A Life Fulfilled: A Qualitative Study on the Desires of Individuals with a Completed Life in light of the Capability Approach

Abstract

Introduction

An increasing number of Dutch citizens support the possibility for euthanasia or physician assisted suicide for elderly people who view their life as being completed. This population, defined as Dutch citizens aged 55 or over with a persistent death wish, with no serious illness, is estimated to count over 75.600 people. A recent study ("The Perspective Study") assessed their characteristics and factors influencing this death wish. However, their wishes and desires have not yet been studied thoroughly. This study aims to identify those desires using Nussbaum's Capability Approach as a framework.

Methods

Secondary analysis of interview data from the Perspective study using codes based on the capability approach. Participants were included through the survey in the Perspective project. Participants without serious illness answering positively to the question whether they had little to no perspective on life and longed for death were asked to participate in an in-depth interview.

Results & discussion

Participants (n=36) articulated most deficits in capabilities 3 (bodily integrity), 5 (emotions), and 7 (affiliation). The three most mentioned desires were 1) Feeling useful, always in context to other people and society (C5); 2) having social interactions (C7); and 3) having access to a lethal drug and to have more autonomy in death, often due to fear of deterioration (C3). Both desire 1 and 2 imply a certain detachment from others or society. Desire 3 shows how strong the wish for autonomy and control at the end of life and in death is. The question if a last-will pill is the only or most effective way to provide more autonomy at the end of life, remains unanswered. More research into possible ways to intervene needs to be conducted to adequately care for this population, ideally assessed through social as well as medical and ethical research. The Capability Approach formed a well-rounded framework in identifying desires in this population and may be a foundation for use in clinical practice.

Eindproduct Wetenschappelijke Stage Medische Ethiek – UMC Utrecht – GNK Master jaar 3
Ó.M. Witteman – studentnr. 5835771
Supervisie: dr. G.J.M.W. (Ghislaine) van Thiel en drs. M.L. (Margot) Zomers

Introduction

The political debate if euthanasia or physician assisted suicide (EAS) for elderly people who view their life as being completed should be legalised, polarises politicians and citizens in The Netherlands. An increasing amount of people support the idea that elderly people should be able to receive a lethal drug to autonomously end their life.[1] However, until recently, little research had been done to identify and estimate the prevalence of people with a wish to end their life whilst not being severely ill. In 2019 a large study was commissioned by the Dutch Ministry of Health, in which over 21.000 Dutch citizens over 55 replied to a survey ("The Perspective study").[2] They were asked if they have a wish to die (WTD), as well as questions concerning their health. Results showed that 1.34% of participants had a persistent death wish and no severe illness (PDW-NSI), the so-called *completed life* population. Extrapolating this percentage to the nation's population, researchers estimate that over 75.600 Dutch citizens aged 55 years or over experience this PDW-NSI. Important contributing factors to this wish to die were fretting, the feeling of having no control over one's life, loneliness, physical or cognitive deterioration and illness.[2] In this study both quantitative and qualitative data were analysed, mostly concerning the characteristics of this population. The wishes and needs of people experiencing a PDW-NSI had been sought through the quantitative segment of this study. However, until now the qualitative data was not analysed questioning the desires these people have.

It remains unclear what leads to a death wish in an otherwise healthy population. The Perspective study showed factors contributing to the death wish. A structured analysis of the qualitative interview data from this population may help us gain insight in the underlying desires of this population.

A known framework for identifying general human needs comes from Martha Nussbaum's and Amartya Sen's *Capability Approach*.[3] This philosophical theory states that humans are a dignified, free being who shape their own life in cooperation and reciprocity with others.[3] A capability is defined as a space in which everyone can do what they want to do and be who they want to be.[3] Nussbaum defined ten core capabilities which should allow people to achieve wellbeing.[4] In this study, the Capability Approach (CA) was used as a tool to structure the identification of participants desires. Multiple studies have applied this framework in other fields, showing it to be a way to categorize qualitative data.[5,6]

The aim of this study was to identify the wishes and needs of Dutch people aged 55 or over, with a persistent death wish, without severe illness, in the light of the ten capabilities proposed by Nussbaum and Sen. The purpose is not to answer the question whether physician assisted suicide should be available to this population. This article is a descriptive, ethical paper and aims to answer the question: What are the desires, based on Nussbaum's capabilities, of Dutch people aged 55 or over with a persistent death wish, without serious illness?

