamic way and is characterized by ambivalence and ambiguity.

If the complexity of a "completed life" experience is not sufficiently acknowledged, potential vulnerabilities of older adults with "completed life" might not be taken into account. Empirical findings suggest that there are particular situations which could make older adults with a death wish without severe illness vulnerable to non-autonomously deciding to end their lives and to being deprived of adequate help and support. For instance, situations in which one suffers from mental health problems or decline, in which one is led by involuntary pressures, and in which one lacks social contact.

These potential vulnerabilities ask for a response in which autonomy is promoted and harm is prevented. In line with the "positive" interpretation of autonomy, which holds that autonomy can be promoted by interaction with others, we might position ourselves next to people with "completed life" to explore together how potential vulnerabilities and the death wish can best be taken care of. Good conversations or other care and support might enable these people to find out what they truly wish, what possible responses to the death wish could be, and how sources of distress and suffering can be relieved or needs can be fulfilled.

The public and political debate about “completed life” is highly focused on the question whether older adults with “completed life” who are not eligible for EAS but wish for a self-directed death should have legal options for assisted dying. Empirical findings show that policymaking only targeted at legal options for assisted dying would be too narrow-focused. There can be much more answers to “completed life” than assistance in dying. Assistance in living can also be needed by older adults with a death wish without severe illness

With regard to assistance in living, policymaking might be directed towards tackling or towards assigning sense and meaning to the challenges faced by older adults with a death wish without severe illness. This policy direction seems logical given the physical, psychological, social, and existential dimensions of suffering that came forward in our studies. Besides, older adults with a persistent death wish without severe illness report all kinds of needs, suggesting that they face challenges for which they wish help and support. It seems vital to provide personalized help and support given that the group of older adults with a death wish without severe illness is heterogeneous and the background of their death wishes is diverse.

But what if help and support to tackle challenges or to assign sense and meaning to challenges is rejected or one’s wish to end life continues despite such help and support? Should policymakers provide legal options for assisted dying for such cases? On the one hand, it might in some cases be desirable to help those with a continuing wish to end life, who might eventually nonetheless realize this wish, to end life in a peaceful, non-violent way, if existing options such as voluntarily stopping with eating and drinking under supervision do not sufficiently provide for this. Longitudinal research has shown that in some cases the death wish intensifies and becomes realized over the long-term. On the other hand, there are many counterarguments with regard to the provision of a legal option for assisted dying to older adults with “completed life” who are not eligible for EAS but wish for a self-directed death. For example, the negative message it may convey about getting older, the choice it may impose on older adults who consider their lives “completed”, the danger it may create by potential easier access to lethal substances, and the undermining it may cause of the well-functioning and careful EAS legislation and practice.

Perhaps, expanding the current EAS legislation and practice is the most promising option to reconcile the call for legal options for assisted dying with counterarguments. This option prevents the danger of easier access to lethal substances and the emergence of two routes (i.e., the existing route and a new route with less due care) by which the current EAS legislation and practice might be undermined. Besides, compared to some other possibilities, this option may have less negative impact on the perception of getting older and on potential pressure on older adults, since an expanded version of the current EAS legislation and practice would approach the death wish of older adults without severe illness with all kinds of safeguards. However, as the current EAS legislation and practice are medicalized, there are obstacles for the realization of this option. In addition, this option will probably not satisfy all proponents because it requires the assessment of due care criteria by physicians. Some proponents express the preference of no interference and wish, for example, for a “Drion pill” or “last-will-pill” which can be taken at a self-chosen moment without the approval of someone else.

Yet, no interference is undesirable. If future developments would at some point result in legal options for assisted dying for older adults with “completed life” who wish for a self-directed death, due care is required. Among others, to verify that the decision to end life is an autonomous decision, which includes being able to make a well-informed decision by being aware of possible, reasonable other ways to respond to the death wish than by ending one’s life. Just like all other cases of assisted dying, this due care is important to prevent the situation that the irreversible decision is made to end the life of someone who actually does not want to die. There is no reason to omit such due care in cases of older adults with a death wish without severe illness, especially considering the potential vulnerabilities of these older adults.

