Non-punishable assistance in intentionally ending one's own life outside the Termination of life on request and assisted suicide review procedures Act

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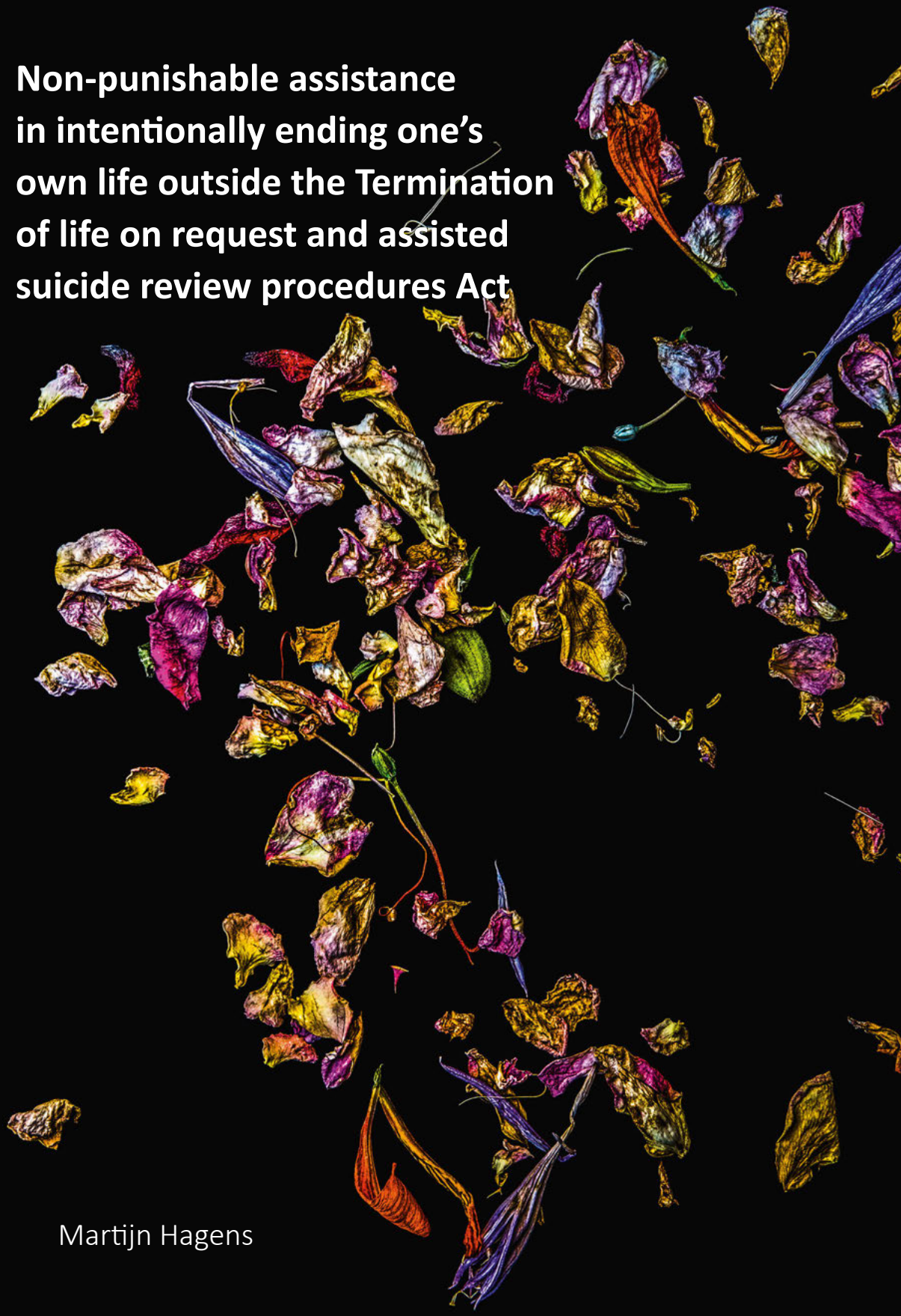

Martijn Hagens

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NON-PUNISHABLE ASSISTANCE IN INTENTIONALLY ENDING ONE'S OWN LIFE OUTSIDE THE TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE REVIEW PROCEDURES ACT

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	dr. E.E. Bolt
	dr. H.A.M. Weyers

Table of Contents

Abbreviations

CLW	Cooperation Last Will (*in Dutch*: Coöperatie Laatste Wil)
DAS	Demedicalised assistance in suicide
FAS	Family assisted suicide
GP	General practitioner
KNMG	Royal Dutch Medical Assosication (*in Dutch*: Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst)
MED	Self-ingesting self-collected medication
LAD	Lay assisted death
Non-PAS	Non-physician assisted suicide
NVVE	Right-to-Die Netherlands (*in Dutch*: Nederlandse Vereniging voor een Vrijwillig Levenseinde)
PAD	Physician assistance in dying as under the Dutch Termination of life on request and assisted suicide review procedures Act (or similar laws on physician assistance in dying when referring to countries outside the Netherlands)
PAS	Physician assistance in suicide as under the Dutch Termination of life on request and assisted suicide review procedures Act (or similar laws on physician assistance in suicide when referring to countries outside the Netherlands)
RAD	Relative assisted death
RAS	Relative assisted suicide
RDMA	Royal Dutch Medical Assosication (*in Dutch*: Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst)
SDE	Foundation De Einder (*in Dutch*: Stichting de Einder)
SLC	Foundation End-of-Life Counseling (*in Dutch*: Stichting LevenseindeCounselling)
SVE	Foundation Voluntary Euthanasia (*in Dutch*: Stichting Vrijwillige Euthanasie)
SVL	Foundation Voluntary Life (*in Dutch*: Stichting Vrijwillig Leven)
SWS	Foundation Dignified Dying (*in Dutch*: Stichting Waardig Sterven)
VSED	Voluntary stopping eating and drinking

WOZZ	Foundation for Scientific Research into Careful Suicide (*in Dutch*: Stichting Wetenschappelijk Onderzoek naar Zorgvuldige Zelfdoding)
Wtlh	Termination of life on request and assisted suicide review procedures Act (*in Dutch*: Wet Toetsing levensbeëindiging op verzoek en hulp bij zeldoding)

Prologue

This thesis is dedicated to Tanny. Who has introduced me to this subject about fifteen years ago, and who has not only been at the very cradle of my existence, but also at the cradle of this path I have walked in life. Who has introduced me to the work of right-to-die organisation Foundation De Einder and motivated me to work together with this organisation as a counsellor for several years. It offered a unique insight into a practice that is not well-known.

It took about ten years to finish the work for this thesis, and during this period formed an essential part of my life. Stacks of papers, shelves full of books and an ever-expanding digital library asking to be read. So many viewpoints to (re)consider. All the thoughts, sentences, and chapters slowly but surely evolving in the process. An always renewed interest when the subject came up in conversations, in the news, in books and in movies. It provided inspiration to dive even deeper in this immensely interesting subject. It therefor was a tough decision to decide to have to exclude so many things I would have liked to include.

Finishing up this thesis occurred during almost two years of Covid-19 restrictions. The coming to a standstill of society did offer me the opportunity to find space for reading so many of these interesting books, articles and reports about the subject (and those subjects related to it). Working from home was by far my number one favourite spot (despite all the tropical places, pools and hotel rooms I've worked from as well). Although working from home also had its challenges. Amidst all the precious family moments, distractions, and temporarily stored building materials, I was able to create a space to work, to stack up my books, and create a little library. A little world about the end of life I was writing about.

During writing, I often found myself staring into a non-defined spot in space somewhere in front of me, where I'd hope all these thoughts, numbers, knowledge, viewpoints and words in my mind would miraculously combine into that one perfect sentence or insight. My eye was often drawn to one book in my little library on life's end: 'Fading Beauty' by Dale Grant. His photos not only capture a world in which beauty is fading, but also change your perspective by capturing the beauty of fading. How the photos of the decaying flowers remind us about the circle of life, its beginning and its inevitable ending. How some seem to be sad and grieving, others seem to be whirling quite joyful through their final days. Like humans who depart life in many different ways, and in many different states of mind.

This cycle of life is also our human fate. Though some do not like to await their faltering fate. While this thesis focusses on the wish to decide oneself on the time and manner of one's own death, I would like to emphasize this should not let us lose sight of our ability and strength to have a renewed look at our very faltering fate. From all the life stories I've heard in my private life, in my work as a counsellor and in my work as a researcher I see it as our task to influence the balance between the burden one carries and one's ability to carry that burden. By finding ways to diminish the burden, and to find ways to strengthen one's ability to carry it. For that matter, Dale's work inspires to new ways of looking.

For some people I have met and known in my life, the burden was greater than their ability to carry it. As a tribute to Tanny, as a tribute to all the precious time I spend thinking and writing on this thesis, as a tribute to Dale's work, and as a tribute to all people whom I wish their ability to carry will be greater than the burden they have to carry I've included – with the much appreciated courtesy of Dale – some of his beautiful photos.

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1

General introduction

GENERAL INTRODUCTION

This thesis focusses on people who have intentionally ended their own life or wish to do so. People can do this entirely by themselves, but they can also receive assistance in seeking their own death. An example of this assistance is physician assistance in dying (PAD) under the Dutch Termination of life on request and assisted suicide review procedures Act.[1] This thesis, however, focuses on people who seek assistance in intentionally ending their own life *outside* this legalized medical practice of PAD in The Netherlands.

This thesis primarily aims to gain insight into which people seek assistance in intentionally ending one's own life *outside* the Dutch law on PAD, their reasons to do so, and how they have experienced this assistance. Furthermore, this thesis aims to gain insight into who passes away in which manner after receiving this assistance. This thesis also provides an estimate of the frequency of and a description of the characteristics of people who have intentionally ended their own life in the Netherlands.

To explain which specific assistance in intentionally ending one's own life is the main focus in this thesis, this first chapter briefly introduces the terminology and the legal background of assisting people who intentionally (wish to) end their own life. This is followed by a description of the practice of and available research about this assistance in the Netherlands. Also, the international perspective is briefly discussed.

Terminology

Throughout time, many different terms have been used to describe the act of intentionally ending one's own life. "Suicide" is probably the most well-known and most widely used one. Other examples are "self-murder" and "self-euthanasia".[2-6] There is debate whether these different descriptions of intentionally ending one's own life are helpful in the debate on the matter.[7] In this thesis, intentionally ending one's own life is the preferred terminology. It is regarded as a neutral and factual description of the act. Furthermore, it includes the act of voluntarily stopping eating and drinking (VSED) for which it is debated whether this can be regarded as "suicide".[8-10] "Suicide" will be used when referring to the original wording in other publications, for example legislation.

As further chapters in this thesis use different terminology for intentionally ending one's own life, the origin and meaning of this terminology are described more elaborately in Appendix 1. As language plays an important role in the academic and public debate on the matter, more attention to terminology will be given in the discussion of this thesis.

Assisting someone who intentionally ends one's own life: a brief overview of the legal situation in the Netherlands

This paragraph briefly describes the Dutch legal situation on assisting someone who intentionally ends one's own life. In the Netherlands, intentionally ending one's own life is not punishable by law. However, *assisting* someone who intentionally ends one's own life is punishable. Article 294 of the Dutch Penal code states that it is a crime to incite another to end his or her own life, and to deliberately assist another or provide the means thereto.[11] There are, however, exceptions to the criminalization of assisting someone who intentionally ends one's own life.

The first example of de-criminalising assisting someone who intentionally ends one's own life is the Termination of life on request and assisted suicide review procedures Act, also known as the Dutch "Euthanasia Law", and referred to in this thesis as the Dutch law on PAD.[1] This Act came into effect in 2002 and reflects a long and intensive public debate on PAD. It is the product of several decades of case law on PAD and a parliamentary history on codifying that practice.[12] It has been specifically drafted to exclude physicians from prosecution. It allows a physician to either prescribe lethal medication which patients ingest themselves (physician assistance in suicide; PAS) or to intravenously administer lethal medication at the patient's own request (voluntarily termination of life on request). Both forms of PAD are only allowed when the physician acts in accordance with all criteria of due care laid out in the law.[1]

Assistance to people who intentionally end their own life has also been offered *outside* the Dutch law on PAD. The second exception to the criminality of assistance in intentionally ending one's own life is assistance offered during voluntarily stopping eating and drinking (VSED). The third exception is formed by case law concerning article 294 of the Dutch Penal Code, which has clarified it is not a criminal offence to "have conversations about the wish to end life, to offer moral support (including being present on the condition that no active assistance has

been offered), and to provide general information about methods to end one's own life."[13-16] Such assistance has been offered by relatives and friends (referred to as significant others), but also by professional caregivers like physicians, and by professionals or volunteers related to right-to-die organisations. This latter assistance can be described as non-directive counselling which is not regarded as a criminal offense by the European Court of Human Rights.[8,17]

In this thesis, I focus on the non-punishable assistance (consisting of having conversations, offering moral support and providing general information) in the form of non-directive counselling offered by counsellors working in cooperation with the Dutch right-to-die organisation Foundation De Einder. Background information on right-to-die organisation Foundation De Einder is described in Box 1.1. Foundation De Einder is only one of several Dutch right-to-die organisations currently active in the Netherlands. An overview of Dutch Right-to-die organisations can be found in Appendix 2. Chapter 2 offers a more detailed introduction to the history and juridical background of assistance in intentionally ending one´s own life in the Netherlands.

Box 1.1
Right-to-die organisation Foundation De Einder

Foundation De Einder was founded in 1995 with the aim to "ameliorate and offer professional counselling for people with a wish to end life, with respect for the autonomy of the person asking for assistance…".[18] Since it regards the ending of one's own life as a possible outcome of the counselling, it distinguishes itself from suicide prevention organizations that try to prevent this from happening. Foundation De Einder refers people to independently working consultants. The non-directive counselling by consultants consists of having conversations, offering emotional and psychological support and providing general information on non-mutilating methods to end one's own life. The counselling is aimed at creating as much clarity as possible regarding the wish to end one's own life, and the possibility of ending of one's own life. This covers the emotional and psychological process of decision-making and may include matters like considering alternatives, timing of death, and consideration of others. In the situation where the counselee decides to act upon the wish to end one's own life, the counselling is aimed at realising the best possible preparations for the ending of one's own life. This covers information about practical matters and may include information on gathering means for, and on the effectuation of, ending of one's own life. The counselling is not aimed at a specific choice or outcome, but is aimed at attaining the highest possible quality of the choice and – if it comes to that – the highest possible quality of the implementation of the wish to end one's own life.[18,19]

Assisting someone who intentionally ends one's own life: research in the Netherlands

In this section, I discuss prior research about people who offer non-punishable assistance to those who have intentionally ended their own life in the Netherlands outside the Dutch law on PAD.

Assistance offered by significant others

While this thesis focusses on professionally involved people who offer assistance to someone intentionally ending one's own life outside the Dutch law on PAD, for a complete overview on this assistance the position of significant others will also be discussed. Significant others can be involved in both the preparation of and during the process of someone intentionally ending one's own life.[20,21] In one study that looked into people that were confidants for someone who intentionally ended one's own life, the great majority (73-80%) of the involved persons were not medical caregivers, but significant others like partners, parents, children, brothers and sisters and friends.[20] Family and friends were a source of information in about one out of every seven or eight cases of VSED or self-ingesting self-collected lethal medication (MED).[20] In 40-45% of the cases, the involved person was present during the passing away of the person ending one's own life.[20] In another study amongst family physicians who were asked about their last patient who intentionally ended their own life by VSED, in about half of the cases proxies were involved in the preparation (44%) and/or during the process (53%).[21]

Assistance offered by professionally involved people

The focus of this thesis is on professionally involved people who assist someone who intentionally wishes to end one's own life. "Professionally involved people" refers to people who are not personally related to the person wishing to end one's own life, but are involved as representatives of professional (right-to-die) organisations or are involved as professional caregivers, for example as a physician.

In half of the cases of VSED, the physician had been informed about the intention of the patient to end life by VSED. In about two thirds of the cases of VSED, physicians were involved in the preparation and/or during the process of VSED.[21,22] In about one out of every five cases of VSED the physician suggested this method.[20-22] For deaths by MED the physician is generally not involved.[22] Although an older nationwide survey in the Netherlands has shown that in a quarter of the researched cases of MED the physician offered information about this.[20]

Besides professional caregivers, several Dutch right-to-die organisations offer non-directive counselling for people who wish to intentionally end their own life. Studies into Dutch right-to-die organisations are scarce. Chabot was the first to study this in a qualitative interview study which described 18 cases of MED and VSED.[23] In two thirds of the cases, besides the counsellor or volunteer from a right-to-die organisation, also significant others or medical caregivers (e.g. the physician or psychiatrist) were included.[23] Annual reports from Right-to-die Netherlands (Nederlandse Vereniging voor een Vrijwillig Levenseinde; NVVE) over the past years do not provide a conclusive image on the assistance in a "careful suicide" provided by volunteers from their support desk and consultancy service.[24] In 2018, about 20% of the 2,669 enquiries for help concerned a "careful suicide" or VSED.[24] Foundation De Einder has published annual reports with data about the people seeking their assistance since their founding in 1995. While the number of people receiving counselling from a counsellor over the years has gradually risen to 607 in 2014, the number has decreased to 142 in 2020.[25,26]

There have been no other studies that focus on Dutch right-to-die organisations and the assistance they offer to people who wish to intentionally end their own life. Most research in this field focusses on the frequency of non-mutilating methods of dying that right-to-die organisations inform about – primarily aimed at VSED and MED – and the characteristics of people choosing to end life by these methods.[20,27] Between 0.5% and 2.1% of all annual deaths occur by VSED. In general, these people are primarily over 80 years old, and suffer from somatic diseases, especially an accumulation of problems related to old age.[20,27] Between 0.2% and 1.1% of all annual deaths occur by MED. In general, these people are primarily under 80 years old and more often have psychiatric and psychosocial problems compared to people who intentionally end their own life through VSED.[20,27] However, it is not known how many of the deaths in these studies have been assisted by counsellors or volunteers from right-to-die organisations.

