



OPEN ACCESS

Experiences with counselling to people who wish to be able to self-determine the timing and manner of one's own end of life: a qualitative in-depth interview study

Martijn Hagens,¹ Marianne C Snijdewind,^{2,3} Kirsten Evenblij,¹
Bregje D Onwuteaka-Philipsen,¹ H Roline W Pasman¹

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/medethics-2019-105564>).

¹Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Amsterdam UMC—Location VUMC, Amsterdam, The Netherlands

²Department of Medical Humanities, Amsterdam Public Health Research Institute, Amsterdam UMC—Location AMC, Amsterdam, The Netherlands

³Department of Medical Ethics, Amsterdam Public Health Research Institute, Amsterdam UMC—Location VUMC, Amsterdam, The Netherlands

Correspondence to

Martijn Hagens, Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Amsterdam UMC—Location VUMC, Amsterdam 1081 HV, The Netherlands; m.hagens@amsterdamumc.nl; eol@vumc.nl

Received 11 May 2019

Revised 5 September 2019

Accepted 27 November 2019

Published Online First

23 December 2019



© Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Hagens M, Snijdewind MC, Evenblij K, et al. *J Med Ethics* 2021;**47**:39–46.

ABSTRACT

Background In the Netherlands, Foundation De Einder offers counselling to people who wish to be able to self-determine the timing and manner of their end of life.

Aim This study explores the experiences with counselling that counselees receive(d) from counsellors facilitated by Foundation De Einder.

Methods Open coding and inductive analysis of in-depth interviews with 17 counselees.

Results Counselling ranged from solely receiving information about lethal medication to combining this with psychological counselling about matters of life and death, and the effects for close ones. Counselees appreciated the availability of the counsellor, their careful and open attitude, feeling respected and being reminded about their own responsibility. Some counselees felt dependent on the counsellor, or questioned their competency. Most counselees collected lethal medication. This gave them peace of mind and increased their quality of life, but also led to new concerns. Few were inclined to use their self-collected medication. Counselling contributed to thinking about if, when and how counselees would like to end their life.

Conclusion Having obtained means to end their lives can offer people feelings of reassurance, which can increase their quality of life, but can also give rise to new concerns. Next to providing information on (collecting) lethal medication, counsellors can play an important role by having an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of counselling are also relevant for physicians taking care of patients who wish to self-determine the timing and manner of their end of life.

INTRODUCTION

In the Netherlands, people with a wish to end their life have the option to request for physician assistance in dying (PAD) under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act.¹ Not everyone who requests PAD meets the criteria of due care laid out in this law which allows them to receive PAD, and physicians are not obliged to perform PAD.¹

A position paper of the Royal Dutch Medical Association about the role of the physician in a self-chosen death by the patient,² and a report from the Advisory Committee Completed Life state that physicians—or others like loved ones—can offer non-punishable demedicalised assistance in suicide

(DAS).³ DAS consists of having conversations about the wish to end life, offering moral support and providing general information on ways to end your own life in a non-violent manner. This assistance is allowed under jurisprudence concerning Penal Code Article 294.⁴ It is referred to as *demedicalised* assistance to distinguish it from PAD, which is medicalised assistance that falls under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act. Hagens *et al* offer a more detailed description on the differences between DAS and PAD.⁵

Several organisations in the Netherlands provide DAS, for example, Right-to-Die Netherlands, Foundation De Einder and Foundation End-of-Life Counselling, by counselling people who wish to self-determine the timing and manner of their end of life. These organisations provide information from publications about methods to end your life in a non-violent manner, also referred to as self-euthanasia.^{6–10} In practice, this usually entails ending your own life by self-ingesting self-collected lethal medication, or voluntarily stopping eating and drinking.

Research into Foundation De Einder—see [table 1](#) for a description of history, aim and working method of Foundation De Einder—has shown that people who seek DAS are not always currently suffering, often have not requested their physician for PAD, nor have an active wish to end their life (yet).¹¹ These findings are explained by distinguishing a group of people who are seeking reassurance to prevent possible future suffering. This is in line with an idea that Huib Drion had already expressed in 1991, ‘*without much doubt, I have the feeling that many older people would be greatly relieved by knowing that there is a means to end their life respectably at the moment suitable to them, based on what they can reasonably expect from that point on.*’¹² By seeking DAS, people (know how to) obtain means to be able to self-determine the timing and manner of their end of life.