Abbreviations:
EAS = euthanasia and assisted suicide
EEC = Euthanasia Expertise Center
RTEs = Regional Euthanasia Review Committees

NEDERLANDSTALIGE SAMENVATTING

Dit proefschrift gaat over ouderen die een doodswens hebben zonder dat zij ernstig ziek zijn. Er zijn ouderen die tot de conclusie komen dat de kwaliteit en betekenis van hun leven zodanig is afgenomen dat zij, ondanks dat zij niet ernstig ziek zijn, geen toekomst voor zichzelf meer zien en de dood boven het leven verkiezen. Zij ontwikkelen een doodswens en soms ook een wens om hun leven te beëindigen. “Voltooid leven” is een veelgebruikte uitdrukking voor deze ervaring.

Om in aanmerking te komen voor euthanasie en hulp bij zelfdoding (EHBZ) in Nederland is, onder andere, vereist dat het lijden van de patiënt in overwegende mate voortkomt uit een medische grondslag. Dit betekent dat patiënten die niet één of meer medisch classificeerbare lichamelijke of psychiatrische ziekten of aandoeningen hebben, of wiens lijden niet in overwegende mate daaruit voortkomt, niet in aanmerking komen voor EHBZ.

Strikt genomen kan “voltooid leven” zich voordoen zowel bij de aan- als afwezigheid van lijden dat in overwegende mate voortkomt uit een medische grondslag. Daarom is beschreven dat “voltooid leven” zowel binnen als buiten de reikwijdte van de huidige EHBZ wetgeving zou kunnen vallen. Het zou binnen de reikwijdte kunnen vallen, omdat “voltooid leven” casussen worden gezien als casussen die nauw gerelateerd zijn aan casussen waarbij sprake is van een stapeling van ouderdomsaandoeningen. Lijden dat voortkomt uit een stapeling van ouderdomsaandoeningen kan beoordeeld worden als lijden dat in overwegende mate voortkomt uit een medische grondslag.

Het publieke en politieke debat focust zich echter op ouderen met “voltooid leven” wiens lijden niet in overwegende mate voortkomt uit een medische grondslag en die daarom niet in aanmerking komen voor EHBZ onder de huidige EHBZ wetgeving. Er zijn mensen die vinden dat de huidige EHBZ wetgeving uitgebreid zou moeten worden of dat er anderszins legale mogelijkheden voor stervenshulp geregeld zouden moeten worden voor deze ouderen.

Begin 2019 toen het werk voor dit proefschrift van start ging, was er sprake van een voortgaand publiek en politiek debat omtrent “voltooid leven”. Het debat ging vaak over de vraag of ouderen met “voltooid leven” die niet in aanmerking komen voor EHBZ, maar wel de wens hebben om hun leven te beëindigen, legale mogelijkheden zouden moeten hebben voor stervenshulp. Tegelijkertijd waren argumenten voor en tegen het aanbieden van dergelijke legale mogelijkheden hoofdzakelijk ideologisch en theoretisch van aard, vanwege de beperkte beschikbaarheid van empirische kennis. Voor het maken van goed geïnformeerd beleid aangaande hoe op een passende manier gereageerd kan worden op de doodswens van ouderen met “voltooid leven”, was meer empirische kennis nodig. Er was onvoldoende empirische kennis over hoeveel ouderen een doodswens hebben zonder dat zij ernstig ziek zijn, wie deze ouderen zijn, wat de achtergrond van hun doodswens is, en hoe door medisch professionals wordt omgegaan met hun verzoek tot EHBZ. Dit proefschrift had tot doel deze kennislacune weg te nemen door middel van het beantwoorden van de volgende onderzoeksvragen:

1. Wat is de prevalentie van ouderen met een doodswens zonder ernstig ziekzijn?
2. Hoe kunnen ouderen met een doodswens zonder ernstig ziekzijn beschreven worden in termen van kenmerken en omstandigheden?
3. Wat is de achtergrond van de doodswens van ouderen die niet ernstig ziek zijn als het gaat om de aard van de doodswens, beweegredenen en behoeften achter de doodswens, en communicatie over de doodswens?
4. Hoe worden verzoeken tot euthanasie en hulp bij zelfdoding (EHBZ) van ouderen met een doodswens zonder ernstig ziekzijn beoordeeld door het Expertisecentrum Euthanasie (EE) en getoetst door de Regionale Toetsingscommissies Euthanasie (RTEs)?
5. Op welke manieren kan passend gereageerd worden op de doodswens van ouderen die niet ernstig ziek zijn in het licht van de empirische bevindingen?

Verschillende bronnen werden geraadpleegd om de onderzoeksvragen in dit proefschrift te beantwoorden. Ten eerste werd een literatuurreview uitgevoerd om de stand van zaken van internationale wetenschappelijke kennis over ouderen met een doodswens zonder ernstig ziekzijn in kaart te brengen. (**Hoofdstuk 2**) Ten tweede werd een vragenlijstonderzoek uitgevoerd onder een representatieve steekproef van ruim tweeëndertigduizend Nederlandse burgers van 55+ om inzicht te krijgen in ouderen met een doodswens zonder ernstig ziekzijn in de Nederlandse algemene bevolking. (**Hoofdstuk 3**) Dit vragenlijstonderzoek leidde tot twee deelstudies. Eén van die deelstudies bestudeerde de subgroep ouderen van 75+, omdat deze groep werd beoogd in een voorstel voor een nieuw juridisch kader voor het faciliteren van stervenshulp aan ouderen die niet ernstig ziek zijn. (**Hoofdstuk 4**) De andere deelstudie bestudeerde een relatief grote subgroep die naar voren was gekomen in de hoofdstudie, namelijk een groep ouderen met een levenslange doodswens. (**Hoofdstuk 5**) Het onderscheiden van deze groep ouderen met een levenslange doodswens van de groep ouderen die later in hun leven een doodswens ontwikkelde, kan relevant zijn voor het bieden van adequate hulp en ondersteuning.

Daarnaast werden twee andere bronnen geraadpleegd die specifiek gericht waren op actief handelen naar aanleiding van de doodswens door een verzoek tot EHBZ te doen. De derde bron betrof het dossier van het Expertisecentrum Euthanasie (EE) van verzoeken tot EHBZ die niet hadden geresulteerd in EHBZ. (**Hoofdstuk 6**) Met behulp van deze bron konden daadwerkelijke verzoeken tot EHBZ binnen de categorieën "stapeling van ouderdomsaandoeningen" en "geen medische grondslag" bestudeerd worden. Daarnaast bood deze bron de mogelijkheid om het beoordelingsproces van het EE bij dit type verzoeken te bestuderen. Tot slot, de vierde bron was de nationale, vrij toegankelijke database van de Regionale Toetsingscommissies Euthanasie (RTEs). (**Hoofdstuk 7**) In deze database worden samenvattingen gepubliceerd van casussen waarin EHBZ werd toegekend, onder andere binnen de categorie "stapeling van ouderdomsaandoeningen". Naast het bestuderen van daadwerkelijke verzoeken tot EHBZ die werden toegekend binnen de categorie "stapeling van ouderdomsaandoeningen", maakte de database van de RTEs het mogelijk om de toetsing van de RTEs bij dit type verzoeken te bestuderen.