Assisting someone who intentionally ends one's own life: an international perspective

Up to now, the focus is on the Dutch situation. This paragraph will briefly place legislation and research about assisting someone intentionally ending one's own life in an international perspective.

Like in the Netherlands, in most countries worldwide it is not a crime to (attempt to) intentionally end one's own life. In the vast majority of countries it is a crime to assist therein.[28] Nevertheless, assistance in intentionally ending one's own life occurs in multiple countries.

Though there are substantial differences, several countries have legalized physician assistance in suicide or the voluntary termination of the life of the patient at the patient's own request. In 2021, these are The Netherlands, Belgium, Luxembourg, Spain, Canada, New Zealand, the Australian states of Victoria, Western Australia, Tasmania, Southern Australia, and Queensland and the American states of Oregon, Washington, Vermont, California, Colorado, Hawaii, New Jersey, Maine, New Mexico, and Washington DC.[1,29-48] In Colombia, Montana (US), Germany, Italy and Austria court judgments allow for physician assistance in dying, but this practice has not yet been regulated in a specific Act.[49-53] All countries differ in the requirements for accessing PAD. In countries that allow for PAD, as well as in countries that criminalize all assistance in intentionally ending one's own life, it occurs that significant others and other professionally involved persons do assist people who intentionally end their own life outside these legal regulations or prohibitions. Despite this being a covert practice, it has been reported on, for example in the United States of America,[54-57] the United and Italy.[60]

Switzerland has been allowing assisting others in intentionally ending their own life for decades without a specific Act regulating the matter. The Swiss Criminal Code article 115 penalizes assistance in suicide "*for selfish motives"* which 'e contrario' signifies that assistance in suicide which is not the result of selfish motives remains unpunished.[61] This resulted in a practice wherein physicians and non-physicians (e.g. relatives or employees of right-to-die organisations) offer assistance to people intentionally ending their own life. Swiss right-to-die organisation are involved in almost all assisted suicides in Switzerland, and this usually occurs in cooperation with Swiss physicians.[62]

There are countries that do not have a law that penalizes assisting someone who intentionally ends one's own life, for example Belgium, Denmark, Finland and Sweden.[28] Germany saw a special development in that this assistance was not specifically regulated and not a crime, until in 2005 Penal Code article 217 made repeated and thus professional assistance in

intentionally ending one's own life a crime. In 2020, the German Federal Constitutional Court judged this article to be unconstitutional and void.[51] Little research is available about the practice of assising someone who intentionally ends one's own life in these countries.

This thesis

Research aims

First, this thesis aims to give an estimate of the frequency of people who intentionally ended their own life in the Netherlands, and to describe their characteristics.

Secondly, this thesis focuses on which people *seek* assistance in intentionally ending their own life *outside* the Dutch Termination of life on request and assisted suicide review procedures Act, how seeking this assistance is related to seeking PAD *under* this Dutch law on PAD, and how counselees experience the assistance they received.

Finally, this thesis aims to describe the incidence and the characteristics of people who have intentionally ended their own life *after* receiving assistance in intentionally ending one's own life *outside* the Dutch law on PAD, and to describe the characteristics of the counselling they received.

Methods

The data for this thesis were derived from three studies: a mortality follow-back study amongst physicians as part of the third evaluation of the Termination of life on request and assisted suicide review procedures Act, a cross-sectional questionnaire study amongst counsellors working in cooperation with right-to-die organisation Foundation De Einder, and an in-depth interview study with people receiving assistance from counsellors working in cooperation with right-to-die organisation Foundation De Einder.
Mortality follow-back study

Since the Dutch Termination of life and assisted suicide review procedures Act was enacted, its effectiveness and side-effects have been evaluated every five years. In 2015-2016, this Act has been evaluated for the third time. The evaluation study consisted of multiple studies, and for this thesis the mortality follow-back study was relevant. Certifying physicians of a sample of 9,351 deceased people received a questionnaire through mail of whom 7,277 participated (response rate 78%). The questionnaire contained questions about end-of-life decision making, including questions about patients intentionally ending their own life.

Cross-sectional questionnaire study

To describe characteristics of people who received assistance in intentionally ending one´s own life *outside* the Dutch law on PAD, a cross-sectional study was designed. Counsellors working in cooperation with right-to-die organisation Foundation De Einder filled out annual registration forms about the counselees they have had contact with in the prior year. Data was collected from these questionnaires over the years 2011 until 2015, and was filled out by all 12 counsellors working with Foundation De Einder during those years (response rate 100%). This resulted in data on 2,302 counselees.

In-depth interview study

An in-depth interview study was performed to obtain more insight into the reasons to seek assistance for intentionally ending one's own life *outside* the Dutch law on PAD, and the experiences of the counselees with this assistance. Participants were recruited through the former quarterly magazine of Foundation De Einder and through the counsellors working in cooperation with this foundation. This resulted in in-depth interviews with 17 people.

Outline of thesis

To better understand the Dutch context and practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD, this thesis starts with a more detailed introduction of the history and legal background of assisting someone who intentionally ends one's own life in the Netherlands in Chapter 2, before reporting on the empirical research.

The third chapter of this thesis provides an estimate of the frequency of – and describes the characteristics of – the people that choose to end their own life through VSED, MED and other non-mutilating and mutilating methods in the Netherlands. It addresses the accuracy of the available frequencies of people ending their own life, and the role of the presence of a medical condition when people have chosen to end their own life. This chapter presents the results from the mortality follow-back study as part of the third evaluation of the Termination of life on request and assisted suicide review procedures Act. The characteristics of persons who ended their life were drawn from 521 cases reported by physicians.

The fourth chapter studies the characteristics of people that seek assistance in intentionally ending one's own life *outside* the Dutch law on PAD. This study distinguishes one group of people who are seeking a peaceful death from current suffering and another group of people who are looking for reassurance to prevent possible future suffering. This chapter presents the results from the cross-sectional questionnaire study under counsellors working with Foundation De Einder. It includes all the counselees in the years 2011 and 2012 whom the counsellor has personally seen during a consultation (N=595).

The fifth chapter explores the reasons for seeking assistance in intentionally ending one's own life *outside* the Dutch law on PAD, and how this is related to seeking physician assistance in dying *under* this law. It distinguishes three different trajectories that lead people to seek assistance in intentionally ending one's own life. Furthermore, it describes how patient-physician communication can play an important role in this process. This chapter draws data from the in-depth interview study.

The sixth chapter focuses on the content of assistance in intentionally ending one's own life *outside* the Dutch law on PAD, and how counselees experience this assistance. This chapter also uses data from the in-depth interview study.

The seventh chapter focuses on a subset of the people who seek assistance for intentionally ending one's own life *outside* the Dutch law on PAD, namely those that have ended their own life after having received this assistance. It describes the role of having a medical disease and requesting PAD, and the characteristics of the counselling received. This chapter presents the results from the cross-sectional questionnaire study under counsellors working with

Foundation De Einder. It includes the counselees whom the counsellor has personally seen during a consultation, and who passed away by MED between 2011 and 2015 (N=273).

This thesis concludes with a final chapter that summarizes the results of the studies, interprets them in relation to the literature, and discusses several overarching themes like the terminology of assistance in dying, physician involvement with people intentionally ending their own life, and the practice of assistance in intentionally ending one's own life *outside* the Dutch law on PAD. The chapter concludes with several implications and recommendations.

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2

Introduction to the historical and legal background on assisting someone who intentionally ends one's own life

Article 294 of the Dutch Penal Code

In the Netherlands, intentionally ending your own life is not punishable by law. However, *assisting* someone who intentionally ends one's own life is punishable. Article 294 of the Dutch Penal Code states that "*he who deliberately incites another to suicide is, if the suicide follows, punished with a prison sentence of at most three years or a fine of the fourth category (section 1); he who deliberately assists another in suicide or provides him with the means is, if the suicide follows, punished with a prison sentence of at most three years or a fine of the fourth category (section 2)*".[1]

Back in 1886, the Dutch Council of State and other people opposed the introduction of article 294 of the Penal Code which was going to criminalize assisting someone who intentionally ends one's own life. For example, because of the logic that an accessory act ('assistance in') could not be punishable if the principal act ('suicide') was not punishable.[2-6] Several explanations for the introduction of Article 294 exist. Intentionally ending one's own life in itself was regarded as something that had to be prevented due to the prevailing values that ending one's own life was a crime against oneself or human nature, against society, and/or against God's will.[5,7] Introducing Article 294 was regarded to be more effective in preventing people to end their own life rather than punishing the act itself. The latter could motivate people to try to be more successful in their attempt to end their own life, to escape possible punishment after a possible failed attempt or as a result of the agony caused by the punishment.[4,6-10] Also, preventing situations like the Dettemeijer court case (1858) – which is described in Appendix 4 – might have motivated the acceptance of introducing this article.[5,9,11]

Many things have changed since 1886, since the time Article 294 of the Penal Code came into effect. For example, life expectancy has almost doubled from just over 40 years in 1886 to just over 80 years in 2019.[12-15] Amongst others, this is the result of ameliorations in standards of living, public health, personal hygiene and medical care.[16] Furthermore, growing older – together with advancements in medical technology, the growth of treatment options, and the growing importance of self-determination – have resulted in people making more choices regarding their end of life, about their death and dying.[6] This resulted in situations that were not foreseen at the time the Penal Code was drafted at the end of the

19th century. The opinion that intentionally ending one's own life should always be regarded as something criminal that should be prevented at any cost has changed.[6,17] Hence, new laws and case law now provide exceptions to the criminalization of assisting someone who intentionally ends one's own life.

Assisting patients under the Dutch law on PAD

The first example of de-criminalising assisting someone who intentionally ends one's own life is the Dutch "Termination of life on request and assisted suicide review procedures Act" which came into effect in 2002.[18] This Act is the result of several decades of multiple court cases on a practice in which physicians offered assistance in dying, and a parliamentary history on codifying that very same practice.[6,19] The verdicts of the Postma, Wertheim, Schoonheim, Chabot and Brongersma court cases are regarded as the most influential ones in forming (the practice of) this Act.[6,11,20] These key judgements are described in Appendix 3.

The Termination of life on request and assisted suicide review procedures Act, referred to as the Dutch law on physician assisted dying (PAD), has been specifically drafted to exclude physicians from prosecution under both Article 293 and 294 of the Penal Code. These articles respectively state that it is a crime to end someone's life on his or her persistent desire (Article 293), and to deliberately encourage someone to end his or her own life, to provide the means thereto or to assist therein (Article 294).[1] The Dutch law on PAD allows the physician to either prescribe lethal medication which the patient ingests him or herself in the presence of the physician (physician assistance in suicide; PAS) or allows the physician to intravenously administer a lethal drug at the patient's own request (voluntarily termination of life on request). Both forms of physician assistance in dying are only permitted when the physician acts in accordance with all six criteria of due care laid out in the law. The criteria state that 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.[18]

Several Dutch Supreme Court judgments have set requirements supplementary to the Act. The Supreme Court, citing the parliamentary history of the Act, held that the patient's suffering must on the whole be the result of one or more medically recognised diseases or conditions. Therefore, the concept of 'completed life' as a grounds to receive assistance in ending one's own life falls outside the scope of the Act as it goes beyond the medical domain.[21] The Supreme Court also reiterated the opinion it held in the Chabot verdict that this medical condition may be either somatic or psychiatric.[22] Furthermore, the Supreme Court confirmed that acting upon a written advanced directive in case of an incompetent patient can meet due care requirements.[23]

While assistance in dying under the Dutch law on PAD is only permitted for physicians, the Dutch practice shows that several non-physicians can be involved in preparatory acts under this official procedure. First, nursing staff (registered nurses or certified care assistants) can be involved by being present and by performing preparatory acts for the physician. Their role is clarified in the professional guidelines of the Dutch national nurses' and physicians' associations which state that nursing staff are not allowed to administer the lethal drugs. Nursing staff are advised that – if they are present – they should only perform tasks whereby at least one other essential act by the physician must follow to end the life of the patient. Like, physicians they can also have conscientious objections.[24-27] Secondly, in the official procedures pharmacist have the task to distribute the lethal medication to the physician under the final responsibility of the physician. Their responsibilities and criteria for due care are laid out in a professional guideline from the Dutch national pharmacists' and physicians' associations. Like physicians, they can also have conscientious objections.[28-30]

Assisting someone who intentionally ends one's own life outside the Dutch law on PAD

Other forms of assistance for people who intentionally end their own life are available *outside* the Dutch law on PAD. It is important to distinguish the assistance described in this paragraph from the approach of "suicide prevention". "Suicide prevention" is aimed at diminishing the risk of people intentionally ending their own life and/or reducing the incidence of people intentionally ending their own life under lonely and desperate circumstances.[31-34] Furthermore, the focus in this thesis is on assisting people who intentionally end their own life and *not* on the termination of life on request. The Dutch judiciary has chosen for a medical monopoly in the voluntary termination of life on request. For a non-physician who has terminated the life of someone else at this person's request, not a single appeal for exceptional circumstances has ever been granted, and for all these non-physicians there have been penalties.[6] This situation, however, is different for assisting someone who intentionally ends one's own life.

When someone wishes to intentionally end one's own life, people can offer assistance that is not aimed at preventing someone to end one's life, but to assist a person to be able to act upon this wish. Concerning which person offers this assistance, the focus in this thesis is on people who are acting out of their profession or as a representative of a professional organisation. They are referred to as professionally involved people. One can also distinguish relatives and friends, referred to as significant others, who offer assistance.[6]

Assistance offered by significant others

While the focus of this thesis is on professionally involved people, in practice significant others are also often involved. Therefore, the position of significant others in offering this assistance is briefly discussed. They are judged according to the adherence of article 294 of the Penal Code and the case law concerning it. This has once more become evident by the verdicts in the court cases of Albert Heringa who assisted his mother who intentionally ended her own life (see Box 2.1).[35] An overview of cases of significant others assisting people who intentionally ended their own life that have been brought to court or have been subpoenaed can be found in Appendix 4.

Box 2.1
The Heringa court case

The Heringa court case concerns a man who assisted his 99-year old (step)mother with her intention to end her life in 2008. He had multiple conversations with her, informed and instructed her before and during the act, and provided her the lethal medication to take her own life. He filmed the act when she was taking her own life which was broadcasted as a documentary in 2010 after which Heringa was prosecuted. An initial guilty without punishment and acquittal were overruled by the Supreme Court stating that the criteria of due care from the Termination of life on request and assisted suicide review procedures Act were incorrectly applied to a non-physician, because they were specifically designed for physicians.[36-38] The Higher Court of 's Hertogenbosch (2018) sentenced him to a six months' conditional imprisonment with a two-year probation period. Despite acknowledging the son acted out of compassion, and the long duration of the trial, several aspects of the case negatively influenced the sentence: not enough efforts to change his mother's mind, being motivated by his conviction that the law on assistance in dying should be changed, leaving his mother alone after she fell asleep but before she died (and not recognizing the possibilities of complications), and not being transparent about his mother's death and his assistance in the years before the broadcasting of the documentary.[39] The Dutch Supreme Court upheld this judgement.[34]

The position of significant others seems to differ from professionally involved people. The Dutch Public Prosecutor does not seem to actively prosecute all cases of significant others who offered punishable assistance according to Article 294 of the Dutch Penal Code and the case law concerning it. These cases are described in Appendix 4. While verdicts are all on a 'casuistic' base, one may infer several aspects that contribute to (the severity of) punishment from the verdicts in cases brought to court, and the grounds for subpoena in subpoenaed cases. For example, assistance by significant others may face a more sympathetic response from prosecuting authorities than volunteers of right-to-die organizations.[40] Furthermore, judges seem to have an implicit tendency that friends and family members are grosso modo more punishable than partners, because friends and family members are more distanced from the suffering than partners and therefor it should be easier to withdraw oneself from the wish of the person.[6] In rare cases – described in Appendix 4 – punishable offences have not been prosecuted due to the low criminality of the offence, the small role of the punishable offence in the complete fact, or being negatively affected by the death.

Assistance offered by professionally involved people

The focus of this thesis is on professionally involved people who assist someone who intentionally wishes to end one's own life. "Professionally involved people" refers to people who are not personally related to the person wishing to end one´s own life, but are involved as representatives (often volunteers) of a professional organisation or as professional caregivers.

Assisting someone who intentionally ends one's own life outside the Dutch medical and legal framework of PAD occurs during voluntarily stopping eating and drinking (VSED). Deaths resulting from VSED are generally regarded as a natural death, and therefore assistance in these deaths is not regarded as a criminal offense.[41] The rationale for this is that patients can express which treatments they do not wish to have performed (including administering food and fluids). The physician is obligated to respect this statement of the patient's wishes, as laid down in Section 7:450 of the Dutch Civil Code, part of the Medical Treatment Contracts Act.[42] Assistance offered by professional caregivers – like nurses or physicians – during the process of VSED can be regarded as taking measures to alleviate the suffering as much as possible, and being a good caregiver.[41,43] There is, however, debate on whether VSED should be regarded as "suicide".[7,44,45] This debate will be described in more detail in the discussion on terminology in Chapter 8.

Whenever a professionally involved person offers assistance to someone who wishes to intentionally end one's own life through other methods than VSED, for example through self-ingesting self-collected lethal medication (MED), then the assistant is judged by the adherence to article 294 of the Penal Code. Court cases involving professionally involved physicians, psychologist, counsellors and volunteers working with right-to-die organisations who have assisted someone who intentionally ended one's own life outside the Dutch law on PAD have resulted in case law concerning article 294 of the Penal Code. An overview of these court cases can be found in Appendix 5. Appendix 2 gives an overview of Dutch right-to-die organisations over the past decades.