The idea of reassurance is supported by research conducted by Chabot.⁹ However, his study did not explore the experiences with the counselling people received. Our study aims to give insight into the experiences with the counselling provided by counsellors working in cooperation with Foundation De Einder by interviewing counselees about (1) what is discussed in the counselling (2) how they

Table 1 History, aim and working method of Foundation De Einder²³

Topic	
Foundation	Foundation De Einder was founded in 1995 as a result of dissatisfaction with the situation that people with a wish to end life were 'being left out in the cold'.
Aim	The goal of the foundation is 'to promote and—if deemed necessary—to offer professional counselling for people with a wish to end life who ask for help, with respect for the autonomy of the person asking for help [...]'. ²³ Contrary to suicide prevention or crisis intervention organisations, Foundation De Einder regards suicide as a possible outcome and gives information about 'self-euthanasia'. ¹⁰ Autonomy is regarded as an important value. Seen as an addition to the—since 2001 in the Netherlands legally regulated—medicalised approach of physician assistance in dying (PAD), Foundation De Einder works in cooperation with independent counsellors to offer counselling focused on demedicalised assistance in suicide (DAS).
Work method	Counsellors working in cooperation with Foundation De Einder offer non-directive counselling, which consists of having conversations, offering mental support and providing general information on 'self-euthanasia'. These three forms of assistance by lay persons are regarded as non-punishable assistance in suicide. ⁴ The counselling is not aimed at a certain choice or direction, but is aimed at attaining the highest possible quality of the choice and—if it comes to that—the highest possible quality of implementation of the wish to end one's own life. ²³ The counselling is aimed at creating an as large as possible clarity regarding the wish to end one's life and possible suicide. This covers the mental process of decision-making and might include matters like considering alternatives, timing of death and consideration of others. If the client decides to act on his or her desire to end their life, the counselling is aimed at realising the best possible preparations for 'self-euthanasia'. This covers the practical preparation and might include gathering means for and the effectuation of the suicide. ^{23 24}

experienced the counselling, and (3) what happened afterwards, especially in relation to collecting medication and the manner and timing of their own end of life.

METHODS

Design

A qualitative interview study was chosen because of the explorative nature of the research objectives.

Recruitment

A notice about this study was published in the magazine of Foundation De Einder, stating we were looking for people who were willing to be interviewed about their experiences with this counselling. This magazine was sent to people donating money to the Foundation, including—but not limited to—people seeking counselling. Also, counsellors were asked to notify people seeking their counselling, either in person, through postal letters or email.

Participants

Twenty-four potential participants enrolled themselves—20 through intermediation of the counsellor, and four through the notice in the magazine—by contacting the researcher (MH) by telephone or email. All potential participants were contacted by telephone to ask five screening questions concerning gender, age, motivation to contact the counsellor, former request for PAD and personal consults with which counsellor. These screening questions, based on a previous quantitative study,¹¹ were asked to ensure diversity in the participants. Some potential participants had not (yet) had a personal consult with a counsellor. These people were excluded from participation (n=3), because they often were still in an orientating phase where counselling does not entail providing information on ways to end their lives.¹¹

Three potential participants were not willing to participate in a personal interview (eg, due to emotional burden). Finally, one potential participant was not selected for participation due to similarity with already selected participants (data saturation). This resulted in 14 interviews with 17 people. Three interviews were conducted with couples who sought counselling together. Counselees from all seven counsellors facilitated by Foundation De Einder at the time of the interviews were included. The selected sample reflected the population of people seeking counselling from a counsellor facilitated by Foundation De Einder.¹⁰

Interviews

Between September and December 2012, in-depth qualitative interviews were held with people who were receiving or had received counselling from counsellors facilitated by Foundation De Einder. The interviewer (MH) has a background in training for professional and personal communication in psychology and had previously worked as a counsellor in cooperation with Foundation De Einder. This prior experience contributed to a considerable knowledge about DAS and experience with discussing the subject, but could also lead to a potential interviewer bias. The difference in position and the necessary skills as an interviewer compared with a counsellor have been addressed in the research team. All interviews took place at the residence of the respondent except for one, which—at the request of the interviewee—was held at a conference room at the VU University Medical Center. All respondents lived in the Netherlands. All were informed about the purpose of the study, and signed an informed consent form for participation in accordance with the procedure approved by the Ethical Committee of the VU University Medical Center. The interviews lasted between 1 and 2.5 hours.

One of the main aims of the interviews was to learn more about the experiences of the respondents with the counselling. Given the sensitive subject, it was decided to start with a general opening question such as '*how are you doing now?*' However, it turned out the respondents were very eager to talk about the subject so later interviews were started with the question, '*What has been the motivation to contact foundation De Einder?*' The consecutive questions were based on what the respondent said. A topic list was used as a reminder of the subjects that should be addressed in the interview. These topics included the content of the counselling, the experiences with the counselling and plans for the timing and manner of their own death. See online supplementary appendix 1 for the complete topic list of the interview.

Analysis

The interviews were recorded and fully transcribed. Field notes were made during and after the interview. For the purpose of this study, all interviews were analysed focusing on the research questions about the experiences with the counselling. Analysis followed the principles of sequential and thematic analysis.¹³ First, all interviews were thoroughly read to become familiar with the data, and case reports of every participant were made by the interviewer (MH), and discussed within the research team (BDOP, HRWP, MCS, KE). Consecutively, all interviews were analysed by the interviewer (MH) and one or two other coders