Hoofdstuk 8 brengt de empirische bevindingen in dit proefschrift en van andere studies bijeen om een start te maken met het geven van een antwoord op onderzoeksvraag 5. Het begin van dit antwoord op onderzoeksvraag 5 wordt verder uitgewerkt in de discussie aan het einde van dit proefschrift. De discussie verbindt onze bevindingen in verschillende studies aan elkaar ter beantwoording van de onderzoeksvragen. Samengevatte versies van de antwoorden op de onderzoeksvragen worden hieronder gepresenteerd:

<u>Antwoord op onderzoeksvraag 1</u> - Ons vragenlijstonderzoek geeft aan dat 1,34% van alle ouderen van 55+ in Nederland een persisterende doodswens heeft zonder ernstig ziekzijn (± 76.000 personen, berekend op basis van CBS-cijfers uit 2019). Dit percentage was 2,07% in de subgroep van ouderen van 75+ (± 29.000 personen, berekend op basis van CBS-cijfers uit 2019). Slechts een deel van hen heeft concrete plannen gemaakt of stappen ondernomen en/of heeft serieus overwogen om een suïcidepoging te doen in de afgelopen 12 maanden. Van hen die dit wel deden en van wie dus gesteld kan worden dat zij een actieve persisterende doodswens hebben, rapporteerde slechts een deel dat hun doodswens – volgens henzelf – het beste omschreven kan worden als een wens om het leven te beëindigen.

Onze literatuurreview en eerdere literatuurreviews laten zien dat er een beperkte hoeveelheid nationale en internationale kwantitatieve databronnen bestaan met informatie over de prevalentie van ouderen met een doodswens zonder ernstig ziekzijn. In de vier studies die wij gevonden hebben, varieerde de gevonden prevalentie van 0,38% tot 7,7%. De prevalentie was moeilijk te vergelijken tussen de studies, bijvoorbeeld vanwege het feit dat de afwezigheid van ernstig ziekzijn op verschillende manieren werd geïnterpreteerd en geoperationaliseerd.

<u>Antwoord op onderzoeksvraag 2</u> - Meerdere hoofdstukken in dit proefschrift laten zien dat de kenmerken en omstandigheden van ouderen met een (persisterende) doodswens zonder ernstig ziekzijn variëren. Zo bestond er variatie ten aanzien van geslacht, leeftijd, opleidingsniveau, sociale klasse, levensbeschouwing, burgerlijke staat, het hebben van (stief)kinderen, en leefomstandigheden. In ons vragenlijstonderzoek werden ouderen met een persisterende doodswens zonder ernstig ziekzijn vergeleken met ouderen die zichzelf niet herkenden in de omschrijving 'ik ervaar geen toekomstperspectief, ik verlang ernaar om dood te zijn, en ik ben niet ernstig ziek'. Deze vergelijking suggereert

dat sommige kenmerken en omstandigheden vaker voorkomen onder ouderen met een persisterende doodswens zonder ernstig ziekzijn. Zij woonden vaker alleen, hadden vaker geen of minder (stief)kinderen, behoorden vaker tot een lagere sociale klasse, woonden vaker in sterk verstedelijkte gebieden, en hadden vaker geen religieuze levensbeschouwing. We vonden geen statistisch significante verschillen voor geslacht, leeftijd en opleidingsniveau. Ten aanzien van leeftijd liet ons vragenlijstonderzoek zien dat een persisterende doodswens zonder ernstig ziekzijn niet alleen voorkomt onder de oudste ouderen. In de totale groep van 55+ was de meerderheid met deze wens jonger dan 75 jaar.

In onze studie bij het EE vonden we dat de meeste hulpvragers 75 jaar en ouder waren en in onze studie bij de RTEs vonden we dat de meeste hulpvragers oudste ouderen waren; tussen de 90 en 100 jaar oud. Beide studies lieten zien dat ongeveer driekwart van de hulpvragers vrouw was.

In onze studie naar ouderen met een levenslange doodswens, vonden we dat zij statistisch significant jonger waren en vaker geen (stief)kinderen hadden in vergelijking met ouderen met een persisterende doodswens die niet levenslang was. Over het algemeen zagen beide groepen er vergelijkbaar uit in termen van kenmerken en omstandigheden.