The legal considerations of the verdicts in these court cases concerning volunteers and counsellors from the right-to-die movement assisting someone who intentionally ends one's own life outside the Dutch law on physician assistance in dying can be summarized as follows:
(a) Section 1 of Article 294 of the Dutch Penal Code stating that encouraging someone to end one's own life is punishable is upheld.
(b) The part of section 2 of article 294 stating that providing the means to someone that allows them to end one's own life is punishable is upheld. Note that when this concerns importing or exporting, producing, trading or owning lethal medication this is also an offence under the Dutch Pharmaceuticals Act.[46]
(c) The part of section 2 of article 294 stating that deliberately assisting a suicide is punishable

is only partly upheld. The Court of Rotterdam stated that having conversations about the wish to end life, offering moral support (also in the form of being present when someone intentionally ends one's own life on the condition that no active assistance has been offered) and providing general information or advice are non-punishable acts of assistance. This has been confirmed in multiple court cases and parliamentary questions.[47-54] Assisting someone who intentionally ends one's own life remains punishable when this concerns an advice with the character of an instruction, is aimed at a practical act or ability, is linked to its execution, makes intentionally ending one's own life possible or easier, and is coming from someone who is more knowledgeable than the one who receives it.[47-50] This latter seem to suggest that an assisting person having expertise makes assistance a (more) punishable offence,[48,50] and seems seems to imply that the Public Prosecutor allows for less legal space for professionally involved people related to right-to-die organisations.[6]

This thesis focusses on the assistance offered by counsellors working in cooperation with the Dutch right-to-die organisation Foundation De Einder (see Box 1.1 and Appendix 2). The assistance provided by counsellors working in cooperation with Foundation De Einder is limited to non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD: having conversations about the wish to end life, offering moral support, and providing general information about methods to end life.[55,56] The legality of this non-directive counselling has been confirmed in the European High Court.[44,57]

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3

Intentionally ending one's own life in the presence or absence of a medical condition: a mortality follow-back study

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Abstract

In the Netherlands, people who wish to intentionally end their own life can request for physician assistance in dying (PAD). Having a classifiable medical condition is a prerequisite to receive PAD. Some people, either in the presence or absence of a medical condition, choose to end life without assistance from a physician. This study estimates the frequency of people who intentionally ended their own life, and describes their demographic and medical characteristics through a nationwide mortality follow-back study based on questionnaires from certifying physicians of a stratified sample of death certificates of people drawn from the central death registry of Statistics Netherlands (n = 7277). In 1.85% of all deaths in 2015 people intentionally ended their own life; of which 0.50% by voluntarily stopping eating and drinking, 0.20% by self-ingesting self-collected medication, and 1.15% using other methods. Estimating the frequency of suicide is influenced by definitions and the information sources. The great majority of people who ended life by voluntarily stopping eating and drinking were over 80 years old and suffered from an accumulation of health problems related to old age, somatic problems, and/or dementia. People who ended their own life through other methods were mostly under 65 years old and primarily suffered from psychiatric, psychosocial and existential problems. Few people who intentionally ended their own life requested PAD, especially those who suffered from solely psychiatric diseases and those without a medical condition. PAD in the Netherlands is embedded in the medical domain as it is currently understood by Dutch law. This raises the question how to address the desire to die from people whose wish to intentionally end their own life is not rooted in a medical condition and therefore fall outside this medical framework of assistance in dying.

Introduction

In the Netherlands, people who wish to end their own life have the possibility to request physician assistance in dying (PAD) under the Dutch Termination of life on request and assisted suicide review procedures Act.[1] To have this request granted, physicians need to meet the six criteria of due care that are laid out in the act. One of the key criteria being the physician has to "be satisfied that the patient's suffering is unbearable, with no prospect of improvement".[1] The Dutch Supreme Court set the additional requirement that the suffering of the patient that motivates his decision to end his life should be caused by a medically classifiable condition. This emphasizes that PAD is embedded in the medical domain as it is presently understood in Dutch law.[2] Nevertheless, about two thirds of physicians regard performing PAD as inconceivable for medical conditions like dementia or psychiatric diseases.[3] In 2015, almost half (45%) of all requests for PAD have not resulted in PAD;[4] for requests of people with a psychiatric illness or with dementia the corresponding figures are 58% and 57%.[5]

People who wish to intentionally end their own life can also do this without assistance from a physician. This can occur in the presence of a medical condition, but also in the absence of a medical condition, for example when someone suffers from existential suffering.[6] Some suicides involve violent methods like jumping from a great height, while others involve non-violent methods like self-ingesting self-collected medication (MED) or voluntarily stopping eating and drinking (VSED). These two non-violent methods to end life are specifically described in Dutch literature.[7,8] Some people who choose to intentionally end their own life do so after their request for PAD was denied, while others believe PAD will not be an option for them or prefer to take their own responsibility for their death instead of burdening the physician.[9]

From 2014 to 2019, Statistics Netherlands estimated the number of suicides between 1.2 and 1.3% of all annual deaths.[10] Estimates for deaths by VSED range from 0.4% to 2.1% of all annual deaths, for deaths by MED from 0.2% to 1.1%, and for deaths by other or unknown methods at 1.0%.[11,12] Ending one's own life often happens in the context of a serious psychiatric and/or somatic medical condition.[11-13] However, it can also occur in the absence of a medical condition, for example, when older people are tired of living without

having medical conditions. In this study, we aim to estimate the frequency of people ending life themselves and to obtain insight in the extent to which this is done in the context of a medical condition. We will answer the following research questions:

1. What is the frequency of VSED, MED, and other methods of ending one's life?
2. What are the demographic and medical characteristics of persons who end their lives through VSED, MED, or other methods?
3. What are the demographic and medical characteristics of persons who end their own life and have solely psychiatric diseases, other medical conditions or no medical conditions?

Method

Design and population

In 2015, a nationwide mortality follow-back study was performed, based on pre-structured questionnaires sent to attending physicians of a stratified sample of death certificates. This study was largely similar to previous mortality follow-back studies done in 1990, 1995, 2001, 2005 and 2010.[11,14-20] A stratified sample of death certificates of persons who died between August 1st and December 1st, 2015 was obtained from the central death registry of Statistics Netherlands. All death certificates in that period were stratified based on the likelihood that the death had been preceded by an end-of-life decision. A special stratum was created when the reported cause of death was suicide. Cases that clearly precluded end-of life decision-making were retained in the sample, but no questionnaires were sent out to the physician (n = 384). For the calculation of the frequency of VSED, MED and other methods of ending one's own life, the cases from the returned questionnaires (n = 7277) plus the cases that precluded end-of life decision-making (n = 384) were included (n = 7661).

For the calculation of the demographical, medical, and care characteristics of persons who ended their life through VSED, MED or other methods we included all cases from the stratum containing suicides plus all cases where the physician had indications that the patient intentionally ended one's own life. Eight cases were excluded because answers by the physician to open ended questions clarified that suicide was not the cause of death. This resulted in a total number of 521 cases of people who ended their life. We distinguished

between VSED (n = 25), MED (n = 73), other non-violent methods of ending one's life that left the body physically intact (e.g. helium, and plastic bag) (n = 44), violent methods (e.g. jumping from heights) (n = 256), and unknown methods (n = 123).

Questionnaire

Certifying physicians of the sampled cases received a written questionnaire containing twenty-nine questions focussing on end-of-life decisions that might have preceded the death of the patient involved. This questionnaire was largely similar to previous mortality follow-back studies.[11,14-20] Amongst others, it contained questions about the underlying medical condition and whether the patient had requested PAD under the Dutch PAD law. Two questions focussed on patients intentionally ending their own life, namely 'Do you have indications that the patient intentionally ended his or her life (without direct help of a physician)?' and 'which method was used: stopping eating and drinking (with or without care from a physician), self-ingesting self-collected medication, or other, namely … ?'. The data collection procedure precluded identification of physician and patient. The Ministry of Justice gave a guarantee that no physician could be prosecuted on the basis of information given to the researchers. A reminder was sent to those who had not returned the questionnaire. Of the 9351 questionnaires sent, 7277 were returned (response 78%).

Analysis

Statistical analyses were carried out using IBM SPSS version 25 (IBM Analytics). The results were made representative of all deaths during 2015 (n = 145,134) by weighting the data for stratification (sampling fractions ranged between $1/12^{th}$ and 1) and missing numbers. Missing observations were not imputed as the numbers of missing observations were lower than 5%. Due to this procedure, the percentages reported cannot be derived from the absolute unweighted numbers. 95% confidence intervals were calculated. For the analysis of the context of a medical condition, data from people with a psychiatric disease were separately analysed as separate guideline exist to address requests for assistance in dying from this group of patients.[21]

Ethics approval

According to Dutch policy the study did not require review by an ethics committee.[22]

Results

The incidence of VSED, MED, and other methods of ending one's own life

The total number of people who ended their own life in the Netherlands in 2015 is estimated at 1.85% of all deaths. Almost a quarter of this percentage (0.50% of all deaths) consisted of people passing away by VSED (see Table 3.1). The remaining 1.35% were categorized into non-violent and violent methods of ending one's own life. Non -violent methods covered 0.33% of all deaths, consisting of MED (0.20%) and other methods like suffocation using helium, a plastic bag or intoxication (0.13%). Violent methods like hanging, jumping from a high place, drowning, or using a gun or a knife occurred in 0.70% of all deaths.

Table 3.1
Incidence of voluntarily stopping eating and drinking (VSED), self-ingesting self-collected medication (MED), and other methods of ending one's own life in 2015 in the Netherlands (n=7661)

	N	Weighted rounded n (95% CI)	Weighted % of all deaths (95% CI)
VSED[a]	25	730 (530-980)	0.50 (0.36-0.67)
MED[b]	73	280 (150-430)	0.20 (0.11-0.31)
Other methods:	423	1690 (1370-2070)	1.15 (0.93-1.41)
- Other non-violent[c]	44	190 (100-340)	0.13 (0.07-0.23)
- Violent[d]	256	1030 (790-1340)	0.70 (0.54-0.91)
- Method not specified	123	470 (310-670)	0.33 (0.22-0.47)

Note. VSED = Voluntarily Stopping Eating and Drinking. MED = self-ingesting self-collected medication. CI = Confidence interval.
[a] None of the VSED cases had suicide registered as official cause of death. [b] All cases of MED were registered as suicide, except for 3 cases (unweighted) in which suicide was not registered as cause of death. [c] Non-violent methods include suffocation using helium or other gas and/or a plastic bag or intoxication. [d] Violent methods include hanging, jumping in front of a train or from a high place, the use of a gun or a knife, drowning, and fire.

Demographic and medical characteristics of people intentionally ending life by VSED, MED or other methods

The majority of the people who intentionally ended life by VSED were female (76%), over 80 years (82%), and widowed (70%) (see Table 2). According to the physician, almost all (94%) had (a combination of) an accumulation of health problems related to old age (63%), somatic disease (61%) and/or dementia (34%). They had little psychosocial or existential problems (3%) and no psychiatric illnesses (0%). Almost half (45%) requested their physician for PAD under the Dutch PAD law.

The majority of people who ended life by MED were female (60%), between 17 and 64 years old (79%), and were unmarried or divorced (67%) (see Table 3.2). According to the physician, a great majority (73%) suffered from psychiatric diseases, with more than half (57%) solely from psychiatric diseases. About a quarter (27%) suffered from psychosocial or existential problems. About one in every eight (13%) requested PAD under the Dutch PAD law.

People who ended life by MED were similar to people who ended life through other non-violent, violent or unknown methods. The majority of each of the four groups was between 17 and 64 years old (respectively 79%, 89%, 77% and 79%), and most were unmarried (respectively 40%, 46%, 32% and 40%) or divorced (respectively 27%, 27%, 19% and 28%). According to the physician many suffered solely from psychiatric diseases (respectively 57%, 44%, 48% and 44%), or had psychosocial or existential problems (respectively 27%, 50% 33% and 32%). Finally, the number of people who had requested for PAD under the Dutch PAD law was low (respectively 13%, 10%, 2% and 4%) (see Table 3.2).

People who ended life by VSED had the highest percentage of females, over 80 years old, widowed persons, an accumulation of health problems related to old age, somatic diseases, dementia, and requests for PAD and the lowest percentage of psychosocial or existential problems and psychiatric illnesses compared to all other methods of ending one's own life.

Table 3.2
Characteristics of people who ended life by voluntarily stopping eating and drinking (VSED), self-ingesting self-collected medication (MED) and other methods of ending one's own life (n=521; absolute unweighted numbers and weighted percentages)

	VSED		MED		Other methods of ending one's own life					
					Other non-violent		Violent		Method unknown	
	N=25		N=73		N=44		N=256		N=123	
	N	w.%	N	w.%	N	w.%	N	w.%	N	w.%
Demographics										
*Gender**										
Male	5	23.7	29	40.0	28	70.0	190	71.7	84	68.0
Female	20	76.3	44	60.0	16	30.0	66	28.3	39	32.0
*Age**										
<17 years	0	-	0	-	1	0.0	6	1.9	3	0.0
17-64 years	1	2.6	59	78.6	35	88.9	198	77.4	97	79.2
65-79 years	4	15.8	8	14.3	6	11.1	43	15.1	18	16.7
80+ years	20	81.6	6	7.1	2	0.0	9	5.7	5	4.2
*Marital status**										
Married	6	21.6	16	26.7	8	18.2	103	41.5	28	24.0
Unmarried	2	8.1	29	40.0	25	45.5	89	32.1	51	40.0
Divorced	0	-	20	26.7	7	27.3	50	18.9	34	28.0
Widowed	17	70.3	8	6.7	4	9.1	14	7.5	10	8.0
Situations that were applicable to the person according to the physician[a]										
Medical conditions:										
Somatic disease*	17	60.5	17	26.7	14	40.0	38	17.0	19	16.0
Psychiatric disease	0	-	55	73.3	31	77.8	149	57.4	65	52.0
Dementia*	7	34.2	0	0.0	0	-	0	-	1	0.0
Accumulation of health problems related to old age*	14	63.2	4	6.7	1	0.0	6	5.6	3	4.0
Any of the above, of which	24	94.3	61	83.7	38	88.8	170	66.6	74	60.0
- Only psychiatric disease	0	-	41	57,1	23	44.4	129	48.8	54	44.0
- Other combinations	24	94.7	20	28.6	15	44.4	41	18.5	20	16.0
Psychosocial or existential problems*	1	2.6	18	26.7	19	50.0	88	33.3	39	32.0
*Earlier requested PAD**	10	44.7	9	13.3	4	10.0	5	1.9	3	4.0

Note. Due to the weighting procedure the percentages that are reported cannot be derived from the absolute unweighted absolute numbers. VSED = Voluntary Stopping Eating and Drinking. MED = self-ingesting self-collected medication. PAD = Physician Assistance in Dying under the Dutch law on PAD. w.% = Weighted percentage.
[a] More than one answer possible.
* The differences between the 5 groups are statistically significant (Fisher Freeman Halton Exact test; p<0.001).

The context of a medical condition

To investigate the context of a medical condition in intentionally ending one's own life, the group of people who intentionally ended their own life and had a medical condition according to the physician (N = 367) was divided into two groups: people with solely psychiatric diseases (N = 120) and people with (a combination of) other diseases (N = 247) (see Table 3.3).

The majority of people who intentionally ended their own life and had (a combination of) medical conditions other than solely psychiatric diseases according to the physician were female (59%), 65 years or older (80%), and widowed (50%), and one in four (28%) requested PAD. They differed from people who intentionally ended their own life who solely had psychiatric diseases according to the physician, who were more often male (61% versus 41%), more often between 17 and 64 years old (88% versus 20%), less often over 80 years old (0% versus 58%), more often unmarried (43% versus 14%) or divorced (27% versus 9%), less often widowed (2% versus 50%), and had requested PAD less often (4% versus 28%) (See Table 3.3).

People who intentionally ended their own life and did not have a medical condition according to the physician (N = 154) were similar to people who intentionally ended their own life and had solely psychiatric diseases concerning gender, age, and requests for PAD. About two thirds (61–69%) were male, the great majority (75–88%) were between 17 and 64 years old, and about one in twenty requested PAD. Among the people without a medical condition, a small group of over 80 years old (9%) was present. This group of over 80 years old was not present within the group of people with solely psychiatric diseases (0%), but were well represented in people with combinations of medical conditions (58%).

Table 3.3
Characteristics of people who ended their own life according to whether they had medical conditions (N=521; absolute unweighted numbers and weighted percentages)

	Medical conditions				No medical conditions	
	Only psychiatric condition(s) n=247		All other combinations n=120		n=154	
	N	w.%	N	w.%	N	w.%
Demographics						
*Gender**						
Male	151	61.2	76	40.7	111	68.8
Female	96	38.8	44	59.3	43	31.3
*Age**						
<17 years	4	2.0	0	-	6	3.1
17-64 years	220	88.0	52	20.3	118	75.0
65-79 years	23	10.0	34	22.0	22	12.5
80+ years	0	-	34	57.6	8	9.4
*Marital status**						
Married	65	28.6	42	27.6	54	36.4
Unmarried	108	42.9	26	13.8	62	36.4
Divorced	67	26.5	19	8.6	25	15.2
Widowed	7	2.0	33	50.0	13	12.1
Earlier requested PAD*	3	4.1	17	27.6	11	6.3

Note. Due to the weighting procedure the percentages that are reported cannot be derived from the absolute unweighted absolute numbers. PAD = Physician Assistance in Dying under the Dutch law on PAD. w.% = Weigthed percentage.
* The differences between the 3 groups are statistically significant (Fisher Freeman Halton Exact test; sex p=0.018; age p<0.001; marital status; p=0.021; earlier request p=0.010).

Discussion

Summary

In the Netherlands, in 1.85% of all deaths in 2015 people ended their own life, of which 0.50% through VSED, 0.20% through MED, 0.13% through other non-violent methods and 0.70% through violent methods. The large majority of the people who ended life by VSED were over 80 years old, widowed, and female, and suffered from an accumulation of health problems related to old age, somatic problems, and dementia. Psychosocial and existential problems were not reported, and almost half had requested PAD. They differed from people who ended their own life through other methods, who were mostly under 65 years old, unmarried, suffering from psychiatric, psychosocial and existential problems, and had

hardly requested PAD. People who ended their own life and had (a combination of) medical conditions other than solely psychiatric diseases were primarily over 65 years old, and one in four had requested PAD. They differed from the people without a medical condition or with solely psychiatric conditions, who were mostly under 65 years old, and had hardly requested for PAD.