Methods

Context and recruitment

This qualitative research was a subanalysis of existing data consisting of interviews, held as a part of the larger PERSPECTIVE-study. The aim of this larger study was to gain insight in the prevalence and characteristics of the group of people who have a persistent wish to die (WTD), without being severely ill.[2] Initially, a survey was used to query 32.477 Dutch citizens aged 55 or over about their perspective on life and a possible wish to die, as well as questions on their physical and mental health. Participants without serious illness answering positively to the question of whether they have little to no perspective on life and long for death were asked to participate in an in-depth interview. 101 possible participants were contacted by telephone for a pre-selection interview. Participants without a WTD were excluded, as well as participants only wanting to participate for political purposes.

Interviews

Interviews were held between May and August of 2019, by 3 individual interviewers using a phenomenological approach. This method allows participants to share lived experiences, which results in rich qualitative descriptions.[7] All interviews were held in person, none of the interviews were held by telephone or online.

In the interviews, participants were presented a case of a 76-year-old woman, who was recently widowed but has loving children and close friends. She however feels lonely, and nobody can fill in the emptiness left by her husband. She is physically and mentally well. She feels as if she has no future and all her good years have passed. She feels her life to be completed and would rather be dead. Participants were asked if they identified with this woman and which aspects resonated the most. Open follow-up questions were used, and participants were encouraged to keep telling their story.

Data analysis

The interviews were analysed using the directed content analysis, entailing that codes for labelling fragments and quotes were established before analysis.[8] When additional codes were deemed relevant these were added during the analysing process.

Codes were based on the ten capabilities in the CA (Table 1). Researchers' interpretation of the capabilities in this study are described in the Results section.

1.	Life	Future perspective, life worth living, treatment restrictions
2.	Bodily health	Physical, mental and cognitive health, independence
3.	Bodily integrity	Autonomy in general and in end-of-life decisions
4.	Senses, imagination & thought	Having pleasurable experiences, religion, disorders of the senses
5.	Emotions	Psychological support, appreciation, talking with like-minded people
6.	Practical reason	Cognitive health, enjoying intellectual activities
7.	Affiliation	Social contacts, family, partner, friends, intimacy
8.	Other species	Nature, pets, animals
9.	Play	Having fun, hobbies
10.	Control over one's environment	Political influence, influence on housing, financial security

Table 1. The 10 Capabilities by Nussbaum with researchers' interpretation for this context. Further clarification in the Results section.

Results

Characteristics

After careful in- and exclusion, 36 in-depth interviews were conducted. 34 participants were included through the survey and pre-selection interviews. The baseline characteristics of these participants are shown in Table 2. Two participants were included after interviews with general practitioners in another subanalysis of the Perspective study.

Capability 1 – Life

The definition of this capability according to Nussbaum is as follows: one should be able to have a life of normal length and to have a life that is not reduced to the point that it is no longer worth living. In this study this was interpreted as the feeling of having perspective for the future, having a purpose in life and about negative anticipation toward ailments or situations to come.

Multiple participants expressed feeling like life has no purpose or that they don't see a future for themselves. Factors contributing to that feeling were having nothing to look forward to, not being able to have a meaningful effect on other's life or not being able to do things they enjoy. About 1/3 of participants expressed negative anticipation toward physical or cognitive deterioration, or dependency on others.