Table 2 Personal characteristics of selected counselees

Counselee	Primary goal*	Gender	Age	Request for PAD	Relationship status	Children present	Health problems
1	PAD unable	F	<65	No request	No partner	No	Psychiatric
2	PAD unable	F	<65	Denied†	Partner‡	No	Physical
3	PAD unable	M	<65	Denied	No partner	No	Physical and psychiatric
4	PAD unable	F	<65	No request	Widowed	Yes	Physical
5	PAD unable	M	65–70	Denied	No partner	No	Psychiatric
6§	Backup	F	65–70	No request	Partner	Yes	Healthy/old age (physical)
7§	Backup	M	70–80	No request	Partner	Yes	Healthy/old age (physical)
8	Backup	M	70–80	No request	Partner	Yes	Psychiatric/old age (physical)
9§	Backup	M	70–80	No request	Partner	Yes	Healthy/old age (physical)
10§	Backup	F	70–80	No request	Partner	Yes	Healthy/old age (physical)
11	Backup	F	80–90	No request	Widowed	Yes	Healthy
12§	Backup	M	80–90	No request	Partner	Yes	Old age (physical)
13§	Backup	F	80–90	No request	Partner	Yes	Old age (physical)
14	Autonomy	M	70–80	No request	No partner	No	Old age (physical)
15	Autonomy	M	70–80	No request	Widowed	Yes	Old age (physical)
16	Autonomy	M	70–80	No request	No partner	No	Old age (physical)
17	Autonomy	F	90–99	No request	Partner	Yes	Old age (physical)

*‘PAD unable’ refers to counselees who sought counselling as a result of current suffering and (thought they) were unable to obtain Physician Assistance in Dying (PAD).

†‘Backup’ refers to counselees seeking demedicalised assistance in suicide (DAS) so self-euthanasia could form a backup in case they were unable to obtain PAD in a future situation. ‘Autonomy’ refers to counselees seeking DAS so self-euthanasia could be possible in a future situation, and preferring this over PAD (see Hagens *et al*¹¹ for more detailed information).

‡Eventually granted by another physician.

§Partner present at interview to support with gaps in memory.

§Couple together.

(MCS, KE). Open, inductive coding was applied to identify recurring themes in the interviews. This was a constant movement between the data set, the coded extracts and the descriptive analysis in process. No prior theory or framework was used in the analysis.¹⁴ The code list extended as more interviews were analysed, and codes were grouped and regrouped in the process of analysis. Online supplementary appendix 2 shows an overview of the codes that were created in relation to the experiences with the counselling provided by a counsellor facilitated by Foundation De Einder. Writing of the article formed part of the analysis because the writing process also pointed out which data, codes or interpretations were not clear yet, which led to new analysis cycles of the data. The writing process, the coding and descriptive analysis were discussed between all authors, and led to a clearer understanding and better representation of the data.

RESULTS

Characteristics of counselees and counselling

The majority of the counselees were over 70 years old. All counselees lived in independent housing, more than half together with their partner. About two-thirds described their health status as healthy or as experiencing problems of old age. Most counselees were hoping for a natural death. When having to self-determine death, most counselees preferred PAD, if this would be available to them, over a self-directed death that did not fall under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act. Some valued autonomy and their own responsibility and preferred ending their lives by self-ingesting self-collected lethal medication (see table 2) (see box 1, Quote 1).

The start of the current counselling ranged from as long as 10 years ago until as recently as 2 months ago. Counselees received between 1 and 24 personal counselling sessions. Almost half of the interviewed couples and individuals involved other people to their counselling. The majority of the counselees had already obtained lethal medication (see table 3).

Content of counselling

All counselees received information about ways to end their lives. While some received information about PAD, voluntarily stopping eating and drinking, and/or inhaling helium, all counselees received information about lethal medication (see table 3). For example, which (combination of) lethal medication to use, the availability of this medication, storing and testing medication, careful preparation and performance of a self-euthanasia by self-ingesting lethal medication, and preparations for the situation after death. For some counselees this was the only reason they sought counselling (see box 1, Quote 2).

A ‘screening’ of the counselees’ wish to seek counselling was part of the counselling for most counselees. Some also specifically sought counselling to discuss psychological or mental aspects of the process to be able to self-determine the timing and manner of their end of life. For example, having conversations about the moral aspects of ending your own life and the meaning of life and death (see box 1, Quotes 3 and 4).

Besides having loved ones involved, discussing the subject of loved ones was part of the counselling for about half of the counselees. For example, the effects of ending your life on others, acting responsibly towards others and/or the counselling of loved ones (see box 1, Quotes 5 and 6).

Box 1 Quotes about the characteristics of counselees, and content of and experiences with counselling

Quotes about preferred manner of passing away

Quote 1 'R1: I'd rather die from a heart attack, in a natural way. (Counselee 06)

R2: We expect to pass away from a natural cause, be it a traffic accident, be it a heart attack, be it something else. That we just die like that. But if that is not the case [...] then we like to take the decision to end our lives ourselves. [...] I would go to the physician [to request PAD—MH], because then your bereaved ones don't have that problem [being suspected of unlawful assistance in suicide—MH]. That's the main reason. (Counselee 07)

R1: And then at least you are completely sure dying goes well.' (Counselee 06)

Quotes about the content of the counselling

Quote 2 'But okay, I thought I will go and talk to the counsellor how to obtain sleeping medication. So not at all because I was looking for psychological.... And that's what I like so much about the counsellor. The counsellor also thinks it's okay if you come to just talk about the pills.' (Counselee 08)