Strengths and limitations

Major strengths of this study are the large nationwide sample, which is representative of all deaths in the Netherlands in 2015, the high response rate and few missing data. Also, there are only a few cases in which the physician's estimate there are 'indications the patient has ended life him or herself' does not coincide with the official death registry. This can be an affirmation of the reliability of the data. A limitation of this study is that the patient's perspective is lacking as the questionnaires are filled in by the attending physician. Related to this, while we know whether patients had a medical condition, it is not known to what extent these condition(s) contributed to the wish to end life. Perhaps other non-medical reasons (like loneliness) could have played a role, making the presence or absence of a medical condition less relevant. Finally, the attribution of cases to the group of violent or non-violent methods can be debated as we lacked information on the presence or absence of an intermediate phase of deep sleep. Determining the violence or non-violence of methods like intoxication and suffocation depends largely on the presence or absence of an intermediate phase of deep sleep.[23]

Incidence of suicide or intentionally ending one's own life

The estimate of the number of people ending their own life in the Netherlands in 2015 in our study is higher than the estimate of the number of suicides by Statistics Netherlands, namely 1.85% versus 1.3% of all annual deaths.[10] This difference can be explained by differences in interpreting which forms of dying are regarded as suicide or intentionally ending one's own life. For example, Statistics Netherlands does not include people who pass away by VSED, estimated at 0.50% of all annual deaths. In 99% of the cases, VSED is registered as a natural death. There is debate whether VSED should be regarded as suicide.[24-27] It is also debated whether physician assisted suicide under the Dutch Termination of life on request

and assisted suicide review procedures Act could be regarded as a suicide,[28] which is estimated at 0.1% of all annual deaths.[4]

The estimation of the frequency of VSED and MED from our physician-based study is lower than these estimates from a population-based study.[12] This can be explained by the finding that physicians – who fill out the death certificates in the Netherlands – are not always aware of death wishes of their patient.[29] A patient – especially at old age – who has ended life by MED might be incorrectly registered as a natural death. Also, anecdotal evidence exists where physicians are aware of the death wish and the patient having ended their own life, but register a natural death to prevent stigma for bereaved ones who otherwise will have to deal with the arrival and involvement of the police and the public prosecutor.[30,31] In this study, we found three cases of MED that did not have suicide as the registered cause of death.

Demographic and medical characteristics of people who ended life through VSED and MED

In line with others studies into MED most people who ended life by MED are under 65 years old and without a partner.[11,12,23] These characteristics are different for people who ended life by MED after receiving counselling from counsellors working in cooperation with a right-to-die organisation. They were more often over 65 years old, more often had somatic diseases, an accumulation of problems related to old age and dementia, less often had psychiatric problems, and had more often requested PAD.[32] These characteristics were similar to those of people who intentionally ended life by VSED.

People who ended their own life by VSED differed from people who had chosen other methods than VSED. Amongst others, they were older than people ending life by MED. This might be explained by the fact VSED is not advised for people under 60 years without a life threatening disease.[33] Compared to other studies into VSED,[11,12,34] this study finds a greater percentage of people ending life by VSED that were over 80 years old (82% as to respectively 48–75% in the other studies), and females (78% as to respectively 51–62%). Furthermore, the absence of psychosocial or existential problems in the group of people who had ended life by VSED contrasts with other studies that find that existential problems play

a major role in the patients' motives to decide to hasten death by VSED.[23,33,34] Perhaps the reporting physicians focus less on the psycho-existential suffering, and more on physical suffering as has been reported in other studies.[35,36] This, however, does not explain why psycho-existential suffering has been found in other groups. Another explanation can be that these patients have not discussed their psycho-existential problems with the physician. Especially in relation to requests for PAD – which almost half of the people who ended life by VSED had requested – patients might be aware there is more chance that their request will be granted if they emphasize the somatic problems and problems related to old age instead of mentioning feelings of completed life or existential suffering.[4,7,37]

The context of a medical condition

Many people in this study who ended their own life suffered from a medical condition. These people potentially would have had access to PAD under the Dutch PAD law, that is if the request stemmed from their medical condition and under condition that all criteria of due care could be met.[1] Yet only a minority had requested PAD. Possibly people value their autonomy and self-determination and prefer to take their own responsibility and end their own life.[9] Other explanations are that requests for PAD might be impeded by a disturbed relationship with one's own physician, fear of provisional detention (especially for those patients with a psychiatric disease when physicians infer patients are 'a risk to themselves'), or the conviction that PAD is not possible in their specific situation.[9] People who ended their own life in the absence of a medical condition or with solely psychiatric conditions rarely requested PAD under the Dutch PAD law. This could reflect awareness of patients that most physicians consider providing PAD to people with psychiatric problems or to people without a serious illness inconceivable.[3,4] This also illustrates that more factors than the presence or absence of a medical condition and whether this contributes to a wish to die may be relevant in whether people who want to end their own life wish to realize this via PAD.

The requirement of having a medical condition reflects the fact that PAD in the Netherlands is primarily embedded in the medical domain as it is presently understood in Dutch law. In this study, however, a minority of people who ended their own life did not have a medical condition. Their wishes to die could have originated from non-medical traumatic life events, like for example abuse, death or divorce of a partner or because they feel their life

is completed.[6,38] This raises the question how to address the desire to die from people whose wish to end life is not rooted in a medical condition and therefore falls outside the medical framework of assistance in dying. Recently, a law for assistance in suicide for people over 70 years old that does not require a medical condition has been proposed.[39] This study, however, shows that of the people without a medical condition who ended their own life, relatively few were over 65 years old. These results are in line with two recent studies that found only small groups of older people with an active wish to die that did not stem from a medical condition,[40] or in absence of a medical condition.[41] This seems to confirm the statement from the Committee Completed Life that the group of older people without an accumulation of problems of old age and without a medical condition who end their own life seems small,[42] and questions the necessity for such a far reaching and controversial law. However, the Committee Completed Life gave several recommendations that could result in preventing people experiencing their life as completed. At the same time they recognized that in the current situation people do have the possibility to end one's own life by non-violent means, for example by VSED, and can receive non-punishable assistance with this. [42]

Conclusion

Estimating the frequency of suicide or intentionally ending one's own life is influenced by definitions and information sources. Few people who had intentionally ended their own life requested PAD, especially those suffering from solely psychiatric diseases and those without a medical condition. Possible explanations may be the wish to take one's own responsibility, a disturbed relationship with one's own physician, the fear of provisional detention or an awareness of patients about the (in)conceivability of physicians to grant requests for PAD under the Dutch PAD law in certain situations. PAD in the Netherlands is embedded in the medical domain as it is presently understood in Dutch law. This raises the question how to address the desire to die from people whose wish to intentionally end their own life is not rooted in a medical condition and therefore fall outside the medical framework of assistance in dying.

Ethics approval statement

According to Dutch policy,[22] the study did not require review by an ethics committee. Informed consent of the certifying physicians was assumed on return of the survey.

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CRediT authorship contribution statement

Martijn Hagens: Conceptualization, Writing – original draft, Visualization. H. Roeline W. Pasman: Conceptualization, Writing – review & editing, Supervision. Agnes van der Heide: Conceptualization, Methodology, Project administration, Writing – review & editing, Funding acquisition. Bregje D. Onwuteaka-Philipsen: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition.

Declaration of competing interest

The authors declare that they have no competing interests.

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4

Cross-sectional research into counselling for non-physician assisted suicide: who asks for it and what happens?

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Abstract

Background In the Netherlands, people with a wish to die can request physician assistance in dying. However, almost two thirds of the explicit requests do not result in physician assistance in dying. Some people with a wish to end life seek counselling outside the medical context to end their own life. The aim of this cross-sectional research was to obtain information about clients receiving counselling for non-physician assisted suicide, and the characteristics and outcome of the counselling itself.

Methods All counsellors working with Foundation De Einder (an organisation that offers professional counselling for people with a wish to end life) (N=12) filled in registration forms about all clients they counselled in 2011 and/or 2012. Only client registration data forms with at least one face-to-face contact with the counsellor were selected for analysis (n=595).

Results More than half of the clients were over 65 years old. More than one third of the clients had no wish to end life and 16% had an urgent wish to end life. Almost two thirds of the clients had not requested physician assistance in dying. Half of the clients had others involved in the counselling. More than half of the clients received explicit practical information concerning non-physician assisted suicide, while 13% of all clients actually ended their own life through non-physician assisted suicide. Clients without a (severe) disease were older than clients with a severe disease. They also had more problems of old age and existential suffering and more often wanted to be prepared for self-determination. The clients without a (severe) disease more often had no wish to end life and requested physician assistance in dying less often than clients with a severe disease.

Conclusion While some of the clients receiving counselling for non-physician assisted suicide seem to be looking for a peaceful death to escape from current suffering, others have no wish to end life and seem to be looking for reassurance in anticipation of prospective suffering. If non-physician assisted suicide is to be distinguished from 'mutilating' suicide, this asks for a different approach than suicide crisis intervention, for example suicide-attempt prevention.

Background

Death wishes occur in about 10% of the general population in the Netherlands.[1] The ones acting upon this wish can roughly be divided into three categories: suicide, physician assisted dying (PAD) and non-physician assisted suicide (non-PAS).

In the Netherlands, people with a wish to die can request physician assistance in dying under the Termination of Life on Request and Assisted Suicide Review Procedures Act.[2] In 2010 2.9% of all annual deaths – about 4,000 people – occurred through PAD.[3] However, it is known that many patients that request physician assistance in dying do not receive it.[3,4] PAD is only allowed when an underlying physical or psychiatric disease is present and the legal criteria of due care are met.[2] But even when it is permissible, physicians are reluctant to provide PAD for patients with dementia, psychiatric diseases and elderly people who are weary of life.[5] In the Netherlands, in 2010 about 13,400 patients explicitly requested physician assistance in dying, and another 33,900 requested physician assistance in dying for at an undetermined future time.[5] In the Netherlands, suicide accounts for 1.25% of all annual deaths (1,753 in 2012).[6,7] It is estimated there are an additional 14,000 to 16,000 non-fatal suicide attempts per year.[8] In about half of the suicides, mental disorders are the underlying motive. The majority of these suicides occur through a 'mutilating' method (like hanging, drowning or jumping), and therefore often occur in solitary and isolated circumstances.[7]

In the past few years in the Netherlands, more attention has been given to 'self-euthanasia' or 'non-physician assisted suicide' (non-PAS). These suicides are characterized by a non-mutilating method, like voluntary refusing food and fluid, taking lethal medication or oxygen deprivation by inhalation of inert gas. These suicides are regarded to be more well-considered, more carefully prepared and more often with openness towards others than seen with 'mutilating suicides in solitary and isolated circumstances'.[9-12] Although a physician can be involved with non-PAS (for example by providing care during the process of voluntary refusing food and fluid), there is an important difference from PAD. With non-PAS a medical professional does not carry the responsibility for distributing or administering the means that cause death, as under the Dutch PAD law. It's estimated that in 2010 between 0.4% and 2.1% of all annual deaths have occurred through voluntarily refusing food and flood

and between 0.2% and 1.1% of all annual deaths through taking lethal medication.[13,14] The prevalence of oxygen deprivation by inhalation of inert gas has not been researched in the Netherlands, but a rise in its occurrence has been noted in the Netherlands and abroad. [15,16]

While 'mutilating' suicides and PAD have been more often researched, less is known about people that want non-PAS. They have the option to look for information on and counselling for non-PAS as provided by – for example – Foundation De Einder (see Table 4.1 for founding history, goal and work method of Foundation De Einder). As little information is available on the trajectory of counselling non-PAS we focus on answering the following research questions:

- What are the characteristics and underlying sources of suffering of people receiving counselling for non-PAS?
- What are the characteristics and outcome of the counselling for non-PAS?
- Are there differences in the characteristics and underlying sources of suffering of people receiving counselling for non-PAS and characteristics and outcome of this counselling between people with a severe(or terminal) illness and people without a (severe) illness?

Table 4.1
History, aim and working method of Foundation De Einder

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".
Goal	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 […]".[17] Contrary to suicide prevention or crisis intervention organisations, foundation De Einder regards suicide as a possible outcome and gives information about non-physician assisted suicide (non-PAS). Autonomy is regarded as an important value. Seen as an addition to the – since 2001 in the Netherlands legalized – medicalized approach of physician assistance in dying, foundation De Einder works in cooperation with independent counsellors to offer counselling focused on non-PAS, which is a demedicalized approach.
Work method	The work of these counsellors entails non-directive counselling and consists of having conversations, offering mental support and providing general information on non-physician assisted suicide. These three forms of assistance by lay persons are regarded as legal assistance in suicide.[18] The counselling is aimed at creating as much clarity as possible 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. In the situation the client decides to act upon his or her desire to end life, the counselling is aimed at realising the best possible preparations for non-PAS. This covers the practical preparation and might include gathering means for and the effectuation of the suicide.[12,17] 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 life.[17]

Methods

Design

Data was collected from annual registration forms that counsellors working together with foundation De Einder filled out for all clients they had contact with that year.

Population

Data collection over the years 2011 and 2012 took place in the first two months of the consecutive year. All counsellors working in cooperation with De Einder in 2011 and 2012 (N = 12) filled out the registration form (response rate 100%). Eight of them filled in the data for two years, while two only for 2011 and two others only for 2012. This resulted in data of 547 clients from 2011 and 444 clients from 2012. Only clients with whom at least one face-

to-face contact had occurred with the counsellor were included in this study, because clients without face-to-face contact are usually in an orientating phase where counselling consists of offering general information and/or moral support. Furthermore counsellors only share explicit information about non-PAS (concerning gathering the means for and the effectuation of the suicide) during face-to-face contacts due to the sensitivity of the information. This resulted in 325 clients in 2011 and 310 in 2012. Forty clients who were registered both years were excluded from the oldest dataset to ensure the most recent information about these clients was available. This resulted in a total number of 595 clients for analysis.

Measurement instruments

The researcher digitalised the registration form that was previously used by the board of foundation De Einder and – in consultation with counsellors – expanded the form. To increase reliability and uniformity and to avoid bias, several meetings with the counsellors were held to explain the instructions for filling out the form. After counsellors filled in the form for 2011, their feedback on the form resulted in several changes in the form for the following year. The registration form consisted of four areas: (1) personal characteristics of the client, (2) overview of the situation of the client prior to the start of counselling, (3) characteristics of the counselling process and (4) outcome of the counselling process (see Appendix 6, Additional file 1). All forms returned by the counsellors were processed anonymously.

Analysis

A description was given on frequencies of categories, focusing on characteristics of clients of counsellors working together with De Einder and the characteristics and outcome of the counselling process itself.

Based on the information provided by the clients, the counsellor classified the clients into four categories: (1) Terminal disease when cancer in a terminal or earlier phase or other disease with deadly diagnose was medically diagnosed, (2) Severe disease when a serious somatic disease (not terminal cancer) (e.g. heart failure, Chronic Obstructive Pulmonary Disease, Multiple Sclerosis/Amyotrophic Lateral Sclerosis, Cerebrovascular Accident) and/or serious psychiatric disease (e.g. severe depression) was medically diagnosed, (3) A non-

severe disease (e.g. problems of old age, deterioration of mobility, problems of vision or hearing) or (4) No disease, when clients presented no physical or psychiatric complaints. For analysis purposes groups 1 and 2 and groups 3 and 4 were dichotomized into clients with a severe disease (including terminal diseases) and clients without a (severe) disease. Statistical significance was calculated by means of the Chi-square test. When requirements for the Chi-square Test were not met the Fisher's Exact Test (two-sided) was used.

Results

Severity of the disease

A minority of the clients (5%) had a terminal disease, whereas 38% had a severe disease. Almost half of the clients (47%) had no (severe) disease. Of the remaining 10% of the clients the severity of or presence of a disease was unknown and they were excluded from the comparison between clients with a severe disease (including terminal disease) (n = 255) and clients without a (severe) disease (n = 280) (not in Table; see Appendix 6, Additional file 2). For the latter group, in 2012 a distinction was made, showing that 54% had 'no severe disease' and 46% had 'no disease' (not in Table; see Appendix 6, Additional file 3).

Client characteristics

Almost two-thirds (61%) of the clients of counsellors working with De Einder were female (see Table 4.2). More than half (56%) of the clients were 65 years or older. This group was larger for clients without a (severe) disease (70%) than for clients with a severe disease (44%). Eleven per cent of the clients were under 40 years old.

Over one third (38%) of the clients had no wish to end life. This group was larger for clients without a (severe) disease (49%) than for clients with a severe disease (26%). Of all clients, 16% wanted to end their life within three months and another 24% between three to twelve months. The group wanting to end life within a year was smaller for clients without a (severe) disease (26%) than for clients with a severe disease (62%).

The majority of all clients (61%) had not requested physician assistance in dying prior to or during counselling, often as a result of wishing to stay autonomous or judging they would

not qualify for PAD (not in Table; see Appendix 6, Additional file 4). Clients without a (severe) disease had requested physician assistance in dying less frequently (24%) than clients with a severe disease (51%). Of the clients that requested physician assistance in dying, almost two thirds (63%) were confronted with a refusal, mostly due to not meeting the legal criteria of due care and/or moral objections of the physician (not in Table; see Appendix 6, Additional file 5). For 29% the request was still pending and for 8% the request was granted.

Table 4.2
Characteristics of people with face-to-face contact with a counsellor working with Foundation De Einder

	Total[a] n=595	Severe disease n=255	No (severe) disease n=280	
	%	%	%	P-value*
Gender	39	36	41	0.205
Male	61	64	59	
Female				
Age	[b]	[b]		<0.001
18-39	11	18	5	
40-64	33	39	25	
65-79	29	24	37	
≥80	27	20	33	
Clients' wish to end life at first contact and urgency[d]	[c]	[c]	[c]	<0.001
Wants to end life within 3 months	16	25	9	
Wants to end life between 3 and 12 months	24	37	17	
Wants to end life longer than 12 months away	23	13	25	
No wish to end life	38	26	49	
Former request for PAD	[c]	[b]	[b]	<0.001
With no former request for PAD	61	49	76	
With a former request for PAD	39	51	24	
Outcome if requested for PAD[e]				0.825
Refused	63	63	66	
Pending	29	28	28	
Granted	8	9	6	

Note. Percentages are rounded therefore the total does not always add up to 100% exactly. PAD = Physician assisted dying under the Dutch law on PAD. Missing observations between 0 and 37.
[a] Including 60 clients with unknown severeness of/or disease. [b] Missing is equal to or less than 5% (X). [c] Missing is between 5-10%. [d] This variable only for 2012. The N of the respective colums are N = 310 (for Total, including 25 clients with unknown severeness of/or illness), N = 119 (for severe disease) and N = 166 (for No (severe) disease). [e] Only if a request for PAD. The N of the respective colums are N=218 (for Total, including 29 clients with unknown severeness of/or illness), N = 125 (for Severe disease) and N = 64 (for No (severe) disease).
* Pearson Chi-square test asymptotic significance 2-sided.