Antwoord op onderzoeksvraag 3 - Ons vragenlijstonderzoek laat zien dat persisterende doodswensen van ouderen die niet ernstig ziek zijn, divers van aard zijn (de doodswens wordt bijvoorbeeld op verschillende manieren omschreven en de duur varieert van een jaar tot levenslang). Daarnaast is de doodswens vaak onderhevig aan verandering (zo is het ene moment de wens om te leven sterker terwijl op een ander moment de doodswens voorop staat).

Ouderen met een (persisterende) doodswens zonder ernstig ziekzijn rapporteren beweegredenen die wijzen op lichamelijke, geestelijke, sociale en existentiële dimensies van lijden. Gezondheidsproblemen kwamen naar voren als een aspect dat de doodswens versterkt, als onderdeel van het lijden, en als reden om een verzoek tot EHBZ te doen. Behoeften die het meest tot uitdrukking kwamen onder ouderen met een persisterende doodswens zonder ernstig ziekzijn, waren toegang tot een zelfdodingsmiddel en hulp bij zelfdoding door een dokter. Echter, niet alle ouderen benoemden behoeften omtrent levensbeëindiging. Bovendien benoemden zij ook andere behoeften; sociale behoeften, behoeften aan activiteiten, behoeften aan zorg en begeleiding, en behoeften aan praktische en materiële zaken. Deze laatstgenoemde behoeften lijken aan te sluiten bij aspecten die de doodswens versterkten zoals eenzaamheid, te weinig fijne sociale contacten en activiteiten, lichamelijke of geestelijke achteruitgang, ziekten, afhankelijkheid van anderen, en financiële problemen.

Van de ouderen met een persisterende doodswens zonder ernstig ziekzijn, besprak bijna 40% de doodswens met niemand. Van de ongeveer 60% die wel communiceerde over de doodswens, bespraken de meesten het met hun dokter en/of andere hulpverleners. Het tot uitdrukking brengen van een doodswens kent ambivalentie en ambiguïteit, aangezien de doodswens respectievelijk gepaard kan gaan met tegenstrijdige gevoelens en verschillende betekenissen kan hebben.

In onze studie naar ouderen met een levenslange doodswens, vonden we dat zij statistisch significant minder vaak terugkeken op een mooi en voldoend leven met veel goede herinneringen dan ouderen met een persisterende doodswens die niet levenslang was. Zij rapporteerden vaker trauma. Ouderen met een persisterende doodswens die niet levenslang was rapporteerden daarentegen vaker het wegvallen van geliefden als een aspect dat hun doodswens versterkt.

Antwoord op onderzoeksvraag 4 - Onze studie bij het EE laat zien dat artsen binnen het EE reflecteren op de medische grondslag vereiste en deze toepassen als reden om verzoeken tot EHBZ af te wijzen. Hulpvragers wezen lichamelijke problematiek het vaakst aan als onderdeel van het lijden en als reden om een verzoek tot EHBZ te doen. Echter, vanuit het perspectief van de arts, bleek in een aanzienlijk deel van de casussen, geen of onvoldoende sprake te zijn van een medische grondslag voor het lijden om het verzoek tot EHBZ toe te kennen. Op basis van de bevindingen in deze studie, lijkt het zo te zijn dat er mensen zijn wiens verzoek tot EHBZ daadwerkelijk buiten de reikwijdte van de huidige EHBZ wetgeving valt, enkel omdat er geen of onvoldoende sprake is van een medische grondslag voor het lijden. Ook verscheidene verzoeken tot EHBZ die gerelateerd waren aan een stapeling van ouderdomsaandoeningen werden afgewezen vanwege de medische grondslag vereiste.