Quote 3 'Also, the awareness "what am I doing to society if I choose suicide?" Then you do make a statement. [...] So, I wanted some more counselling on that—on the moral aspect of suicide. Actually, it's abject, bad. Well, the society I'm part of... I ignore it, I contempt it when I choose for suicide [...] and then I thought: yes, I need a counsellor. Because I am an ambivalent person with a lot of contradictory wishes.' (Counselee 11)

Quote 4 'And actually. Yes, how shall I put it. The counsellor looks at the whole situation from a completely different angle. So, what are your expectations and disappointments in life? What gives meaning in life? And yes, also, because that is the question you arrive with, questions and decisions about the end of life.' (Counselee 01)

Quote 5 'The counsellor was so kind to honour my proposal to invite the children all together with the counsellor and me, so the counsellor could get an impression of each child. I liked that idea. In case the counselling would be for a longer period of time. The counsellor also thought that was very pleasant. So the counsellor acknowledged my situation and my position in the greater picture. I am very attached to my five children.' (Counselee 11)

Quote 6 'I noticed the counsellor had thought things over a lot better than I had [...] because the counsellor is just a lot more careful in all the steps. And also towards the people surrounding you, for example about the enactment of the suicide and even about what happens after the suicide. I really thought that was very decent and considerate.' (Counselee 01)

Quotes about the experiences with the counselling

Quote 7 'Yes, because it also gives the counsellor a certain kind of power in deciding you can have the [information about the—MH] medication or not. That's true. But the counsellor also has to take into account the politics, and cover for the police and the law and so on. And the counsellor has to manoeuvre carefully, so I understand that. And I think that is good in a way.' (Counselee 06)

Quote 8 'What I think is still regrettable is the fact it [collecting lethal medication—MH] all goes through dubious routes [eg, through internet or abroad—MH]. (Counselee 01)

Quote 9 'The advantage is that something [your wish to self-determine your own end of life—MH] is being regarded from all possible angles—even separate from the practical side—like aren't you in a tunnel vision. Thoughts like "this is it" and "this situation I'm in is unsolvable and unbearable" and so on. The advantage of De Einder is [...] that someone listens seriously to your question. Without any taboo, they address your request, your question. Physicians often don't do that. People around you often don't do that, the Right to Die NL doesn't do that—well maybe, a few good ones. And here is someone who does do that, and who knows more about it.' (Counselee 02)

Quote 10 'Well, the counsellor is someone who recognizes you for what you are and what you want. It's all about respect for life and someone's choice to want to die. That is important.' (Counselee 05)

Quote 11 'At the first conversation, I was really surprised by the attitude of the counsellor and that gave me a lot of good energy, to say it like that, it was just very pleasant. [...] I had expected I would have had to defend myself the whole time [...] and then it turned out it was just a very open conversation [...] I felt—that was very good—my own responsibility. So yes, the counsellor's attitude has played a part in that, that I could do that. That was outstandingly good.' (Counselee 01)

Quote 12 'And that the counsellor gives me the full freedom... No force or stimulation from the counsellors side. That felt very pleasant. Not in any single matter. You have to process it all yourself.' (Counselee 11)

Quote 13 'The counsellor did not help you, but he gave you the tools to do it yourself. And that... yes, gave a very sympathetic impression.' (Counselee 04)

Quote 14 'I call the counsellor sometimes. But I try to do this as sporadically as possible because I do not want to burden the counsellor too much in daily life. But I'm allowed to. The counsellor hasn't set any limits, and yes, I think that's special.' (Counselee 03)

Quote 15 'Well, I understand also, with those people [the physicians—MH] you have to be outside in six minutes. I don't feel like that. You don't feel real then. The counsellor "opens up all registers" and the consult may take one and a half hour. It never lasts that long. And now I notice I do need that [laughs]. (Counselee 08)

Experiences with the counsellor and counselling

All participants were positive about the counselling and/or counsellor, while some also expressed criticism. Criticism concerned feeling dependent on the counsellor who owned information that a counselee wished to obtain, secrecy around how to obtain medication and a counsellor being regarded as

incompetent in psychological guidance due to a background in an unrelated work field (see box 1, Quotes 7 and 8).

The positive remarks focused on the trustful and careful attitude of the counsellor. The matter of preparing for a suicide could be openly discussed as a normal subject and was not treated as a taboo. It resulted in people experiencing being