Sources of underlying suffering

Physical suffering was the most common mentioned reason of underlying suffering for contacting a counsellor and/or for having a wish to end life (42%), while psychiatric and psychological suffering accounted for respectively 23% and 16%. Almost one fifth (19%) mentioned no suffering at present (see Table 4.3).

Clients without a (severe) disease more often had no underlying source of suffering at present (36%) followed by physical suffering (30%) and psychological suffering (26%). The most often mentioned clarifications for the (absence of) underlying suffering for this group were existential suffering (including being weary of life) (29%), problems of old age (27%), wanting to be prepared for self-determination (16%), depression (11%), avoiding dependency (10%) or having no diseases or complaints (10%).

Clients with a severe disease most often mentioned physical suffering (55%) and psychiatric suffering (35%). The most often mentioned clarifications were other physical problems (28%), depression (19%), personality disorders (17%), cancer (14%), dementia (11%) and existential suffering (including being weary of life) (10%).

Table 4.3
Sources of underlying suffering of clients with face-to-face contact with a counsellor working with Foundation De Einder (according to the counsellor)

	Total[a] n=595	Severe disease n=255	No (severe) disease n=280	
	%	%	%	P-value*
Main source of underlying suffering	[b]	[b]	[b]	<0.001
Physical suffering	42	55	30	
Psychiatric suffering	23	35	8	
Psychological suffering	16	7	26	
No suffering at presence	19	4	36	
Clarification of suffering[d]	[c]	[b]	[c]	
Physical suffering				
Problems of old age	17	9	27	<0.001
Cancer	7	14	1	<0.001
Dementia	6	11	1	<0.001
Heart problems	4	4	4	0.788
Reuma	3	5	1	0.017
Lung problems	3	5	0	0.002
Other physical problems[e]	19	28	9	<0.001
Psychiatric suffering				
Depression	16	19	11	0.007
Personality disorder	13	17	7	<0.001
Fear Disorders	5	6	4	0.140
Other Psychiatric problems[f]	6	7	2	0.017
Psychological suffering	19	10	29	<0.001
Existential suffering (incl weary of life / completed life)	6	6	5	0.412
Youth trauma (incl child abuse)	5	3	7	0.018
Loneliness	3	4	3	0.320
Tiredness	5	3	7	0.040
Other psychological problems[g]				
No suffering at presence	9	2	16	<0.001
Selfdetermination/Be prepared	5	1	10	<0.001
Avoiding dependency	5	0	10	<0.001
No diseases or complaints				

Note. Percentages are rounded therefore the total does not always add up to 100% exactly. Missing observations between 1 and 53.
[a] Including 60 clients with unknown severity of/or disease. [b] Missing is equal to or less than 5% (X). [c] Missing is between 5-10%. [d] Categories add up to more than 100% because more than one clarification per client possible. [e] = Consisting of (amongst others): visual problems, cerebrovascular accident, osteoporosis/ortrosis, pain, multiple sclerosis, muscular disease. [f] Consisting of (amongst others): Post traumatic stress syndrome, autism, eating disorder, attention deficit hyperactivity disorder. [h] Consisting of (amongst others): mourning, age, trauma, addiction, not wanting to suffer, financial problems.
* Pearson Chi-square test asymptotic significance 2-sided.

Characteristics of counselling

Almost all clients (91%) started the counselling in the year of or one year prior to the year of registration. The majority of the clients (73%) had one face-to-face contact and in most cases (93%) the face-to-face contacts were complemented by other contacts by phone, email or in writing. More than half of the clients (54%) had 4 or more contacts (see Table 4.4).

In half of the cases (49%) the client involved another person whom the counsellor had spoken with or seen. Clients with a severe disease involved others more (61%) than clients without a (severe) disease (38%). Most often the involved others were a partner (41%) and/or children (35%). Of those who did not involve others in the counselling, more than half also had not told anyone about the counselling, reflecting 28% of all clients. Reasons for not involving others in the counselling were that it was regarded as a private matter, the client had a fear of the reactions of others, or the client was alone or had no network (not in Table; see Appendix 6, Additional file 6).

Finally, the counsellor discussed explicit practical aspects of non-PAS (concerning gathering the means for and the effectuation of the suicide) with over half of the clients (55%). This percentage was larger when the client had no (severe) disease (62%) than when the client had a severe disease (45%).

Outcome of the counselling process

Almost one fifth (18%) of the clients were confirmed to have died at the moment the registration forms were filled out (see Table 4.5). A few passed away through a natural death (2%) or received PAD (3%). The remaining 13% ended their life through non-PAS, the majority through taking lethal medication (90%) and a few through voluntarily refusing food and fluid (5%) or oxygen deprivation by inhalation of inert gas (5%) (not in Table; see Appendix 6, Additional file7). Clients with a severe disease more often passed away within the registered period (24%) than clients who had no (severe) disease (11%).

In another 7% the counselling ended due to other reasons (e.g. having a wish to live on, referred for treatment elsewhere, or because the client had prepared their non-PAS).

Theoretically this group of clients could have died without the counsellor knowing and therefore the number of deceased clients could be underestimated.

Another 22% of the clients also prepared their method to end their life but the counselling was regarded to be 'on hold', pending future contacts so the client could check on their medication or discuss precautions for performing non-PAS. Clients 'on hold' were more common for those without a (severe) disease (29%) than for those with a severe disease (17%).

For the remaining clients (54%) the counselling was on-going at the moment of registration. For 17% the counselling (still) consisted of offering general information, a listening ear and/or moral support, while in 37% the client was being counselled for the mental aspects of the wish to end life and/or practical preparation for non-PAS.

Table 4.4
Characteristics of counselling in cooperation with foundation De Einder

	Total[a] n=595	Severe disease n=255	No (severe) disease n=280	
	%	%	%	P-value*
Year of first contact				0.512
Year of data collection	78	81	77	
One year before year of data collection	13	12	13	
Two to eight years before year of data collection	9	7	10	
Number of face-to-face consults				0.055
1	73	70	76	
2	15	15	15	
3 or more (3 to 21)	12	15	9	
Number of total contacts[c]				0.109
1	7	5	8	
2-3	39	37	43	
4-6	30	30	30	
7 or more (7 to 37)	24	28	20	
Involvement of other(s) in counselling and/or openness about counselling towards other(s)[d]				0.001
Involvement and openness	25	34	20	
Involvement but no openness	13	16	8	

	Total[a] n=595	Severe disease n=255	No (severe) disease n=280	
	%	%	%	P-value*
Involvement, openness unknown	11	11	10	
No involvement but openness	15	17	14	
No involvement nor openness	28	18	38	
No involvement, openness unknown	10	4	10	
Involvement of which other[e]	[b]			
Partner	41	40	44	0.625
Children	35	39	30	0.288
Friend	17	17	16	0.901
Parents	7	10	2	*0.067*
Brother /Sister	9	7	10	0.585
Other family (cousin, grandchild)	5	6	5	*1.000*
Medical Professional	1	1	0	*1.000*
Non Medical Professional	1	0	2	*0.467*
Counselling of explicit practical preparation (of gathering means and/or effectuation of suicide)	[b]	[b]	[b]	<0.001
Explicit practical preparation mentioned by counsellor	55	45	62	
No explicit practical preparation mentioned by counsellor	45	55	38	

Note. Percentages are rounded therefore the total does not always add up to 100% exactly. Missing observations between 0 and 11.

[a] Including 60 clients with unknown severity of/or disease. [b] Missing is equal to or less than 5% (X). [c] Consisting of face-to-face contacts and contacts in writing or by e-mail or by phone. [d] This variable only for 2012. The N of the respective columns are N = 310 (for Total, including 25 clients with unknown severity of/or disease), N = 119 (for Severe disease) and N = 166 (for No (severe) disease. [e] This variable only for 2012 and if others involved; adds up to more than 100% because more than one answer possible. The N of the respective columns are N = 148 (for Total, including 13 clients with unknown severity of/or disease), N = 72 (for Severe disease) and N = 63 (for No (severe) disease.

* Pearson Chi-square test asymptotic significance 2-sided; unless *in cursive* Fisher's Exact Test 2-sided.

Table 4.5
Characteristics of outcome of counselling in cooperation with foundation De Einder

	Total[a] n=595	Severe disease n=255	No (severe) disease n=280	
	%	%	%	P-value*
	[b]	[b]	[b]	
Counselling ended due to passing away of client	*18*	*24*	*11*	<0.001
Natural death	2	3	1	
Physician Assisted Dying	3	4	1	
Non Physician Assisted Suicide	13	17	9	
Counselling ended for other reasons	*7*	*7*	*7*	
Client wants to continue living	2	2	1	
Referred to physician/treatment	1	2	1	
Ended after preparing method	4	3	4	
Counselling on hold (method non-PAS prepared; pending future contacts)	*22*	*17*	*29*	
Counselling on-going	*54*	*52*	*54*	
General information & support	17	18	19	
Mental & Practical counselling	37	34	35	

Note. Percentages are rounded therefore the total does not always add up to 100% exactly. Missing observations between 0 and 11.
[a] Missing is equal to or less than 5%. [a] Including 60 clients with unknown severity of/or disease.
* Pearson Chi-square test asymptotic significance 2-sided. Result for main categories (*in cursive*).

Discussion and conclusions

Summary of results

More than half of the clients of counsellors working with foundation De Einder are over 65 years old. More than one third of the clients have no wish to end life and almost two thirds of the clients have not requested physician assistance in dying. Sixteen per cent of all clients wish to end life within three months.

In half of the cases others are involved in the counselling, often the partner and/or children. More than half of the clients receive explicit practical information on non- PAS, while only 13% of all clients have ended life through non-PAS – most often through an overdose of lethal medication.

There are differences in characteristics of clients without a (severe) disease and clients with a severe disease. The clients without a (severe) disease are older, more often have no wish to end life, request physician assistance in dying less often, have more problems of old age and existential suffering and more often want to be prepared for self-determination. Less often they have other persons involved in the counselling, more often receive explicit practical information and less often pass away within the registered period.

Strengths and shortcomings

The 100%-response rate of counsellors Foundation De Einder refers to, gives a reliable view on the client group. While in recent years more attention has been given to the existence of non-PAS,[5,9-14,19-21] research into the assistance offered by non-physicians was unavailable. This research is the first to provide insight into counselling for non-PAS in a quantitative way and has been able to include a large group of clients (N = 595).

However, results cannot be generalized to non-PAS in general because deceased clients of counsellors working together with foundation De Einder only form a small group of all people that died through non-PAS. Secondly, other assisting non-physicians, like volunteers from other right-to-die organisations or relatives and friends, may have a different position and approach towards non-PAS than professional counsellors. Furthermore, information bias may have influenced the data. Information about the clients is collected through counsellors and the available information is dependent on what clients share with the counsellor.

Many clients do not have a death wish

Over one third (38%) of clients of counsellors working with De Einder have no wish to end life, while 16% of the clients have a wish to end life within three months. This raises the question what reasons these different groups of clients have for receiving counselling for non-PAS.

Looking for a peaceful death

The first reason for receiving counselling for non-PAS may be that especially clients with a severe disease are looking for a peaceful death for current suffering. Almost two thirds of these clients wish to end life within a year. Half of the clients with a severe disease have requested physician assistance in dying, which resulted in a denial in two thirds of the requests. A quarter of the clients with a severe disease have passed away, of which two thirds died by non-PAS.

It is plausible that some of these clients may have had difficulties receiving PAD. Research has shown that physicians are reluctant to offer PAD to patients with psychiatric problems or dementia.[5] These diseases are reported by counsellors to be more common with clients with a severe disease. Also moral objections of the physician have played a role in the denial of the requests. Finally, clients who believe they do not qualify for PAD and wish to stay autonomous may lead them to seek counselling rather than ask for PAD.

Since the opening of the End of Life Clinic in The Hague, the Netherlands – consisting of ambulatory teams that help people with a death wish, if they fall within the scope of the Dutch PAD law – patients have another possibility instead of asking their own physician. However, there will always be people falling outside the scope of the Dutch PAD law or who wish to stay autonomous. A foundation like De Einder provides in the possibility for these people to carefully deliberate on their wish to end life and prepare for non-PAS.

Looking for reassurance

A second reason for receiving counselling for non-PAS may be that people are looking for reassurance in anticipation of prospective suffering. These clients seem to be more clearly distinguished in the group of clients without a (severe) disease. Half of these clients have no wish to end life and a considerable number of these clients want to be prepared for self-determination and/or avoid dependence on others. While almost two thirds of the clients have been explicitly informed, for example on gathering the means for non-PAS, only 9% has ended life through non-PAS and almost one third put the counselling ‘on hold’ after having prepared a method of non-PAS.

The idea that people are looking for reassurance to prevent future suffering is probably reflected in the large amount of patients requesting physician assistance in dying for in due time (about 33,900 in 2010) as compared to the patients explicitly requesting physician assistance in dying for current situations (about 13,400 in 2010).[5] This reassurance to prevent future suffering can also explain why only a minority of patients, that are deemed eligible to receive assistance with dying from the Swiss right-to-die organisation Dignitas, actually make use of this assistance. They seem to regard this possibility as an 'emergency exit' option for when the deterioration of their health may become unbearable.[22,23] This idea of reassurance by having an emergency exit option available, has also been reported in interviews with elderly people who are weary of life.[19] The wish for reassurance can be related to the idea that death wishes serve as "a way of autonomous protection against the threat of continued living, feeling and thinking".[24] The counselling and having the knowledge to be able to prepare or being prepared for non-PAS may give feelings of reassurance and the perception of control for these clients.

Implications

In recent years, non-PAS through voluntarily refusing food and fluid or taking lethal medication has gotten more attention in the Netherlands.[5,9-14,19-21] About half of the Dutch general public finds it acceptable if a professional assists by informing on non-PAS.[20] The Royal Dutch Medical Association has explicated the role of the physician concerning non-PAS. When the patient decides to voluntarily refuse food and fluid, then the physician must have due regard for the care provided by a good care provider.[21,25] When the patient opts for taking lethal medication, then the physician can hold conversations about the topic and provide information. The physician can, but is not obligated to, refer the patient to available resources and experts.[21] As the data has shown, counsellors working together with Foundation De Einder have experience with people ending their lives through non-PAS with lethal medication. Therefore they could be a valuable source of information and knowledge and we recommend that physicians also consult them.

If non-PAS is to be distinguished from 'mutilating' suicide, then another approach than suicide prevention or crisis intervention is asked for by health care professionals. Berghmans et al. notices that "policy for the past years has mainly focussed on suicide prevention, as

an act of justified paternalism that it is better (and morally obligatory) to save life than to respect the wish of the person. However, from an ethical point of view, it can be argued that preventing rational suicides by limiting the freedom and liberty of a competent person cannot be justified on paternalistic grounds".[26] In this line of thinking, we recommend to complement suicide prevention with 'suicide-attempt prevention', a term coined by Minelli from the Swiss organisation Dignitas. Hereby people with death wishes can talk openly about the wish to die and where possible a sensible and attainable solution to their unbearable situation can be searched for. When this is not possible also non-PAS can be discussed. Minelli suggests this approach might be able to prevent lonely suicide attempts.[27] While this is partly due to open communication about the death wish – a feature also shared with many suicide prevention organisations – another reason is the relief experienced by offering the possibility to an accompanied suicide by Dignitas. This approach seems to be in line with the work offered by counsellors working together with foundation De Einder. Respect for the autonomy of the person, the acceptance of the possibility of suicide and the provision of information on non-PAS are key features.

Evidence of the suggested effect that suicide attempt prevention prevents lonely suicide attempts cannot, however, be deducted from the available data. We recommend follow-up research into the results of the counselling, and interviewing clients and counsellors and others involved, to help answer these questions. The approach of suicide-attempt-prevention does, however, offer physicians a way to openly communicate about wishes to die with the patient. It is argued that discussing death wishes – even outside the context of PAD – are important because if people feel unable to talk about them, their quality of life may be further diminished.[28] The Royal Dutch Medical Association recommends having a conversation on the subject of life's end and death wishes as a way to get to know the patient better.[29] Actually, we also recommend discussing non-PAS so to offer a chance to give the patient an improved perception of control, hopefully leading to a better level of coping and more quality of life.

Approval by Ethics Committee

This research has been granted an exemption from requiring ethics approval because the research does not require approval under the Dutch law on Medical-Scientific Research with Humans (Wet Medisch-Wetenschappelijk Onderzoek met Mensen; WMO). This approval has been granted by the VU Medical Center Medical Ethics Committee.

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Consent

All data has been received anonymously through the board of Foundation De Einder and the counsellors the foundation refers to.

Authors' contributions

MH had the initial idea for this study and wrote the research protocol, collected data, performed statistical analysis and drafted the manuscript. HRWP and BDO-P commented on and contributed to the design, the analysis of data and to 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.

Authors' information

MH: Psychologist, PhD student and junior researcher. HRWP: Sociologist, PhD and senior researcher end-of-life research. BOP: Health Scientist and professor end-of life research.

Competing interests

Martijn Hagens organises training about twice a year for counsellors working in cooperation with Foundation De Einder. For organising this training he receives a fee covering for voluntary work.

Abbreviations

Non-PAS: Non-physician assisted suicide; PAD: Physician assisted dying (entailing Termination of life by the physician on request of the patient and Physician-assisted suicide).

Additional files

See Appendix 6.

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5

Trajectories to seeking demedicalised assistance in suicide: a qualitative in-depth interview study

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Abstract

Background In the Netherlands, people can receive (limited) demedicalised assistance in suicide (DAS)—an option less well known than physician-assisted dying (PAD).