"I don't have a future; I have a past." – *participant 34*

"I: how do you see the future? P: It is the way it is. I don't look at the future, I don't have a future, I don't have a future. I am not ill, well, I'm developing dementia but there's nothing they can do about that, a pill won't help. Can you imagine? No, you can't, no." – *participant 11*

Participants who did see a future or who feel they are having a meaningful life, described family, social contacts, and a life partner to be the reason they appreciate life at that moment.

Multiple participants articulated a strong wish for a dignified death. The underlying fear was that of suffering at the end of life and not being able to prevent it. Participants described seeing loves ones at the end of life, having lost all independence and decorum. Accompanying this feeling is the frustration that policymakers who are not experiencing a WTD are the ones to decide if a chosen death should be legalised for this population. In the same category, many participants articulated a wish for a lethal drug to be available.

	n = 34
Sex	
Male	13
Female	21
Age	
55 - 60	4
61 - 65	5
66 - 70	4
71 - 75	11
76 - 80	5
81 - 85	3
86 - 90	2
Average age	71
Partner status	
Living together	6
Partner in a nursing home	1
Long distance relationship	1
Widowed	11
Divorced	9
No partner	6
Children	
No children	7
1 child	3
2 children	19
3 or more children	5
Religion or philosophy	
Humanist	1
Christianity (protestant church)	6
Christianity (catholic church)	4
Spiritual/esoteric	5
Agnostic	1
None or none reported	17
Medical complaints[1]	
None or none reported	11
Pain	7
Cardiac complaints	5
Neuropathy or rheumatoid arthritis	5
Psychological complaints	2
COPD	1
Intestinal complaints	2
Physical deterioration	3
Handicap due to loss of limb or eye	2

Table 2. Baseline characteristics. *Continues on next page.*

Depression (HADS-D[2], scores 1-21)	
1-7 (no indication for depression)	15
8-10 (indication for light depression)	8
11-15 (indication for moderate depression)	11
16 or higher (indication for severe depression)	1
Perceived health (VAS[3], scores 1-10)	
1	-
2	-
3	1
4	8
5	2
6	4
7	7
8	8
9	2
10	2

Table 2. Baseline characteristics.
1 Cumulative > 34 due to multiple complaints per participant
2 HADS-D: a tool used in clinical settings to assess the probability for depression
3 VAS: visual analogue scale to which participants could score their perceived health, 1 being the worst health imaginable, 10 being the best.

The desire for a lethal drug fits within the capability concerning life. Especially since C1 is also defined as "to not live a life that is reduced to be not worth living". When participants spoke of a wish to have a more dignified death and to have access to a suicide drug, this was mostly due to a fear of deterioration. Some spoke of loved ones losing all dignity at the end of life, and how they would never wish that upon anyone. To have access to a more "humane" way to end their life, this fear could be reduced.

Capability 2 – Bodily health

Being able to have adequate physical health, adequate nourishment, and adequate shelter. In this study this was interpreted as physical and mental health, as well as independence.

Almost half of all participants mentioned their physical health being inadequate. Physical health was mostly deemed important when it affected the ability to do things participants enjoy doing. In some cases, pain affected the possibility of going into the city or being able to craft, for example. Some participants spoke about severe pain or tiredness, affecting their daily life. Two participants mentioned faecal incontinence which severely impacted their quality of life.

"I: What might help you? P: Even if I won €100.000, I would still not be relieved from my pain." – *participant 4*

Mental health was not mentioned frequently. However, as shown in the baseline table (Table 2), 20 participants scored high enough to indicate depression, most of them light to moderate in severity according to the Hospital Anxiety and Depression (HADS-D) scale.[9]

Capability 3 – Bodily integrity

Nussbaum defines this capability as being able to be secure from violence, to have bodily boundaries respected and to move freely from place to place. In this study, this was interpreted somewhat more extensively, specifically about the right to self-determination and autonomy in end-of-life (EOL) decisions.

Having autonomy over one's life and more specifically over the end of their life was mentioned by nine participants. Most of them refer to it as the right to self-determination.