Table 3 Setting and content of counselling and collection of lethal medication

Counselee	Start of counselling (time ago)	Personal contacts, n	Involved others	Information about manners to end own life*	Collected lethal medicine	Counselling about mental aspects	Counselling about/of others
1	2 months	2	No	MED (which medication, obtaining, careful performance, consequences of law, after death)	No	Meaning and expectations life and death, hope, passion, ambivalence, responsibility	Current relationships, effect of self-euthanasia on others, saying goodbye, consequences of law on others
2†	3 years	6	Yes	VSED, MED (which medication, obtaining, careful preparation, performance)	No	Death wish, meaning life and death, preparing for suicide, emotions	Effect of self-euthanasia on others, preparing others for goodbye, consequences of law on others
3	3 months	6	Yes	PAD, Helium, MED (which medication, obtaining, after death)	Yes	Meaning completed life, death wish, fear of dying alone, emotions	Preparing others for goodbye
4	1 year‡	1	No	MED (which medication, obtaining, careful preparation (withdrawal), performance)	Yes	Not mentioned	Not mentioned
5	8 years§	24	Yes	MED (which medication, obtaining, storing, performance)	Yes	Meaning life and death	Current relationships, saying goodbye, presence of others
6/7¶	5 years	1	No	MED (which medication, obtaining)	Yes	Intake, screening death wish	Not mentioned
8	3–4 years	1	No	MED (which medication, obtaining, delivery)	Ordered	Not mentioned	Not mentioned
9/10¶	2 years	1	No	MED (which medication, obtaining, storing, testing)	No	Intake, screening death wish	Meaning relationship
11	1 year	3	Yes	MED (obtaining)	No	Righteousness to end own life	Counselling of others (system)
12/13¶	3 years	3	Yes	PAD, MED (which medication, obtaining, storing)	Yes	Not mentioned	Counselling of others (system)
14	10 years	3	No	PAD, VSED, Helium, MED (which medication, consequences of law, obtaining, careful performance, after death)	Yes	Meaning life (events), timing	Effect of self-euthanasia on others, consequences of law on others
15	1 year	1	No	VSED, Helium, MED (which medication, careful performance, consequences of law, after death)	Yes	Current life situation (grief)	Preventing harm to others, consequences of law for others
16	8–9 years	3–4	No	MED (which medication, obtaining)	Yes	Not mentioned	Not mentioned
17	1 year	1	Yes	MED (which medication, obtaining)	Yes	Not mentioned	Not mentioned

*PAD: Physician assistance in dying (as under Termination of Life on Request and Assisted Suicide Review Procedures Act); VSED: Self-euthanasia by voluntary stopping of eating and drinking; Helium: Self-euthanasia by helium method; MED: Self-euthanasia by self-ingesting self-collected lethal medication.

†Partner present at interview to support with gaps in memory.

‡10 years ago present at counselling as partner.

§Received counselling 12 years ago from counsellor not active at time of interviews.

¶Couple together.

listened to, and feeling recognised and respected (see [box 1](#), Quotes 9–11). They regarded the counsellor to be critical in an open respectful manner. The counsellor clearly reminded people about their own responsibility in preparing for self-euthanasia. They experienced not being stimulated, pushed or forced in a certain direction (see [box 1](#), Quotes 11–13). Finally, people expressed being positive about the availability of the counsellor (see [box 1](#), Quotes 14 and 15).

After counselling: self-collected lethal medication

Most counselees had already obtained lethal medication (see [table 3](#)). This lethal medication was ordered via internet from countries abroad or via the black market in the Netherlands. Some had not (yet) obtained medication

because the idea that they could was satisfying enough for now, or felt they ‘*did not yet reach that stage*’. (Knowing how) to obtain medication brought reassurance, which was expressed by giving peace of mind, a safe feeling, reassurance to be able to decide for yourself and take your own responsibility (self-determination), and to be independent of healthcare professionals (see [box 2](#), Quotes 16–18). This reassurance added to their quality of life because they experienced less uncertainty about the possibility of having to continue in a state of unwanted suffering, memory problems felt less threatening, a depression became easier to deal with and it offered energy to continue with life (see [box 2](#), Quotes 16, 17, 19–21).

Box 2 Quotes about what happens after counselling

Quotes about self-collected lethal medication

Quote 16 'So, it's peace of mind that I have. I have received the information from someone I trust. I have the means of which the counsellor has sworn they are adequate. So, that's all stored in a very good, airtight environment. Ready! [...] Now I can continue with daily living.' (Counselee 14)

Quote 17 'It gives a very relieved feeling. Now, I have the feeling that I have something as insurance. And every time I panic, because I think I'm starting to have dementia, then at least I have a means as insurance. So it doesn't have to get that bad. And that gives me peace of mind [...] That I don't panic when I forget something.' (Counselee 15)

Quote 18 'The feeling that you have the medication in your own house and that you can decide for yourself. Maybe you will never use it. But just the feeling that when it is necessary, then I can use it: that is pleasant when you are older.' (Counselee 07)

Quote 19 'MH: Because you already have the medication at home for seven years, the possibility to end your life for seven years.

R: Yes, it gives a safe feeling.

MH: Can you tell me more about that safe feeling?