Onze studie bij de RTEs laat zien dat naast een optelsom van ouderdomsaandoeningen, ook de aanwezigheid van één ouderdomsaandoening beoordeeld kan worden als voldoende medische grondslag voor het lijden om EHBZ toe te kennen, zowel door de arts die EHBZ uitvoert als door de RTEs die de uitvoering daarvan naderhand toetsen. Gedurende het toetsingsproces hadden de RTEs in sommige casussen aanvullende vragen ten aanzien van de rechtvaardiging van de arts om EHBZ uit te voeren. Ongeveer een derde betrof vragen met betrekking tot de ondraaglijkheid van het lijden van de patiënt en of dit lijden voortkwam uit een medisch classificeerbare ziekte. De medische grondslag vereiste komt dus terug in de toetsing van de RTEs. De RTEs concludeerden in op één na alle casussen dat EHBZ was uitgevoerd in lijn met de zorgvuldigheidseisen van de EHBZ wetgeving. In de casus die niet werd goedgekeurd, was aan meerdere zorgvuldigheidseisen niet voldaan.

Antwoord op onderzoeksvraag 5 - Op basis van de empirische bevindingen in dit proefschrift en van andere studies, verschijnt een complexer beeld van "voltooid leven" dan hoe de ervaring is gepresenteerd in het publieke en politieke debat. Het is gepresenteerd als de ervaring van mensen op een veelal hoge leeftijd die niet ziek zijn.

Zij kijken terug op een mooi leven waarin zij de meeste wensen bereikt hebben. Nu de toekomst weinig tot geen perspectief meer biedt, wensen zij hun leven te beëindigen. Hun doodswens is gepresenteerd als weloverwogen, vrijwillig, consistent, stabiel en duurzaam. Empirische bevindingen laten echter zien dat dit een te versimpelde opvatting is. Onze bevindingen tonen dat de meerderheid van de ouderen met een persisterende doodswens zonder ernstig ziekzijn relatief jong is en dat zij niet gekarakteriseerd kunnen worden als een groep gezonde ouderen. Daarnaast kijken zeker niet al deze ouderen terug op een mooi en voldoend leven. Naast beperkt tot geen toekomstperspectief versterken ook andere aspecten de doodswens zoals piekeren, eenzaamheid, te weinig fijne sociale contacten en activiteiten, het gevoel anderen tot last te zijn, en financiële problemen. Verder uiten de betreffende ouderen ook andere behoeften dan de behoefte om het leven te beëindigen. Tot slot is de doodswens vaak onderhevig aan verandering en kent deze ambivalentie en ambiguïteit.

Als de complexiteit van een “voltooid leven” ervaring niet voldoende wordt erkend, zou het kunnen dat er geen rekening wordt gehouden met mogelijke kwetsbaarheden van ouderen met “voltooid leven”. Empirische bevindingen suggereren dat er bepaalde situaties zijn die zouden kunnen maken dat ouderen met een doodswens zonder ernstig ziekzijn kwetsbaar zijn voor niet-autonome beslissingen over levensbeëindiging en voor een gebrek aan adequate hulp en ondersteuning. Bijvoorbeeld situaties waarin er sprake is van geestelijke gezondheidsproblemen of achteruitgang, waarin onvrijwillige impulsen een rol spelen, en waarin iemand tekortkomingen ervaart op het gebied van sociaal contact.

Deze mogelijke kwetsbaarheden vragen om een reactie waarbij autonomie wordt bevorderd en schade wordt voorkomen. In lijn met de “positieve” interpretatie van autonomie, die ervan uitgaat dat autonomie bevorderd kan worden door interactie met anderen, zouden we onszelf naast mensen met “voltooid leven” kunnen positioneren om samen uit te zoeken hoe het beste omgegaan kan worden met mogelijke kwetsbaarheden en de doodswens. Goede gesprekken of andere zorg en ondersteuning zouden deze mensen bijvoorbeeld kunnen helpen om uit te vinden wat zij werkelijk wensen, wat mogelijke reacties op de doodswens zouden kunnen zijn, en hoe bronnen van stress en lijden verlicht kunnen worden of hoe behoeften vervuld kunnen worden.