Additionally, some participants are a member of associations advocating for more autonomy in death. A way to obtain more autonomy was the availability of a *last-will pill (LWP)*, a lethal drug sold by such associations. A participant mentioned that she had wanted to buy the LWP, but it had been banned before she had the chance to get to the top of the waiting list.

Capability 4 – Senses, imagination and thought

Nussbaum's definition of this capability is to be able to use the senses, to have religious freedom, to have the ability to have pleasurable experiences and being able to avoid unnecessary pain.

This capability yielded few defined desires. It was, however, used to identify if participants mentioned being able to have positive experiences, or had lost the ability to do so. About 1/3 of participants mentioned that they were able to have positive experiences, whereas 2 participants mentioned not being able to have these at all. The remaining participants did not mention anything about this ability.

Capability 5 - Emotions

Originally defined as being able to have attachment to people and things outside ourselves. In this study this was interpreted as the ability to feel useful, to have psychological support and to feel acknowledged.

The most mentioned desire was the wish to feel useful to others. Some participants said that that was the only way to matter in life. This was shown both ways; people described that the feeling of usefulness they experienced was beneficial to their quality of life and vice versa participants actively described the wish to feel more useful.

Furthermore, the desire to have either psychological support from a professional or to have someone likeminded to talk to was mentioned by multiple participants. Similarly, the desire to feel heard was described various times. Adding to these comments was the fact that multiple participants thanked the interviewer for the opportunity to tell their story and have someone listen without judgement.

When asked about what might aid in the wish to have somebody to talk to, someone proposed a "Secretary of the Lonely" in the government.

Capability 6 – Practical reason

Defined as the ability to form a conception of the good and engage in critical reflection about the planning of one's life, as well as the liberty of consciousness. In this study this was interpreted as cognitive health and being able to engage in intellectual activities.

Almost all participants described being cognitively well, but many described the fear of deterioration in this domain (as is described in Capability 1). Two participants described feeling like they were slowly developing dementia, indicated by short-term memory loss and an incident of getting lost. This was accompanied by an increased fear of the future and a feeling of "What am I doing it all for? It'll only get worse from here".

A desire to engage in intellectual activities was mentioned by one participant.

Capability 7 – Affiliation

Defined as the ability to live with and toward others, to have social interactions and to have a basis of self-respect. In this study it was interpreted as to have the ability to engage in social interactions and to have meaningful connections, as well as romantic relationships and intimacy.

Just like the wish to feel useful, many participants spoke about the importance of social connection. Even though not all participants who spoke about social connections explicitly spoke of a desire to have more friends or family, an implicit desire to have more interpersonal experiences was observed. Some people spoke about how they watched peers interact with their (grand)children and how they had more reason to live. Another example is the loss of close friends. This did not always result in a wish to *make* friends, but it was implied that participants wished to *have* friends, especially the ones they lost.

This was observed in context to intimate, romantic relationships as well. Participants who had been widowed or divorced often spoke about the empty feeling this had left, and how children or friends could not fill that void. As well as with friends, most did not try to find new relationships. Two participants spoke openly over the desire for more intimacy and physical contact, which one described as *"skin hunger"*.

"That kind of love does not come again, that is a one-time thing. […] And I won't settle for less." – *participant 21*

Notably, participants who did find a new partner often described this as a valuable addition to their life.

When a desire to have more social interaction was described more specifically, this often entailed relatively small connections. I.e., speaking to a neighbour on the street, having a place close by where they could meet other people or connecting with the household help.

On the contrary, multiple participants described the fear of being a burden to loved ones, sometimes keeping them from reaching out when they needed it.

Capability 8 – Other species

Both originally and in this study defined as living in and with animals, plants and nature, pets were specifically included.

Both spending time in nature and with animals showed to be helpful for many participants.

Mainly pets; many participants who spoke about their pet described that they were a reason to want to stay alive. One participant described it as having a task, which helped in the feeling of being useful.