R: The feeling that you just—when you've reached your limits, when you really can't continue any longer—that there's a door you can enter and that will release you from life [...] that gives a good feeling. That gives a safe feeling [...] I also think only the fact you would have a legal possibility to end life in a humane way. If you know that, that knowledge is reason enough for people to live longer. That also counts for this medication. I have that medication at home. And it gives me peace. It sounds crazy, but that's how it works.' (Counselee 05)

Quote 20 'To get the maximum out of life. Yes, I'm not depressed. So I do all these things that I think are important at such a last moment. Yes, many paradoxes [...] I will probably leave at the peak of the party. Yes, that's what it is. I grant myself to leave the party at its peak.' (Counselee 03)

Quote 21 'And I sometimes have the urge to check if the medication is still there. Because if you take that away, then you take a piece of security away from me. And at the same time, the crazy thing, the ambivalence of that medication is that they maybe keep me living longer than when I would not have them. It also has...the whole procedure with taking anti-emetics beforehand, 24 hours before, there's a certain time frame. That also gives an inhibition. There are moments that I think that when the 24 hours would not be there, I would take them right away ...' (Counselee 05)

Quote 22 'But then, we do face a dilemma. Concerning our daughter. She also wants to end life by herself, but that will happen through the medical circuit [...] See, the dilemma is: we have the medication in the house for ourselves. But you can't give that to her, if she would want to.' (Counselee 07)

Quotes 23 'To be able to make an end to my own life in a humane way. And I won't do that before I have had another conversation with the counsellor, also with the children present [...] That I will only do it if there really are no other possibilities to continue life in a dignified way anymore [...] That could be a topic to discuss. Yes, imagine I would be in so much pain, and after a conversation with the counsellor, who would say 'well, you could try this, think about it' I'm just saying as an example—then I could reconsider my choice.' (Counselee 15)

Continued

Box 2 Continued

Quotes about the timing and manner of their end of life

Quote 24 'MH: If you have the medication in the house, do you have an image of when you would like to use it?

R: Not! We do not want to use it at all. We just want to keep on living.' (Counselee 07)

Quote 25 'I can describe it as when I'm totally dependent. Totally dependent on another. And that things happen I don't want to happen, and especially if I—that would be really important to me—if I foresee a moment in which I can't decide for myself. Then I would do it.' (Counselee 17)

Quote 26 'R: Then you think—yes, thank God we are not that far—but if at a certain moment you will say "I don't want anymore and now I will stop." [...] (Counselee 10)

R2: We don't know that. (Counselee 09)

R: Of course we don't... (Counselee 10)

R2: That's the dilemma that you can't get away from, certainly not as an outsider. You can't foresee the experience of the moment. That is a well known fact...that people postpone.' (Counselee 09)

However, possessing lethal medication also offered new concerns and dilemmas to some counselees who had obtained them. For example, concerns about preserving medication and medication being taken away by the police or loved ones, and a moral dilemma when a loved one wanted to self-determine their own end of life while the counselee owned the means to do so (see box 2, Quotes 21 and 22). Counselees did not worry about impulsivity. They possessed the medication for a long time already, and regarded the necessary 24 hours' period for taking antiemetics and the wish to have more counselling before acting on a wish to end their life as safeguards against impulsivity (see box 2, Quotes 19, 21, 23).

After counselling: the timing of their own end of life

The counselling and/or collecting the lethal medication contributed to a process in which counselees thought about if, when and how they would like to end their own life (see box 2, Quote 24). While one participant had an appointed date for PAD, and two persons mentioned a time frame ('the end of the year', 'within five years'), most counselees described future situations in which the option to end their lives would become more likely. These situations were overtreatment, memory problems, when life was not dignified anymore or would become unbearable or hopeless, when no other alternatives than a hospital or nursing home would be available, dependency of others and when the burden was greater than the capacity to carry it (see box 2, Quote 25). Often counselees made the side note that one cannot foresee the experience of a future situation, and the likelihood of postponing one's death due to a gradual acceptance of declining health conditions (see box 2, Quote 26).

DISCUSSION

Summary

People seeking counselling to be able to self-determine the timing and manner of their end of life have all received information about self-euthanasia through self-ingesting self-collected lethal medication. For half of the counselees, this has been accompanied by counselling about psychological aspects and/or the effect of self-determining your end of life on loved ones. All

counselees are positive about the availability of the counsellor, the trustful, careful and critical attitude of the counsellor, being able to openly discuss the subject, the feeling of being respected, and being reminded about their own responsibility without being pushed or forced in a certain direction. Some counselees are critical about feeling dependent on the counsellor and mentioned incompetency of the counsellor. The majority have obtained lethal medication, which can give rise to new concerns, but also gives counselees peace of mind and reassurance. It adds to their quality of life because of less uncertainty about having to continue in a state of unwanted suffering. Collecting lethal medication does not imply people want to end their lives themselves, nor that they want to end their life soon.

Limitations

A limitation of this study is that only people receiving DAS from counsellors facilitated by Foundation De Einder have been selected. Conclusions therefore cannot be generalised to the whole population of people receiving DAS. Also, counselees have enrolled themselves in this study and most counselees were recruited through a counsellor, which can lead to a possible self-selection bias. This might result in the expression of mainly positive experiences. Furthermore, the subset of people who died shortly after receiving counselling is missing. Therefore, the data may be biased in reflecting that many counselees have no intention to use their collected lethal medication and regard it as a safeguard to prevent situations of future suffering.^{5 11} However, a previous study shows that the group who seeks counselling to prevent possible future suffering forms at least one-third of people receiving counselling.¹¹

Reassurance and quality of life

Drion published the idea that older people would find reassurance in knowing they would have means available to end their own life at a moment suitable to them.¹² This idea clearly resonates in the stories of the counselees, and forms a replication of other interview studies.^{9 15 16} Having obtained the means to be able to end their lives in a respectable manner (and for some just the knowledge how to obtain these means) does indeed give people reassurance to be able to self-determine the timing and manner of their end of life.