Het publieke en politieke debat over “voltooid leven” is sterk gefocust op de vraag of ouderen met “voltooid leven” die niet in aanmerking komen voor EHBZ, maar wel de wens hebben om hun leven te beëindigen, legale mogelijkheden zouden moeten hebben voor stervenshulp. Empirische bevindingen laten zien dat het maken van beleid dat alleen gericht is op legale mogelijkheden voor stervenshulp, te kortzichtig zou zijn. Er kunnen veel meer antwoorden op “voltooid leven” zijn dan stervenshulp. Hulp bij leven kan ook nodig zijn voor ouderen met een doodswens zonder ernstig ziekzijn.

Ten aanzien van hulp bij leven, zou het maken van beleid gericht kunnen zijn op het aanpakken van, of op het geven van zin en betekenis aan, de uitdagingen die ouderen met een doodswens zonder ernstig ziekzijn tegenkomen. Deze beleidsrichting lijkt logisch gegeven de lichamelijke, geestelijke, sociale en existentiële dimensies van lijden die naar voren kwamen in onze studies. Bovendien rapporteerden de betreffende ouderen allerlei soorten behoeften, wat suggereert dat zij uitdagingen tegenkomen waarvoor zij hulp en ondersteuning wensen. Het lijkt essentieel om gepersonaliseerde hulp en ondersteuning te bieden aangezien de groep ouderen met een doodswens zonder ernstig ziekzijn heterogeen is en de achtergrond van hun doodswensen divers is.

Maar wat als hulp en ondersteuning om uitdagingen aan te pakken of om zin en betekenis te geven aan uitdagingen, wordt afgewezen, of de wens om het leven te beëindigen voortduurt ondanks dergelijke hulp en ondersteuning? Zouden beleidsmakers voor dergelijke casussen moeten voorzien in legale mogelijkheden voor stervenshulp? Enerzijds zou het in sommige casussen wenselijk kunnen zijn om mensen met een voortdurende wens om het leven te beëindigen, die deze wens uiteindelijk hoe dan ook zouden realiseren, te helpen om hun leven op een vredige, niet gewelddadige manier te beëindigen, als bestaande mogelijkheden zoals vrijwillig stoppen met eten en drinken onder begeleiding niet volstaan. Longitudinaal onderzoek heeft laten zien dat de doodswens in sommige gevallen op de lange termijn sterker wordt en wordt gerealiseerd. Anderzijds zijn er veel tegenargumenten als het gaat om het voorzien in legale mogelijkheden voor stervenshulp aan ouderen met "voltooid leven" die niet in aanmerking komen voor EHBZ, maar wel de wens hebben om hun leven te beëindigen. Zo zou hierdoor een negatieve boodschap afgegeven kunnen worden met betrekking tot ouder worden, het zou ouderen die hun leven als "voltooid" beschouwen een keuze op kunnen leggen, het zou gepaard kunnen gaan met gevaar door mogelijk gemakkelijker toegang tot dodelijke middelen, en het zou kunnen resulteren in ondermijning van de goed functionerende en zorgvuldige wetgeving en praktijk zoals we die nu kennen voor EHBZ.

Wellicht zou het uitbreiden van de huidige EHBZ wetgeving en praktijk de meest veelbelovende optie zijn om een midden te vinden tussen enerzijds de vraag naar legale mogelijkheden voor stervenshulp en anderzijds de tegenargumenten. Deze optie voorkomt het gevaar van gemakkelijker toegang tot dodelijke middelen en het ontstaan van twee routes (namelijk de bestaande route en een nieuwe route met minder zorgvuldigheid) waardoor de huidige EHBZ wetgeving en praktijk ondermijnd zouden kunnen worden. Bovendien zou deze optie, in vergelijking met sommige andere opties, minder negatieve invloed kunnen hebben op de perceptie van ouder worden en op mogelijke druk op ouderen, aangezien een uitgebreide versie van de huidige EHBZ wetgeving en praktijk de doodswens van ouderen zonder ernstig ziekzijn zou benaderen met allerlei waarborgen. Echter, omdat de huidige EHBZ wetgeving en praktijk gemedicaliseerd zijn, zijn er obstakels om deze optie te realiseren. Daarnaast zal deze optie waarschijnlijk niet alle voorstanders tevredenstellen, omdat het vereist dat zorgvuldigheidseisen worden beoordeeld door artsen. Sommige voorstanders geven de voorkeur aan geen inmenging en wensen bijvoorbeeld een “pil van Drion” of “laatste-wil-pil” die ingenomen kan worden op een zelfgekozen moment zonder dat daar de goedkeuring van iemand anders voor nodig is.