Capability 9 – Play

Defined as having the ability to laugh, play and enjoy recreational activities.

Having the ability to partake in enjoyable activities was mentioned by a large portion of the participants. Most described still being able to do so, but when the moment should come that they weren't able to perform these activities any longer, they would want to choose to end their life.

Capability 10 – Control over one's environment

Defined in this research as well as in the original CA as being able to participate in political choices and being able to hold property. Additionally, having proportionate financial means was also deemed of importance in this capability.

Not many spoke about the desire for having more political influence, however one participant showed their frustration as to how all the decision-making in the Netherlands took place through only the policymakers, and how citizens are not included in any debate.

Financial security was a large topic for some participants, mostly being the desire to have the means to perform activities they enjoy, which was not the case for these particular participants.

Discussion

This study aimed to identify the wishes and needs of Dutch people aged 55 or over with a persistent death wish, without severe illness, using the Capability Approach by Nussbaum and Sen as a framework.

The capabilities in which participants felt most deficient, were Capability 3 (Bodily integrity), C5 (Emotions) and C7 (Affiliation). The least mentioned capabilities were Capability 2 (Bodily health), C4 (Senses, imagination and thought) and C6 (Practical reason).

The three most mentioned desires arising from the capabilities mentioned above are:

1. Feeling useful (C5)
2. Having social interactions (C7)
3. Having access to a lethal drug and to have more autonomy in death (C3)

Other important desires were the ability and possibility to speak with like-minded people (C7) and to be able to perform enjoyable activities (C9).

The desire to feel useful

When participants spoke of the things that make them feel useful, this ranged from having meaningful volunteer work, to giving a neighbour a valuable tip. This indicates that the wish of feeling useful can be fulfilled through relatively small interactions. It is interesting to note that this desire was always described in context with other people, sometimes pets or society. The usefulness was not described as needing to be useful just for themselves.

The desire to have social interactions

The emphasis on the relations with other people is shown in the second desire – having social interactions. Any kind of social interactions was deemed beneficial according to participants. Ranging from a partner or close friends to a small interaction in the neighbourhood.

Both the feeling of uselessness and the absence of social connections imply a certain detachment from society. The feeling of being inside all day, just watching television while the world spins on outside and the absence of the feeling of being necessary to society imply that re-establishing that connection to society may improve their overall look on life. This corresponds with the findings of van Wijngaarden and colleagues in 2021.[10] They showed the WTD to be a dynamic and fluctuating entity. This study showed that people who had experienced a WTD in the first interview, often experienced a diminished or even vanished WTD later on. Factors that influenced this change were (re-)establishment of connections with other people or society.[10]

The wish for a last-will pill and autonomy in death

The third noteworthy desire was the wish for a lethal pill to have when they felt it was their time to go. This was often accompanied by the strong wish for having more autonomy in death. The fear of deterioration and having to experience dependence on others was so strong that a last-will pill (LWP) felt as a relief.

Autonomy at the end of life (EOL) is related to dignity and control.[11] In a systematic review, Rodríguez-Prat and colleagues (2016) propose that autonomy is a determining factor to perceived dignity.[11] The authors state that the idea of a dignified death is based on the premise that a person's dignity depends on their ability to maintain autonomy and control. The articles in this review studied patients who already suffer from illness impacting their functionality. The participants in our analysis are not (yet) suffering from illness, they do however fear this future suffering. This view on autonomy at the EOL aids in understanding why the fear of the loss of autonomy is strong enough for people to wish for a lethal pill.

The LWP gives people the option for a self-chosen death in their own environment and time, without interference of a doctor. This would fulfil the wish to have the power to decide over one's death, ideally also avoiding the selection process for EAS. Additionally, the majority of people wish to die in their own home.[12] A last -will pill seems to be a fitting solution, but it should not be seen as the only way to provide more autonomy at the end of life. Autonomy could be seen as a spectrum in which a LWP is at one end, and other interventions or decisions are spread out over this spectrum.