In addition to providing reassurance, it can have other positive effects like worrying less about current problems or about having to continue life in a state of unwanted (prospective) suffering. Some even experience a renewed energy to *'get the most out of the time left'*. To have a wish (to be able) to end your life does not imply giving up on the life you are still living. Rurup *et al* described this by the existence of simultaneously having a wish to die *and* a wish to live.^{15 17} This latter might also be an explanation for findings by Van Wijngaarden where people who have a wish to die still *'exercise to keep fit and vital'* or *'consider hip replacement to increase mobility and independence'* while planning their death as well.^{16 18}

Owning lethal medication can lead to risks of impulsivity and misuse.^{3 19} Counselees do not share these concerns. However, a new finding is that owning lethal medication does give rise to other new concerns. For example, concerns about the due date of the collected medication, fear that people want to take that medication (and their peace of mind) away and a dilemma what to do with your lethal medication if loved ones seek a peaceful way to end their own life. This raises the question whether the obtained peace of mind outweighs the possible rise of new concerns, and whether the need for reassurance will ever be fully satisfied.

Counselling is more than just giving information about medication

While information about (obtaining) medication forms an important part of the counselling, it is not the only thing that is important. Also, the attitude of the counsellor which allows for an open conversation in which the wish to (be able to) end your life is not regarded as a taboo, is a positively valued aspect of the counselling as well. The importance of this openness in talking about and a non-judgemental attitude towards a wish to die is regarded as an essential aspect in providing care, and is also endorsed by a Dutch suicide prevention organisation,²⁰ and the multidisciplinary guideline for the diagnostics and treatment of suicidal behaviour.²¹ Also the guideline of the Royal Dutch Medical Association on the position of the physician in a self-chosen death by the patient extends on the possibility of the physician to offer DAS, and focuses on having conversations with the patient about the wish to end their own life.² If patients feel unable to talk about these wishes, their quality of life may be diminished.²²

Concerns for counselling

Some negative experiences with the counselling or counsellor offer points of attention for the counselling itself. Counsellors should be aware that possible feelings of dependency might cause counselees to act in a socially desirable way to obtain information from the counsellor. Furthermore, the competence of the counsellor being questioned raises the discussion about when a person is regarded to be qualified and competent to counsel people in this delicate matter. Finally, concerns after having collected lethal medication may ask for specific care or counselling after having collected lethal medication.

Implications

As counselling can have positive effects for the counselee, one recommendation could be that a physician should have a more open attitude towards the role and importance of counsellors. Also, aspects of the counsellor and counselling valued by counselees can offer recommendations for physicians who want to offer DAS themselves to patients who wish to self-determine the timing and manner of their end of life. Although the counsellor might hold a different position than the physician, for example, because a patient might perceive the physician as a person more focused on treating (a wish to be able to end your own life) instead of understanding the patient. The guideline of the Royal Dutch Medical Association on the position of the physician in a self-chosen death by the patient explicates the judicial possibilities for the physician when it comes to providing DAS.² Our study can provide physicians with valuable recommendations in providing DAS, for example, the importance of an open non-judgemental attitude, experience with and knowledge about a self-chosen death, providing trustworthy information and being available.

CONCLUSION

This study confirms the idea that having the means available to be able to end your own life in a respectable manner can provide people with reassurance and can increase their quality of life. It can, however, also give rise to new concerns like worrying about the shelf-life of medication or not losing the medication. This study also makes clear that counselling entails more than just providing information on (collecting) medication. Counsellors can play an important role for people who wish to self-determine the timing and manner of their end of life, by having

an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of DAS can provide recommendations for physicians taking care of patients who wish to self-determine the timing and manner of their end of life.

Contributors MH had the initial idea for this study, wrote the research protocol, performed the interviews and the analysis, and drafted the manuscript. MCS and KE performed the analysis, and contributed to the drafts of the manuscript. HRWP and BDOP commented on and contributed to the design, the analysis of the data and the final draft of the manuscript. All authors had access to all the data, can take responsibility for the integrity of the data and the accuracy of the data analysis and approved the final manuscript.

Funding This study was funded by Nederlandse Organisatie voor Wetenschappelijk Onderzoek (grant number: VICI 916.96.628).