Aim This study explores which trajectories people take to seek DAS, through open-coding and inductive analysis of in-depth interviews with 17 people who receive(d) DAS from counsellors facilitated by foundation De Einder.

Results People sought DAS as a result of current suffering or as a result of anticipating possible prospective suffering. People with current suffering were unable or assumed they would be unable to obtain PAD. For people anticipating possible prospective suffering, we distinguished two trajectories. In one trajectory, people preferred PAD but were not reassured of help by the physician in due time and sought DAS as a backup plan. In the other trajectory, people expressed a preference for DAS mainly as a result of emphasising self-determination, independence, taking their own responsibility and preparing suicide carefully. In all trajectories, dissatisfaction with physician–patient communication—for instance about (a denied request for) PAD or fearing to discuss this—influenced the decision to seek DAS.

Conclusions While PAD is the preferred option of people in two trajectories, obtaining PAD is uncertain and not always possible. Dissatisfaction with physician–patient communication can result in the physician not being involved in DAS, being unable to diagnose diseases and offer treatment nor offer reassurance that people seem to seek. We plea for more mutual understanding, respect and empathy for the limitations and possibilities of the position of the physician and the patient in discussing assistance in dying.

INTRODUCTION

Assistance in dying is a widely debated theme. Part of this debate centres around the (de) medicalisation of assisted dying. Conrad defines medicalisation as "a process by which nonmedical problems become defined and treated as medical problems".[1] Conversely, demedicalisation can be defined as "the point at which the medicalization of social life is turned back, or reversed".[2] (De)medicalisation of assisted dying can relate to (1) the prerequisite of a medical condition in granting assistance in dying, (2) the role of the physician in distributing or administering the means to end life and (3) the presence of the physician during the termination of life.[3–5] Legislation for the medicalised approach, physician-assisted dying (PAD), exists in the Benelux countries, several states in the USA (Oregon, Washington, Montana, Vermont and California), Canada and Colombia.[6,7] Legislation for demedicalised assistance in suicide (DAS) exists in Switzerland. The daily practice, however, seems partially medicalised as the Swiss right-to-die organisations work together with physicians distributing the lethal medication and some organisations restrict the assistance to certain medical conditions. It is argued that the difference with the medicalised approach is much smaller than initially thought because in Switzerland also non-physicians are not allowed to provide the necessary drugs to effectuate a suicide.[4]

Less well known are the right-to-die organisations in countries other than Switzerland that offer a demedicalised approach to assistance in dying. Examples of these organisations are the Dutch Dying with Dignity Society, Foundation De Einder and Foundation End-of-Life Counselling in the Netherlands;[8,9] Friends at the End in the UK;[10,11] the Final Exit Network in the USA,[12] and Exit International in Australia.[13] These organisations all distribute information on 'how-to' methods for self-deliverance that do not require physician involvement and in some cases do not require a medical diagnosis. Scientific research into these right-to-die organisations offering demedicalised assistance in dying is sparsely available.[10,11,14,15]

When focussing on the Dutch situation, people with a wish to end their life can request PAD under the Termination of Life on Request and Assisted Suicide Review Procedures Act. These people can also opt for DAS, which consists of (the legally allowed assistance of) having conversations about the wish to end life, offering moral support and providing

general information and advice on nonmutilating methods how to end your own life. These two approaches of assistance in dying differ in the applicable laws, the person providing assistance, the form of assistance and the ways of dying (see Table 5.1). Both approaches are to be distinguished from the suicide prevention approach, which focuses on preventing suicides instead of regarding the option to end life as a possibility as well.

Table 5.1
Differences between physician assistance in dying (PAD) and demedicalised assistance in suicide (DAS) in the Netherlands

Features	PAD (medicalised approach)	DAS (demedicalised approach)
Relevant law(s)	Termination of Life on Request and Assisted Suicide Review Procedures Act [16]	Article 294 of the Dutch Penal Code concerning assistance in suicide [17] Jurisprudence concerning Article 294 [18] Law on Narcotics [19] (only applicable to a suicide through lethal medication).
Person providing assistance	Physician	Any person, e.g. a relative, friend, right-to-die volunteer, counsellor or consultant, physician.
Assistance provided	Distributing and/or administering lethal medication after verifying all criteria of due care laid out in the law have been met.	Having conversations about the wish to end life, offering moral support, and giving general information on ways to end life are not a criminal offence.[18] Note: abetting suicide, distributing of means, offering instructions or practical help are forbidden.[17]
Ways of dying	Physician assisted suicide (patient ingests a lethal drink distributed by physician) or termination of life on request of the patient by intravenous injection (euthanasia)	Suicide through a non-mutilating method, like voluntarily stopping eating and drinking, ingesting an overdose of self-collected lethal medication, or oxygen deprivation through inhalation of inert gas.

Note. PAD = Physician assistance in dying as under the Dutch law on PAD. DAS = demedicalised assistance in suicide.

In the Netherlands, DAS has received increasing attention over the past years in the media, most recently through Heringa's court case in which a son helped his 99-year-old mother to end her life.[20–23] Scientific research has mainly focused on the occurrence of specific forms of deaths resulting from DAS, like voluntary stopping eating and drinking and ingesting self-collected lethal medication. It is estimated that in the Netherlands in 2010 between 0.4% to 2.1% of all annual deaths occurred through voluntarily stopping eating and drinking and between 0.2% and 1.1% of all annual deaths occurred through self-ingesting

self-collected lethal medication.[24,25] In the past 5 years, the number of people annually receiving DAS from counsellors facilitated by Foundation De Einder has doubled from about 300 to more than 600.[26] Among these people, two groups of people are distinguished.[15] One group of clients—with a more immediate wish to end life—is looking for a peaceful death to escape current suffering. The second group of clients—without a(n) urgent wish to end life—is looking for reassurance to be able to prevent possible prospective suffering. Interestingly, half of the people with a serious disease who have received this counselling had not requested PAD from their physician before seeking DAS. This raises the question: which trajectories do people take to seek DAS in relation to the availability of the option of PAD. We aimed to clarify these trajectories by conducting a qualitative interview study with people who receive(d) DAS from a counsellor facilitated by Foundation De Einder.

METHOD

Design

A qualitative research design was chosen because of the explorative nature of the research objectives and the unavailability of scientific literature about the trajectories to seek DAS. Data were collected from in-depth qualitative interviews with people who receive(d) DAS from counsellors facilitated by Foundation de Einder held between September and December 2012.

Recruitment

A notice about this upcoming research was published in the quarterly magazine of Foundation De Einder. This magazine was sent to people donating money to the Foundation—not necessarily people seeking DAS—but an overlap was expected. Also, counsellors were asked to notify people seeking DAS of the upcoming research, either in person or through postal letters or email.

Participants

A total of 24 potential participants enrolled themselves—20 through intermediation of the counsellor and 4 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 counsellor, former request for PAD and if they had a personal consult with which counsellor. These screening questions—based on our previous quantitative study – were asked to make sure a diverse group of people could be selected.[15] Potential participants who had not had a personal consult with a counsellor were excluded from participation (n=3), because often these people are still in an orientating phase where counselling does not entail providing information on ways to end life.[15]

Three potential participants were not willing to participate in a personal interview (e.g. due to emotional burdens). Finally, one potential participant was not selected for participation due to similarity with already interviewed or selected participants. For analysis, this resulted in 14 interviews with 17 people. Three interviews were conducted with couples in which both participants sought DAS. While people with a psychiatric background were more difficult to include, the ones included represented specific psychiatric problems well. The selected sample reflected the population of people seeking DAS from a counsellor facilitated by De Einder.[15]

Interview

The principal author (MH)—with a background in training for professional and personal communication in psychology—has previously worked as a counsellor in cooperation with Foundation De Einder and conducted the interviews. This prior experience attributed to a great knowledge about DAS and experience in discussing the subject but could also lead to a possible interviewer bias. The difference in position and the necessary skills have been addressed in the research team. All interviews took place at the residence of the respondent except for one, which was held at a conference room at the VU University Medical Center, Amsterdam, the Netherlands. All respondents lived in the Netherlands. All were informed about the purpose of the study and signed an informed consent for participation in

accordance with the procedure approved by the Ethical Committee of the VU University Medical Centre. The interviews lasted between 1 hour and 2½ hours.

The purpose of the interviews was to learn more about the reasons why the respondent sought DAS and, among other issues, which trajectory preceded this decision. It was decided—given the sensitive matter—to start with a general opening question such as: 'how are you doing now?' but it turned out that the respondents were very eager to talk about the subject so later interviews were started with the question: "This interview is aimed at receiving more information about you, your situation and the counselling offered by a counsellor working with Foundation De Einder. What has led to contacting De Einder?"

After the opening question, the consecutive questions were based on what the respondent said. A topic list was used as a reminder of the issues that should be addressed in the interview. Topics included were as follows: the respondents' health status and their view on their social network and daily living, the reasons leading to contact a counsellor facilitated by De Einder and their contact with their general practitioner (GP) or physician about this subject. See Appendix 7 (supplementary file 1) for the topic list of the interview.

Analysis

The interviews were recorded and fully transcribed. Field notes were made during and after the interview. Analysis started during data collection and this analysis influenced the subsequent data collection, following the principles of sequential and thematic analysis.[27] First, all interviews were thoroughly read to become familiar with the data, and case reports of every participant were made by the principal author and discussed within the research team. Open, inductive coding was then used to identify recurring themes in the interviews, which was a constant movement between the dataset, the coded extracts and the descriptive analysis in process. No prior theory or framework was used in the analysis.[28] The code list extended as more interviews were analysed, codes were grouped and regrouped in the process of analysis. Appendix 7 (supplementary file 2) shows an overview of the codes that were created in relation to the background and reasons to contact a counsellor facilitated by Foundation De Einder. Writing 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

The majority of the selected participants were aged over 65 years, had not requested PAD before seeking DAS and were seeking DAS in anticipation of possible prospective suffering (see Table 5.2).

For the people with current suffering (n=5), we distinguished one trajectory consisting of people who were unable or assumed to be unable to obtain PAD. For people with anticipating possible suffering (n=12), we distinguished two trajectories. In one trajectory, people sought DAS as a backup for when PAD was not possible in due time (n=8). In the other trajectory, people expressed a preference for DAS, primarily as a result of valuing autonomy, self-determination and own responsibility (n=4).

Table 5.2
Personal characteristics of interviewed clients per form of suffering and trajectory

Main suffering	Trajectory	Interviewee	Gender	Age	Request for PAD
Current	Unable to obtain PAD	1	F	<39	No request for PAD
	Unable to obtain PAD	2[a]	F	<39	Request for PAD denied
	Unable to obtain PAD	3	M	40-64	Request for PAD denied
	Unable to obtain PAD	4	F	40-64	No request for PAD
	Unable to obtain PAD	5	M	65-79	Request for PAD denied
Prospective	Back up plan	6[b]	F	65-79	No request for PAD
	Back up plan	7[b]	M	65-79	No request for PAD
	Back up plan	8	M	65-79	No request for PAD
	Back up plan	9[b]	M	65-79	No request for PAD
	Back up plan	10[b]	F	65-79	No request for PAD
	Back up plan	11	F	>80	No request for PAD
	Back up plan	12[b]	M	>80	No request for PAD
	Back up plan	13[b]	F	>80	No request for PAD
	Valuing autonomy	14	M	65-79	No request for PAD
	Valuing autonomy	15	M	65-79	No request for PAD
	Valuing autonomy	16	M	65-79	No request for PAD
	Valuing autonomy	17	F	>80	No request for PAD

Note. PAD = *Note.* PAD = Physician assistance in dying as under the Dutch law on PAD. M = Male. F = Female.
[a] Partner present at interview to support with gaps in memory. [b] Couple together.

Trajectory 'unable to obtain PAD'

People with current suffering were unable or assumed they would be unable to obtain PAD and sought DAS out of negative considerations. Some of them were confronted with a denied request for PAD, after which their death wish was not discussed anymore with their own GP (see Box 5.1 for supporting quote 1). Others, however, never requested PAD with their GP because of a disturbed relationship with the GP. People with psychiatric suffering did not request PAD out of fear for crisis intervention or a provisional detention order when doing so and the idea that PAD was impossible to obtain for psychiatric patients. They also felt it was impossible to seriously discuss the wish to die and to prepare a suicide in a careful humane way and to obtain trustworthy information on suicide methods in the regular healthcare (see Box 5.1 for supporting quote 2).

Despite receiving DAS, these people expressed a preference for PAD. Reasons were the fear of failure of a suicide attempt, the secrecy and illegality surrounding the collection of medication, little support from surrounding people, a negative connotation with suicide and the need for secrecy to avoid others from preventing the suicide (see Box 5.1 for supporting quotes 3 and 4). PAD would offer more certainty, would feel legitimate and societally acceptable and offers the possibility of the presence of a close one without them being regarded as a possible suspect (see Box 5.1 for supporting quotes 3 and 5). Eventually, one interviewee found another physician who granted the request for PAD.

Box 5.1
Supporting quotes for trajectory 'unable to obtain physician assistance in dying' ('PAD')

Quote 1 […] And I don't discuss it [the wish to end life—MH] regularly with the GP [general practitioner]. Actually that chapter is closed. So I went my own way and the GP…well, we don't discuss that anymore. [Respondent 5]

Quote 2 If you want to take the option of suicide serious, they [regular healthcare—MH] see that right away as something pathological. […] At the physician it is crisis intervention right away. [Respondent 1]

Quote 3 [Suicide has—MH] a very negative connotation. Euthanasia is like it's acceptable at a societal level […] People would say "Euthanasia? That's probably ok, because the physician did it". [Respondent 5]

Quote 4 You want to prevent that somebody does something that undermines your suicide—as a result of his or her mental conflict. [Respondent 2]

Quote 5 [PAD—MH] would be good, because I would know the medication is trustworthy and I don't have to deal with "dubious" people. [Respondent 1]

Trajectory 'back up plan'

Among the people anticipating possible prospective suffering, one group expressed a preference for PAD. These people discussed their living wills with their physician and/or enquired about the standpoint of the physician concerning PAD. They, however, also sought DAS, mainly for negative reasons.

The disappointment that followed after the enquiry about the physician's standpoint concerning PAD or discussing living wills for possible prospective situations influenced them to seek DAS (see Box 5.2 for supporting quotes 6 and 7). Possible prospective situations involved situations like dementia or 'completed life', in which people—mainly at an older age—in their opinion have no more perspective to life and as a result develop a persisting active wish to end life.[19] These people also did not want to burden the GP with their own life's end, heard un-reassuring stories of GPs withdrawing help in offering PAD and were critical of the (current practice of the) PAD law. Examples of this criticism were feeling too dependent on the GP, regarding it as asking too much of a favour, the absence of an obligation to refer in case a physician could not help, the difficulty others had in obtaining PAD and being convinced that PAD would not be possible in situations of prospective suffering like 'completed life' or dementia.

Positive reasons for seeking DAS were valuing self-determination, one's own responsibility and independence, wanting to explore their death wish by discussing this seriously with someone and having positive examples of others voluntarily stopping eating and drinking or self-ingesting self-collected lethal medication (see Box 5.2 for supporting quote 8).

The counselling they received made people aware of the downsides of DAS. They were critical about the treatment of family members by the police following a suicide and the fear of failure of a suicide attempt (see Box 5.2 for supporting quotes 9 and 10). In the hypothetical situation that PAD was possible to obtain, they would prefer to make use of that possibility. However, they were aware that opting for PAD might not be an option in the situations of prospective suffering they foresaw and therefore organised a backup plan in which they could decide themselves (see Box 5.2 for supporting quote 11).

Box 5.2
Supporting quotes for trajectory 'backup plan'

Quote 6 Actually, it comes down to this: "We [general practitioners—MH] cannot guarantee anyone [assistance in dying—MH]." And that brings me nothing, because I want certainty. "But you want too much certainty" [the physician said—MH] [Respondent 11]

Quote 7 Everywhere we stood outside within two minutes. Because our question "What is your standpoint concerning euthanasia? Are you willing to assist in due time…?" "Absolutely not!" And outside we were again. Until we found a general practitioner who said it was discussable" [Respondent 7] And then you still have to wait and see if he really does it, but anyway. [Respondent 6]

Quote 8 For many people, the most important reason is, that you—for God's sake—don't want another person to decide if your life is liveable. You should be able to decide that yourself! Not that some physician says: "well, it's not that bad". [Respondent 8]

Quote 9 If you fall under the PAD [physician-assisted dying] law, it is nicer for the ones left behind. When you suicide yourself it does happen a bit in secrecy. For the children and the ones present that is less pleasant. It is quite a thing—and I still remember with my mother—the police arrived and it's all very unpleasant. Like you've done something wrong. [Respondent 9]

Quote 10 With PAD at least you know everything will go well. At least, that's what you can expect. With DAS you have to wait and see you don't vomit up the medication despite the anti-emetics. [Respondent 7]

Quote 11 If, for example, we are ready in a year from now, we can go to the physician. And if he says "But nothing is happening", then we can decide for ourselves. [Respondent 13]

Trajectory 'valuing autonomy'

Another group of people who sought DAS in anticipation of possible prospective suffering sought contact with a counsellor for DAS without wanting to opt for PAD. They primarily expressed positive reasons, like valuing self-determination, independence, taking your own responsibility and a dignified death (see Box 5.3 for supporting quotes 12 to 14). They held a strong plea for DAS. They wanted to prepare suicide carefully, prevent harm to others and talk with a neutral sparring partner concerning the subject of suicide.

While autonomy was very important, negative reasons in this trajectory were the conviction that PAD was only for terminal diseases or that it was not for psychiatric patients or situations of 'completed life'. Also, experiencing too much time pressure in the physician's daily practice for conversations on the subject of the timing and manner of one's own death, wanting to avoid hopeless and unbearable suffering, not wanting to burden the physician and not wanting to beg the physician for help led to seeking DAS (see Box 5.3 for supporting quotes 14 and 15).