Finally, as stated by Zomers and colleagues (2022), PDW-NSI is highly complex, and the vulnerabilities of this population should not be overlooked. By "simply" allowing a last-will pill or EAS, this population would be deprived of adequate care.[13]

Developing a wish to die whilst not being severely ill is a process that takes time. When viewing the process to developing this PDW-NSI as such, a

process, the possibilities for intervening could be more extensive. Most participants in this interview were not (yet) at a point in this process where they felt that they would take the LWP immediately. This implies that they have not reached a "point of no return". Perhaps, if they were to have a feeling of more autonomy or if they had more social interactions or a greater sense of usefulness, the underlying WTD could diminish.

These results call for more research on interventions to improve the feeling of autonomy and to (re-)establish a meaningful connection to society. The question that arises from analysing this data from a medical ethics perspective, is whether other fields of expertise are more equipped to answer to the needs of this population. The desires found in this research mostly show a deficit in the social domain, perhaps more research in this field would yield ways to intervene. Above all, this study shows that the suffering these individuals experience is more of a greater societal issue than solely medical, and needs to be addressed in a multidisciplinary way.

Strengths and weaknesses

This study shows that the Capability Approach is a well-rounded framework to assess the desires people with a PDW-NSI have. All but one desire could initially be coded within the CA, and the one remaining - the wish for a last-will pill - was regarded as a C1 (Life) desire after expanding the interpretation somewhat. This shows that the CA is applicable to the desires in this population.

To the best of our knowledge, this is the first structured study in assessing the wishes and needs of people with a PDW-NSI. It is of importance to acknowledge the burdens these individuals carry and to propose ways to intervene. Larger scale research needs to be conducted to properly establish ways to adequately care for these individuals.

This study has limitations. The Capability Approach was utilised to structure the research, but it is possible that expressed desires were overlooked in the process of coding to the CA framework. Prevention of this happening was attempted by adding a code for when a desire was identified, but did not fit properly in one of the capabilities. Eventually, the capabilities were interpreted somewhat more extensively, as is described in the Results section. It is, however, possible that desires were overlooked in the process.

Additionally, the CA was originally described as an approach to welfare economics, not to the ethics of euthanasia or physician-assisted suicide in people with a completed life.[3] The approach has since been applied to more fields in Medical Ethics and proven to be an asset in understanding people's experiences in more than just welfare economics.[5,6] To be able to apply the CA to this population, it was necessary to interpret the CA in a way that poses risk to confirmation bias. Care was taken to reduce this risk by discussing the interpretation with multiple researchers on multiple occasions, as well as coding the interviews individually and assessing the correspondence.

In The Netherlands, euthanasia is legal and available to anyone with unbearable suffering and without perspective of improvement. The

suffering must have a medical basis. People who have multiple age-related conditions to which they are suffering, are also eligible for EAS.[14] It was attempted to include only those who do *not* qualify for EAS but do have a wish to die. It is, however, not possible to conclude this definitively, as there is an extensive selection process - performed by a doctor - required before someone is found eligible for EAS.[14]

Finally, it is important to note that all interviews were held in Dutch and performed by another researcher than by whom this specific analysis was performed. This poses risk to misinterpretation as the interviews were transcribed and the tone of voice could not be assessed. Translation to English may lead to loss of nuances in quotes or interpretation.

Conclusion

In conclusion, the desires of people aged over 55 with a persistent death wish without serious illness are the desire to feel useful, the desire to have social interactions, and the wish for the availability of a last-will pill. The Capability Approach forms a well-rounded framework in establishing the desires of this population, perhaps forming a foundation for clinical tools or questionnaires. More research into possible ways to intervene needs to be conducted to adequately care for this population, ideally assessed through social as well as medical and ethical research. The struggles this population faces require a multidisciplinary approach.

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