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon request

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

- Onwuteaka-Philipsen BD, Legemaate J, van der Heide A, et al. *Third evaluation of the Termination of Life of Request and Assisted Suicide Review Procedures Act*. In Dutch: *Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. Den Haag: ZonMW, 2017.
- Royal Dutch Medical Association (Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst, KNMG). *The role of the physician in the voluntary termination of life*. Utrecht: KNMG, 2011. <https://www.knmg.nl/advies-richtlijnen/knmg-publicaties/publications-in-english.htm>
- Schnabel P, Meyboom-de Jong B, Schudel WJ, et al. *Completed Life. On assistance in suicide to people who regard their lives completed*. In Dutch: *Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten*. Den Haag: Advisory Committee Completed Life, 2016. <https://www.rijksoverheid.nl/documenten/rapporten/2016/02/04/rapport-adviescommissie-voltooid-leven>
- Dutch Jurisdiction: Assistance in suicide. In Dutch: *Behulpzaamheid bij zelfdoding*. Arrest Mulder-Meiss, Uitspraak Hoge Raad, 5 december 1995, NJ, 1996. Available: <https://www.navigators.nl/document/id3419951205100400nj1996322dosred/eccl-nl-hr-1995-zd0309-nj-1996-322-euthanasie-behulpzaam-zijn-294-sr-moet-worden-uitgelegd-cfm-algemeen-spraakgebruik-beroep-op-noodtoestand-inz-294-sr-toerei> [Accessed Apr 2019].
- Hagens M, Onwuteaka-Philipsen BD, Pasman HRW. Trajectories to seeking demedicalised assistance in suicide: a qualitative in-depth interview study. *J Med Ethics* 2017;43(8):543–8.
- Chabot BE, Admiraal P, Van Loenen A, et al. *Information about a careful ending of life*. In Dutch: *Informatie over zorgvuldige levensbeëindiging*. Amsterdam: Stichting WOZZ, 2008.
- Chabot BE. *A way out. An autonomous dignified end-of-life*. In Dutch: *Uitweg. Een waardig levenseinde in eigen hand*. Amsterdam: Nijgh & van Ditmar, 2019.
- Nitschke PH, Stewart FJ. *The peaceful pill Handbook*. In Dutch: *Handboek de vredige pil*. Haarlem: Exit International, 2018.
- Chabot BE. *Auto-euthanasia. Hidden ways of dying in consultation with proxies*. In Dutch: *Auto-euthanasie. Verborgen stervenswegen in gesprek met naasten*. Amsterdam: Uitgeverij Bert Bakker, 2007.
- Vink T. *Self-euthanasia. A self-delivered death under own autonomy*. In Dutch: *Zelfeuthanasie. Een zelfbezorgde dood onder eigen regie*. Budel: Damon, 2013.
- Hagens M, Pasman HRW, Onwuteaka-Philipsen BD. Cross-Sectional research into counselling for non-physician assisted suicide: who asks for it and what happens? *BMC Health Serv Res* 2014;14(1):455.
- Drion H. *The self-chosen death in the elderly*. In Dutch: *Het zelf gekozen levenseinde*. Amsterdam: NRC Handelsblad, 1991.
- Pope C, Ziebland S, Mays N. Qualitative research in health care. analysing qualitative data. *BMJ* 2000;320(7227):114–6.
- Boeije H. *Analysing in qualitative research. Thinking and acting*. In Dutch: *Analyseren in kwalitatief onderzoek*. Den Haag: Boom Onderwijs, 2008.
- Rurup ML, Pasman HRW, Kerkhof A, et al. Older people who are "ready with life": Expectations about the future and experienced hopelessness. In Dutch: *Ouderen die 'klaar met leven' zijn: Toekomstverwachtingen en ervaren uitzichtloosheid*. *Tijdschr Gerontol Geriatr* 2011;2011(42):159–69.
- Van Wijngaarden EJ. *Ready to give up on life. A study into the lived experience of older people who consider their lives to be completed and no longer worth living*. Amsterdam: Uitgeverij Atlas Contact, 2016.
- Rurup ML, Pasman HRW, Goedhart J, et al. Understanding why older people develop a wish to die: a qualitative interview study. *Crisis* 2011;32(4):204–16.
- van Wijngaarden E, Leget C, Goossens A. Caught between intending and doing: older people ideating on a self-chosen death. *BMJ Open* 2016;6(1):e009895.
- Trappenburg M, van Holsteyn J. The quest for limits. In: Klijn A, Mortier F, Otlowski M, eds. *Regulating physician-negotiated death*. Den Haag: Elsevier, 2001.
- 113Online. Guide suicide prevention for the physicians practice. In Dutch: *Handreiking zelfmoordpreventie voor de huisartsenpraktijk*. Available: <https://www.113.nl/sites/default/files/113/preventie/Handreiking%20113%20huisartsen.pdf> [Accessed Feb 2019].
- Van Hemert AM, Kerkhof A, de Keijser J, et al. *Multidisciplinary guideline diagnostics and treatment of suicidal behaviour*. In Dutch: *Multidisciplinaire richtlijn diagnostiek en behandeling van suicidaal gedrag*. De Tijdstroom: Utrecht, 2012.
- Pasman HRW, Willems DL, Onwuteaka-Philipsen BD. What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives and physicians. *Patient Educ Couns* 2013;92(3):313–8.
- Foundation De Einder. *Brochure: A dignified death under own autonomy*. In Dutch: *Brochure: Een waardig levenseinde onder eigen regie*. Gairle: Stichting De Einder, 2016. <https://www.deeinder.nl/wp-content/uploads/2016/11/De-Einder-brochure-Een-waardig-levenseinde-in-eigen-regie.pdf>
- Vink T. *Self-determination at the end of life. A view at practical experiences*. In Dutch: *Zelf over Het levenseinde beschikken – de praktijk bekeken*. Budel: Damon, 2008.