People openly discussed their own preparations in receiving DAS with the GP. The standpoint of the GP on PAD was sometimes discussed, but clearly the person's conviction that this matter involved them taking their own responsibility prevailed. Some anticipated that the situation in which they wanted to end life would not meet the criteria of the PAD law (see Box 5.3 for supporting quote 15). One interviewee thought PAD was only acceptable in circumstances where he would be physically incapable of ending his own life or if his suicide attempt failed. This form of backup—where PAD is a backup when DAS fails or is impossible—is a reversal from the previously described 'back up trajectory' where DAS is the second option in case PAD is not possible.

Box 5.3
Supporting quotes for trajectory 'valuing autonomy'

Quote 12 I want to do it myself. I don't want to be dependent on another, because I'm not sure if the other one won't say: "well, you can live on for a while longer". When I say it's enough, then it's enough. [Respondent 17]

Quote 13 I want a dignified, respectful life's end at a time that I decide. [Respondent 16]

Quote 14 I actually think that you can't allow the physician to do it, when you're still able to do it yourself. I think it's morally more just if I say I will do it myself […] For the physician it's quite a burden. In the end, he terminates someone's life and that is burdensome for the physician. And actually, I think it's a little bit cowardice if you let the physician do it, while you can do it yourself. [Respondent 14]

Quote 15 And I can read what the law says. I mean I presume the moment I want to end life is not the moment the physician is convinced that I suffer hopelessly and am terminal. [Respondent 15]

DISCUSSION

People with current suffering seek DAS when they are unable or assume that they are unable to obtain PAD. People anticipating possible prospective suffering either seek DAS as a backup for when PAD is not possible in due time or prefer DAS mainly as a result of valuing autonomy, self-determination, taking their own responsibility and carefully preparing a suicide.

A limitation of this study is that only people receiving DAS from counsellors facilitated by Foundation De Einder are selected. In addition, a self-selection bias is apparent. This is the result of participants enrolling themselves in this study and the fact that most participants have been recruited through a counsellor. Furthermore, the subset of people who died after receiving counselling is missing. Conclusions therefore cannot be generalised to the population of people seeking or receiving DAS. However, the goal of selecting participants in this research is not to obtain a representative sample to make generalised assumptions but to obtain a wide range of different participants to explore previously unknown trajectories to seek DAS. This study therefore offers a unique insight into the field of DAS in the Netherlands.

The different trajectories offer relevant knowledge about the current practice of assistance in dying and the different situations and needs of people seeking this. First, the trajectory where people are or assume they are unable to obtain PAD can offer a partial explanation why half of the people seeking DAS who have a severe disease—of which one-third suffer from a psychiatric disease—do not request their physician for PAD.[15] It turns out that

psychiatric patients do not request their physician for PAD out of fear for crisis intervention or a provisional detention order or because they still believe PAD is not available for people with psychiatric diseases. Not requesting PAD result in the GP not being involved at this precarious moment and the patient missing out on important aspects like diagnosing diseases and offering treatment.

Second, in two of the three trajectories to seek DAS, a preference for PAD is prevalent. Rurup (2005) also concluded that people who are weary of life and think about ending their life themselves prefer that physicians will provide the medication.[29] This gives them a safe feeling of good judgement and a painless and societally accepted death. This latter reason is also apparent in this study. However, the provision of medication by a physician is restricted under the PAD law. PAD cannot be guaranteed in advance for situations in which patients anticipate prospective suffering because it depends on whether the due care criteria are met in a situation of a current request for PAD.

Third, the trajectory where people seek DAS as a backup for PAD emphasise the importance—and the difficulty—of patient–physician communication, concerning the subject of seeking PAD. The response of the GP to an enquiry about PAD—or an actual request for PAD—can be disappointing to patients. Perhaps this response is communicated in such a way that patients do not discuss the subject of wanting to influence the timing and manner of their own death with their GP anymore. This suggests that one of the guidelines mentioned in the position paper on the role of the physician in the voluntary termination of life—published in 2011 by the Royal Dutch Medical Association—still has not fully come to practice: to keep the conversation about assistance in dying going—even outside possibilities the PAD law offers.[30] Pasman et al. (2013) noted that discontinuing to talk after a refusal of a request for PAD can lead to the misunderstanding by the physician that the patient's wish to die has disappeared. They emphasise the importance of open communication about wishes to die even outside the context of PAD. If people feel unable to talk about these wishes, their quality of life may be further diminished.[31] The findings of this study support such attempts to talk freely about a wish to die and an assisted death. Besides open communication, we would also like to plea for more mutual understanding, respect and empathy for (the limitations and possibilities related to) the position of the physician and the patient in discussing assistance in dying. People from the trajectory who value autonomy seem to be more aware of these

limitations of the physician and emphasise their own responsibility. This finding might make GPs aware of the own responsibility the patient has (and can take), especially when GPs feel pressured into offering assistance in dying.

Furthermore, the trajectories show that there is a difference between people seeking DAS for now and people seeking DAS for in due time. For the latter, seeking reassurance seems to be important and not so much seeking death itself. This gives rise to the question of what role the physician (and society) can play in offering this reassurance to the patient. It can also be a relief for the GPs, who are confronted with discussing this matter, to realise that many people seeking DAS are not really seeking to end life now. It does remain unknown, however, as to how many will actually decide to end life themselves at the moment suffering is apparent, but our previous study suggests this percentage is relatively small.[15]

In conclusion, this study clarifies the pros and cons of both medicalised assistance in dying and DAS from the perspective of people seeking DAS. While PAD offers a certain and dignified death and allows for the legal presence of others, obtaining PAD is uncertain. This uncertainty regarding the availability of PAD is especially the case for psychiatric patients and patients suffering from dementia or a 'completed life'. Initiatives that clarify the possibilities falling within the scope of the current law on PAD are helpful, for example, initiatives like The End of Life Clinic which provides PAD to patients who meet all legal requirements but whose requests are rejected by their regular physician.[32] On the other hand, there will always be people falling outside the scope of the law on PAD, for example, when it concerns anticipating possible prospective suffering or people who fall in the trajectory that values self-determination above everything else. For them, DAS allows for self-determination and independence but offers a fear of failure, possible legal problems for the close ones involved and stigmatisation. While the possibility to voluntarily end one's own life is mentioned by both the Royal Dutch Medical Association and the Advisory Committee Completed Life,[23,30] this study shows that—from the perspective of people seeking DAS—it compasses several negative (legal) consequences that still need attention.

Ethics approval

VU Medical Center Medical Ethics Committee.

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Contributors

MH had the initial idea for this study and wrote the research protocol, performed the interviews and the analysis and drafted the manuscript. HRWP and BDO-P 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.

Competing interests

MH received an imbursement of expenses in 2015 (amount €150) for analysing the data for the annual report 2014 of Foundation De Einder.

Provenance and peer review

Not commissioned; externally peer reviewed.

Additional files

See Appendix 7.

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6

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

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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 of Request and Assisted Suicide Review Procedures Act. Hagens et al. (2017) 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 6.1 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 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.

Table 6.1
History, aim and working method of Foundation De Einder

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".
Goal	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 […]".[13] 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 – medicalized 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.[13] 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.[13,14]

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—twenty 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 Appendix 7 (supplementary file 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.[15] 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 (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. [16] The code list extended as more interviews were analysed, and codes were grouped and regrouped in the process of analysis. Appendix 7 (supplementary file 3) 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 6.2) (see Box 6.1, 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 6.3).

Table 6.2
Personal characteristics of selected counselees

Cns.	Primary goal	M/F	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[c]	Partner[a]	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[b]	Back up	F	65-70	No request	Partner	Yes	Healthy/Old age (physical)
7[b]	Back up	M	70-80	No request	Partner	Yes	Healthy/Old age (physical)
8	Back up	M	70-80	No request	Partner	Yes	Psychiatric/Old age (physical)
9[b]	Back up	M	70-80	No request	Partner	Yes	Healthy/Old age (physical)
10[b]	Back up	F	70-80	No request	Partner	Yes	Healthy/Old age (physical)
11	Back up	F	80-90	No request	Widowed	Yes	Healthy
12[b]	Back up	M	80-90	No request	Partner	Yes	Old age (physical)
13[b]	Back up	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)

Note. '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 Demedicalised assistance in suicide (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). Cns. = Counselee. M = Male. F = Female.
[a] Partner present at interview to support with gaps in memory. [b] Couple together. [c] Eventually granted by another physician.

Table 6.3 *Setting and content of counselling & collection of lethal medication*

	Start of counselling (time ago)	Number personal contacts	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 law, after death)	No	Meaning and expectations life and death, hope, passion, ambivalence, responsibility.	Current relationships, effect self-euthanasia on others, saying goodbye, consequences law on others
2[a]	3 years	6	Yes	VSED, MED (which medication, obtaining, careful preparation, performance)	No	Death wish, meaning life and death, preparing for suicide, emotions	Effect self-euthanasia on others, preparing others for goodbye, consequences 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[c]	1	No	MED (which medication, obtaining, careful preparation (withdrawal), performance.	Yes	Not mentioned	Not mentioned
5	8 years[d]	24	Yes	MED (which medication, obtaining, storing, performance)	Yes	Meaning life and death	Current relationships, saying goodbye, presence of others
6/7[b]	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[b]	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[b]	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 law on) collecting, careful performance, after death)	Yes	Meaning life (events), timing	Effect self-euthanasia on others, Consequences law on others
15	1 year	1	No	VSED, Helium, MED (which medication, careful performance, consequences law, after death)	Yes	Current life situation (grief)	Preventing harm to others, consequences 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

Note. PAD = Physician Assisted Dying (as under Termination of Life on Request and Assisted Suicide Review Procedures Act). VSED = Self-euthanasia by Voluntarily Stopping Eating and Drinking. Helium = Self-euthanasia by helium method. MED = Self-euthanasia by self-ingesting self-collected lethal medication.
[a] Partner present at interview to support with gaps in memory. [b] Couple together. [c] 10 years ago present at counselling as partner, [d] Received counselling 12 years ago from counsellor not active at time of interview.

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 6.1, 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 6.1, 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 6.1, Quotes 5 and 6).

Box 6.1
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 6)*
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 7)
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 [e.g. 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)

Box 6.1
Quotes about the characteristics of counselees, and content of and experiences with counselling (continued)

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 6.1, 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 listened to, and feeling recognised and respected (see Box 6.1, 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 6.1, Quotes 11–13). Finally, people expressed being positive about the availability of the counsellor (see Box 6.1, Quotes 14 and 15).

After counselling: self-collected lethal medication

Most counselees had already obtained lethal medication (see Table 6.3). 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 6.2, 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 6.2, Quotes 16, 17, 19–21).

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 6.2, 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 6.2, Quotes 19, 21, 23).

Box 6.2
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)

Box 6.2
Quotes about what happens after counselling (continued)

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)

Quote 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)

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
R1: 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)
R1: 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)

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 6.2, 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 6.2, 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 6.2, 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 the 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.[9,17,18] 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.[17,18] 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.[18,20]

Owning lethal medication can lead to risks of impulsivity and misuse.[3,21] 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,[22] and the multidisciplinary guideline for the diagnostics and treatment of suicidal behaviour.[23] 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.[24]

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.

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Patient consent for publication

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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.

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None declared.

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Data availability statement

Data are available upon request.

Additional files

See Appendix 7.

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7

Cross-sectional research into people passing away through self-ingesting self-collected lethal medication after receiving demedicalized assistance in suicide

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Abstract

This study describes the characteristics of—and the counselling received by—counselees who passed away through self-ingesting self-collected lethal medication after receiving demedicalised assistance in suicide. We analyzed registration forms filled in by counsellors working with Foundation De Einder about 273 counselees who passed away from 2011 to 2015. The majority of these counselees had a serious disease and physical or psychiatric suffering. Half of them had requested physician assistance in dying. This shows that patients with a denied request for physician assistance in dying can persist in their wish to end life. This also shows that not all people with an underlying medical disease request for physician assistance in dying. Physicians and psychiatrist are often uninvolved in these self-chosen deaths while they could have a valuable role in the process concerning assessing competency, diagnosing diseases, and offering (or referring for) treatment.

INTRODUCTION

About 8% of adults in the general population in the Netherlands have had suicidal thoughts during their life. The chance to develop a wish to end life is strongly related to childhood traumas and earlier psychiatric disorders.[1] About 5% to 30% of the wish to end life in older people is, however, not associated with psychiatric or depressive disorders but, for example, with physical risk factors (such as physical decline related to old age) or psychological risk factors (such as loss of connectedness).[2-4]

In the Netherlands, people with a wish to end life can request for physician assistance in dying (PAD) under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act. People can only obtain PAD when they meet all criteria of due care laid out in the law. 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 these due care criteria have been fulfilled, and (f) have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.[5] Supreme Court rulings added the requirement that the suffering must be the result of an underlying medical diagnosis, either physical or psychiatric in nature.[5] In the Netherlands, 4.6% of all annual deaths in 2015 have resulted from PAD under the Dutch PAD law. The great majority (92%) of the patients receiving PAD have a (serious) physical disorder, while only a small minority has a psychiatric disorder (3%) or has psychosocial or existential problems (3%).[6]

In the Netherlands, 1,829 people have committed suicide in 2018, which accounts for 1.2% of all annual deaths.[7] Many of these registered suicides have occurred through mutilating methods, such as hanging or strangling (46%) or jumping in front of a moving object or from a great height (19%) and often occur in solitary and isolated circumstances.[8] About two thirds of these suicides are motivated by mental disorders and about 1 in 12 by physical disorders.[8]

However, suicides do not always need to occur through mutilating methods, nor have to occur in solitary and isolated circumstances. In the Netherlands, several organizations offer counselling to be able to self-determine the timing and manner of your end of life.[9-11] This demedicalized assistance in suicide (DAS) exists of having conversations about the wish to end life, offering moral support, and/or providing general information on methods how to end your life in a nonviolent and nonmutilating manner.[10] Research has shown that almost half of the people seeking this counselling suffer from a terminal or serious disease. Almost half primarily suffers from physical conditions, while a quarter primarily has psychiatric suffering. About 4 in 10 wish to end life within a year. These people seem to seek a peaceful death to escape from current suffering.[9] About one third of the people seeking counselling have primarily psychological suffering (e.g., existential suffering) or do not mention any current suffering at the time they start counselling (e.g., healthy people who wish to avoid situations such as being dependent later in life). More than one third does not have a wish to end life when they start counselling. These people seem to seek reassurance to prevent possible prospective suffering.[9] About one eighth of all the people seeking this counselling have ended their lives themselves.[9] Interestingly, this practice of DAS exists next to the medicalized practice of physician assistance in dying (PAD). Counselees who seek DAS who have physical or psychiatric suffering can meet the criteria to obtain PAD, but former research has shown only half of them has requested for such assistance.[9]

The Dutch practice of DAS shows that counselees who decide to end their own life mostly choose to end life through voluntarily stopping eating and drinking (VSED) or self-ingesting self-collected lethal medication (MED).[6,9,12] In the Netherlands, limited information is available about VSED,[6,12-14] and even less about MED.[6,12] Chabot has published a qualitative interview study with relatives, doctors, and right-to-die activists about people who have passed away through MED after receiving DAS and a nationwide quantitative study on self-directed dying through VSED and MED.[15,16] Furthermore, the quinquennial evaluation of the Termination of Life and Assisted Suicide Review Procedures Act has obtained information from physicians about patients who have ended life themselves through VSED and MED.[6] While the latter two studies offer estimates about the occurrence based on greater samples, both studies included a low number of cases to report on personal characteristics. Furthermore, physicians are not always informed about nor involved in the patients' intentions to end life themselves. This especially seems to be the case for people who pass away through MED.[6,16]

We would like to extend on the existing information on people who have passed away through MED by conducting a study with information gathered from counsellors working with Foundation De Einder (see Box 7.1 for history, aim, and work method of Foundation De Einder). These counsellors provide counselling to people who wish to self-determine the timing and manner of their end of life. Previous research has shown the majority of the counselees who pass away, have passed away through MED.[9] Counsellors therefore seem to be more often involved in (the preparation of) a self-directed death by MED than physicians and can form a valuable contribution to the knowledge about this form of dying in the Netherlands.

First of all, we are interested in the personal characteristics of, and the counselling received by, counselees who passed away through MED after receiving counselling to be able to self-determine the timing and manner of their end of life. Furthermore, we are interested in the differences in the characteristics of the counselees and the counselling between counselees with physical, psychiatric, and psychological or no underlying suffering.