Echter, geen inmenging is onwenselijk. Als toekomstige ontwikkelingen op enig moment zouden resulteren in legale mogelijkheden voor stervenshulp aan ouderen met “voltooid leven” die hun leven wensen te beëindigen, dan is zorgvuldigheid vereist. Onder andere, om te verifiëren dat de beslissing om het leven te beëindigen een autonome beslissing is, wat omvat dat iemand in staat is om een goed geïnformeerde beslissing te nemen door zich bewust te zijn van mogelijke, redelijke andere manieren om op de doodswens te reageren dan met levensbeëindiging. Net zoals in alle andere casussen van stervenshulp, is deze zorgvuldigheid belangrijk om te voorkomen dat een situatie ontstaat waarin de onomkeerbare beslissing wordt genomen om het leven te beëindigen van iemand die niet daadwerkelijk wil sterven. Er is geen reden om dergelijke zorgvuldigheid achterwege te laten in casussen van ouderen met een doodswens zonder ernstig ziekzijn, zeker gezien de mogelijke kwetsbaarheden van deze ouderen.

Afkortingen:
EHBZ = euthanasie en hulp bij zelfdoding
EE = Expertisecentrum Euthanasie
RTEs = Regionale Toetsingscommissies Euthanasie

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CURRICULUM VITAE

Margot Lisa Zomers was born on the 25th of April 1990 in Veghel and raised in Uden, the Netherlands. After graduating from high school (Udens College) in 2008, she spent a year working, learning Spanish, and travelling in Spain. Subsequently, she started studying Medicine at Utrecht University in 2009. She obtained her bachelor's degree in Medicine. During her studies, she worked as nursing assistant at the department of Hematology in the University Medical Center (UMC) Utrecht. At the end of the first year of her master Medicine, she decided to switch studies. In the meantime, she continued working via the employment agency of the UMC Utrecht as research assistant and receptionist at the departments of Radiology and Cardio-Thoracic Surgery. After two premaster programs, Margot commenced the master Health Sciences (specialization: prevention and public health) and the master Philosophy, Bioethics and Health at VU University Amsterdam. During these two master programs, she completed internships at the National Institute for Public Health and the Environment (RIVM), VU Medical Center (VUmc), and the Center for Ethics and Health (CEG). Margot graduated cum laude in both master programs. Hereafter, she spent half a year travelling in Asia. In the beginning of 2019, she started her PhD on "completed life" at the department of Bioethics and Health Humanities, part of the Julius Center for Health Sciences and Primary Care in the UMC Utrecht. Next to her PhD, Margot taught classes medical ethics and other parts of Medical Humanities to medical students, was secretary of the Hospital Ethics Committee in the UMC Utrecht, and contributed to a two-year project on the ethical evaluation of the Coverage Lock for new expensive medicines. During her PhD she spent another half year travelling in Europe. After the defense of this dissertation, Margot will continue working at the department of Bioethics and Health Humanities.

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LIST OF ABBREVIATIONS

EAS	euthanasia and (physician-)assisted suicide
EEC	Euthanasia Expertise Center
HADS	Hospital Anxiety and Depression Scale
L-PDW	group of older adults with a lifelong persistent death wish
NL-PDW	group of older adults with a persistent death wish, not lifelong
PDW-NSI	group of older adults with a persistent death wish and no severe illness
RTEs	Regional Euthanasia Review Committees
VAS	Visual Analogue Scale
WTL	Termination of Life on Request and Assisted Suicide (Review Procedures) Act