Box 7.1
History, aim, and work method of Foundation De Einder

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 confronted with closed doors or were only offered ways to cure the wish to end life. This often resulted in these people having to continue life with unbearable suffering, or in committing a mutilating suicide in isolation, causing a lot of suffering for close ones and involuntary involved.[17]
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 [. . .]".[17]. Contrary to suicide prevention or crisis intervention organizations, Foundation De Einder regards ending your own life as a possible outcome and gives information about self-euthanasia.[18] Autonomy is regarded as an important value. Seen as an addition to the—since 2001 in the Netherlands legally regulated—medicalized approach of physician assistance in dying (PAD), Foundation De Einder works in cooperation with independent counsellors to offer counselling focused on demedicalized assistance in suicide (DAS).
Work method People who wish to self-determine the timing and manner of their own end of life contact Foundation De Einder themselves. They are referred to counsellors working in cooperation with Foundation De Einder who offer nondirective counselling, which consists of having conversations, offering mental support, and providing general information on self-euthanasia. These three forms of assistance by laypersons are regarded as nonpunishable assistance in suicide.[19] 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".[17] The counselling is aimed at creating as much clarity as possible regarding the wish to end one's life and possible suicide. This covers the mental process of decision making and might include matters such as considering alternatives, timing of death, and consideration of others. If the counselee decides to act upon his or her desire to end their life, the counselling is aimed at realizing the best possible preparations for self-euthanasia. This covers the practical preparation and might include gathering means for and the effectuation ending your own life.[17,20]

Method

Design

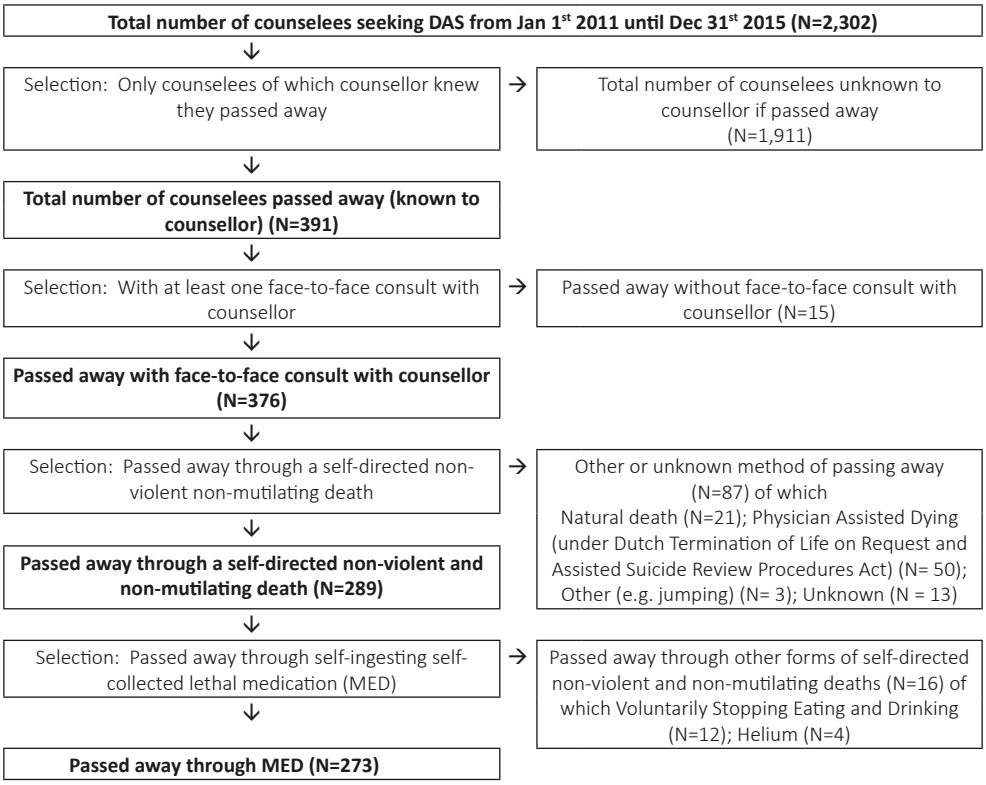
This cross-sectional study consisted of data that were collected from annual registration forms (questionnaires) that counsellors working with Foundation De Einder filled out for all counselees they had had contact with the preceding year.

Population

Data over the years 2011 to 2015 were collected in the first 2 months of the consecutive year. All counsellors working in cooperation with Foundation De Einder in that period (N=12) filled out the registration forms (response rate 100%). Four counsellors filled out the forms for all 5 years, while the other counsellors filled them in for fewer years as a result of starting or ending working as a counsellor within these 5 years. This resulted in data on 2,302 persons seeking DAS. For answering the research questions in this article, we selected people of which the counsellor knew they passed away (N=391). Only people with whom the

counsellor had had at least one face-to-face contact during the counselling were selected for analysis. As explained in our previous study, counsellors only share explicit information about self-collecting and self-ingesting lethal medication during face-to-face contacts due to the sensitivity of the information.[9] This resulted in data on 376 people who passed away in the years from 2011 until September 2015. The majority of these counselees passed away through MED (N=273; see Figure 7.1).

Figure 7.1
Selection of participants for analysis



Measurement instrument

The researcher digitalized the registration form that was previously used by the board of Foundation De Einder and—in consultation with counsellors—expanded the form. To increase reliability and uniformity and to avoid bias, several meetings with the counsellors were held to explain the instructions for filling out the form. The registration form underwent minor changes and expansion as a result of feedback from counsellors and the wish to collect more information. The registration form consisted of four general areas: (a) personal characteristics of the counselee, (b) overview of the situation of the counselee prior to the start of counselling, (c) characteristics of the counselling process, and (d) outcome of the counselling process (see Appendix 6, additional file 1). All forms returned by the counsellors were processed anonymously.

Based on the information provided by the counselees, the counsellors provided a description of the situation of, and/or the suffering experienced by, the counselees, such as cancer, dementia, mood disorders, an accumulation of problems related to old age or completed life. The counsellor assessed the primary underlying suffering of the counselee at the time they sought counselling: physical (when there are primarily physical and somatic complaints, e.g., cancer or stroke), psychiatric (when there are primarily officially diagnosed psychiatric disorders, e.g., depression or personality disorders), psychological suffering (when there is primarily psychological suffering, e.g., grief or suffering from life), or no current suffering (when the prior forms of suffering are absent, e.g., preparing for self-determination or people who wish to have reassurance for possible prospective suffering). Furthermore, the counsellor classified the clients into four categories of severity of the disease (if present): (a) terminal or advanced disease when cancer in a terminal or advanced phase or other disease with terminal diagnose was medically diagnosed, (b) severe disease when a serious somatic disease (not terminal cancer; e.g., heart failure, chronic obstructive pulmonary disease, cerebrovascular accident) and/or serious psychiatric disease (e.g., severe depression) was medically diagnosed, (c) nonsevere disease (e.g., problems of old age, deterioration of mobility, problems of vision or hearing), or (d) no disease, when counselees presented no physical or psychiatric complaints.

Analysis

A description was given on frequencies of categories, focusing on the characteristics of the counselees and the characteristics of the counselling. Furthermore, 95% confidence intervals (CIs) were calculated to compare groups with different primary underlying suffering at the time they sought counselling. Both calculations were made with SPSS version 20.0.0. A comparison was made between counselees with primarily underlying physical suffering, counselees with primarily underlying psychiatric suffering, counselees with primarily underlying psychological suffering, and counselees without underlying suffering. The latter two were combined as both lack an underlying medical diagnosis which is a prerequisite to be able to receive PAD under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act.

Approval by Ethics Committee

This study did not require approval under the Dutch law on medical-scientific research with humans because participants were not subjected nor imposed to certain acts or behaviors. This exemption from requiring ethics approval had been granted by the VU Medical Center Medical Ethics Committee.

Results

Characteristics of counselees passing away through MED

Underlying Suffering. The primary underlying suffering of the majority of counselees who passed away through MED at the time they sought counselling was— according to the counsellor—characterized by physical suffering (42%), mostly an accumulation of problems related to old age (mentioned by 14% of the counselees), dementia (7%), cancer (6%), rheumatic diseases (5%), and pain (4%; see Table 7.1). For a third of the counselees (32%), the primary underlying suffering entailed psychiatric suffering, with mood disorders (22%), personality disorders (13%), trauma and stress disorders (9%), fear disorders (9%), and obsessive-compulsive disorders (7%) mostly mentioned. Furthermore, a quarter of the counselees (26%) primarily had psychological suffering or did not mention underlying

suffering at the start of counselling, for example, completed life (19%), or striving for self-determination (4%; see Table 7.1).

According to the counsellor, around two thirds of the counselees (65%) had a serious or terminal disease at the time they sought counselling. Counselees with primarily psychological or no suffering at the start of counselling less often had a serious (or terminal) disease (25%, 95% CI [15, 37]) than counselees with primarily physical suffering (79%, 95% CI [70, 85]) or psychiatric suffering (82%, 95% CI [72, 89]; see Table 7.1).

Table 7.1
Description of underlying suffering at start of counselling and seriousness of disease (according to counsellor) of counselees passing away through self-ingesting self-collected lethal medication (MED) divided by primary underlying suffering at start of counselling (according to counsellor) (N=273; missing N=2).

			Primary underlying suffering					
	All (N=273)		Physical suffering (N=114)		Psychiatric suffering (N=86)		Psychological or no suffering (N=71)	
	N	%	N	% (CI 95%)	N	% (CI 95%)	N	% (CI 95%)
Description of all underlying suffering			N=114		N=85[a]		N=69[a]	
Physical suffering	114	42						
Accumulation problems of old age[d]	38	14	26	23 (16-31)	0	0 (0-3)	12	17 (10-28)
Dementia	19	7	11	10 (5-16)	1	1 (0-5)	7	10 (5-19)
Cancer	16	6	14	12 (7-19)	0	0 (0-3)	2	3 (1-9)
Rheumatic	13	5	12	11 (6-17)	1	1 (0-5)	0	0 (0-4)
Pain	12	4	12	11 (6-17)	0	0 (0-3)	0	0 (0-4)
Physical other[e]	67	25	49	43 (34-52)	12	14 (8-23)	6	9 (4-17)
Psychiatric suffering	86	32						
Mood disorders	59	22	2	2 (0-6)	51	60 (49-70)	6	9 (4-17)
Personality disorders	36	13	0	0 (0-2)	33	39 (29-49)	3	4 (1-11)
Trauma and stress disorders	24	9	1	1 (0-4)	17	20 (13-29)	6	9 (4-17)
Fear disorders	24	9	0	0 (0-2)	14	16 (10-25)	4	6 (2-13)
Obsessive compulsive disorder	20	7	1	1 (0-4)	14	16 (10-25)	5	7 (3-15)
Psychiatric other[f]	6	2	0	0 (0-2)	5	6 (2-12)	1	1 (0-7)
Psychological or no suffering	71	26						
Completed life	52	19	12	11 (6-17)	6	7 (3-14)	32	46 (35-58)
Self-Determination	11	4	3	3 (1-7)	0	0 (0-3)	8	12 (6-21)
Psychological other[g]	22	8	6	5 (2-11)	2	2 (0-7)	14	20 (12-31)
Seriousness of disease	N=249[b]		N=107[b]		N=76[c]		N=64[b]	
Terminal/serious disease	162	65	84	79 (70-85)	62	82 (72-89)	16	25 (15-37)
No (serious) disease	87	35	23	22 (15-30)	14	18 (11-28)	48	75 (63-84)

Note. Only the clarifications of underlying suffering mentioned if suffering occurred in >4% of all counselees. Underlying suffering adds up to more than 100% due to co-morbidity. CI = Confidence interval.
a Missing less than 5%. b Missing between 5 and 10%. c Missing > 10%. d An accumulation of problems related to old age concerns a comorbidity of lesser nonserious problems of old age, for example, problems with mobility, loss of eyesight, weakening physical condition, and so forth. e Physical other includes sleep-wake disorders, heart and vascular diseases, Parkinson's disease, muscular diseases, osteoporosis, chronic obstructive pulmonary disease, tinnitus, neurological disorders, autism, Lyme disease, deafness. f Psychiatric other includes feeding and eating disorders. g Psychological other includes grief, loneliness, addiction, gender issues, and family problems.

Personal characteristics

Half of the counselees were younger than 65 years old. Counselees with primarily psychiatric suffering were more often aged younger than 65 years old (84%, 95% CI [75, 90]) than counselees with physical suffering (35%, 95% CI [27, 44]) and counselees with psychological or no suffering at the start of counselling (37%, 95% CI [27, 49]) and were less often aged older than 80 years old (2%, 95% CI [0, 7]) than counselees with physical suffering (35%, 95% CI [27, 44]) and counselees with psychological or no suffering at the start of counselling (34%, 95% CI [24, 46]; see Table 7.2).

Wish to end life and prior suicide attempts.

Almost all counselees who passed away through MED (90%) had a wish to end life at the start of counselling. One third of these counselees (38%) wished to end life within 3 months and another third (37%) within 1 year from the start of the counselling. Counselees with primarily psychiatric suffering more often expressed to have a wish to end life at the start of counselling (97%, 95% CI [92, 99]) than counselees with psychological or no suffering at the start of counselling (83%, 95% CI [72, 91]). They, however, more often expressed their wish to be more than 1 year away (46%, 95% CI [35, 57]) compared with both counselees with physical suffering (14%, 95% CI [8, 22]) and counselees with psychological or no suffering at the start of counselling (15%, 95% CI [7, 26]).

One quarter of the counselees who passed away through MED (27%) attempted suicide before. Counselees with primarily psychiatric suffering more often attempted suicide before (58%, 95% CI [45, 71]) than both counselees with physical suffering (9%, 95% CI [4, 17]) and counselees with psychological or no suffering at the start of counselling (26%, 95% CI [15, 39]; see Table 7.2).

Previously sought help

Half of the counselees who passed away through MED had requested PAD before (47%). The majority of them (85%) were confronted with a refusal of their request. Counselees with primarily psychological or no suffering at the start of counselling least often had requested

for PAD (30%, 95% CI [20, 41]) compared with counselees with physical suffering (54%, 95% CI [45, 63]) and psychiatric suffering (54%, 95% CI [44, 65]).

Counselees also contacted other organizations or professionals with their current wish to be able to self-determine the timing and manner to end their life. About two thirds of the counselees (63%) previously sought this help, primarily with a physician (38%), Right-to-Die-Netherlands (31%), a psychiatrist (25%), and/or the Euthanasia Expertise Centre (formerly known as End-of-Life Clinic; 14%). Counselees with primarily psychiatric suffering more often sought aid in dying with a psychiatrist (62%, 95% CI [46, 76]) than counselees with physical suffering (2%, 95% CI [0, 9]) and psychological or no suffering at the start of counselling (20%, 95% CI [9, 35]) and less often with Right-to-Die-Netherlands (14%, 95% CI [5, 27]) than counselees with physical suffering (41%, 95% CI [28, 55]; see Table 7.2).

Table 7.2
Characteristics of counselees passing away through self-ingesting self-collected lethal medication (MED) divided by primary underlying suffering at the start of counselling (according to counsellor) (N=273; missing N=2)

			Primary underlying suffering					
Characteristics	All counselees (N=273)		Physical suffering (N=114)		Psychiatric suffering (N=86)		Psychological or no suffering (N=71)	
	N	%	N	% (CI 95%)	N	% (CI 95%)	N	% (CI 95%)
Gender	N=273		N=114		N=86		N=71	
Male	90	33	39	34 (26-43)	25	29 (20-39)	26	37 (26-48)
Female	183	67	75	66 (57-74)	61	71 (61-80)	45	63 (52-74)
Age groups	N=268[a]		N=111[a]		N=85[a]		N=70[a]	
0 – 64 years	136	51	39	35 (27-44)	71	84 (75-90)	26	37 (27-49)
65 – 79 years	66	25	33	30 (22-39)	12	14 (8-23)	20	29 (19-40)
80 years and older	66	25	39	35 (27-44)	2	2 (0-7)	24	34 (24-46)
Wish to end life at start of counselling[d]	N=244[a]		N=103[a]		N=74[b]		N=65[a]	
Yes,...	219	90	92	89 (82-94)	72	97 (92-99)	54	83 (73-91)
	N=219		N=92		N=72		N=54	
...< 3 months[e]	83	38	37	40 (31-50)	20	28 (18-39)	26	48 (35-61)
... 3-12 months[e]	82	37	42	46 (36-56)	19	26 (17-37)	20	37 (25-50)
...> 1 year ahead[e]	54	25	13	14 (8-22)	33	46 (35-57)	8	15 (7-26)
Prior Suicide Attempt[f]	N=196[b]		N=88[a]		N=55[b]		N=51[c]	
Yes	53	27	8	9 (4-17)	32	58 (45-71)	13	26 (15-39)
Request for PAD	N=268[a]		N=113[a]		N=83[a]		N=70[a]	
No request	141	53	52	46 (37-55)	38	46 (35-56)	49	70 (59-80)
With request	127	47	61	54 (45-63)	45	54 (44-65)	21	30 (20-41)

			Primary underlying suffering					
Characteristics	All counselees (N=273)		Physical suffering (N=114)		Psychiatric suffering (N=86)		Psychological or no suffering (N=71)	
	N	%	N	% (CI 95%)	N	% (CI 95%)	N	% (CI 95%)
Result if request PAD[g]	N=126[a]		N=60[a]		N=45		N=21	
Denied	108	85	50	82 (72-91)	39	87 (75-94)	19	91 (73-100)
Pending	16	13	8	13 (7-24)	6	13 (6-25)	2	10 (2-27)
Granted	2	2	2	3 (1-10)	0	0 (0-5)	0	0 (0-11)
Previous help sought[h]	N=194[b]		N=86[a]		N=55[b]		N=51[c]	
Yes...	122	63	49	57 (46-67)	37	67 (54-79)	35	69 (55-80)
	N=121[a]		N=49		N=37		N=35	
... with physician[j]	46	38	24	49 (35-63)	9	24 (13-40)	13	37 (23-54)
... with Right-to-Die NL[j]	38	31	20	41 (28-55)	5	14 (5-27)	12	34 (20-51)
... with psychiatrist[j]	31	25	1	2 (0-9)	23	62 (46-76)	7	20 (9-35)
... with End of Life Clinic[j]	17	14	5	10 (4-21)	5	14 (5-27)	7	20 (9-35)

Note. PAD = Physician Assisted Dying (as under Termination of Life on Request and Assisted Suicide Review Procedures Act. CI = Confidence interval. Right-to-Die NL = Right-to-Die Netherlands (NVVE). End-of-Life Clinic = also known as Euthanasia Expertise Centre.
[a] Missing less than 5%. [b] Missing 5-10%. [c] Missing > 10%. [d] Category only registered for deaths from 2012 (N=254). [e] Category only registered for deaths from 2012, and wish to end life at start of counselling (N=219). [f] Category only registered for deaths from 2013 (N=209). [g] Only for counselees with a request for PAD (N=127). [h] Previously help sought with wish to be able to self-determine the timing and manner of own end-of-life. [j] Category only registered for deaths from 2013 and seeking aid in dying (N=122).

Characteristics of counselling received by counselees passing away through MED

Almost half of the counselees who passed away through MED (46%) had one personal consult with the counsellor, one third (33%) had two personal consults, and the remaining group (22%) three or more (see Table 7.3). In addition to the personal consults, other contacts such as per email or telephone were registered. One third of the counselees (37%) had four to six contact moments with the counsellor, and half (47%) had seven or more. Almost half of the counselees (46%) passed away within 3 months after seeking counselling and another third (36%) within 1 year (see Table7. 3).

In almost all cases, general information about the foundation, moral support, counselling of mental aspects, practical information on the preparation for and performance of MED, information on others, and legal information was offered (88%–100%). Information on PAD was discussed with 70% of the counselees (see Table 7.3).

Two thirds (68%) of the counselees involved others in the counselling, most often their children (34%), their partner (23%), or other family members and/or friends (29%). Other professionals, among others physicians, were involved in few cases (7%). One fifth of the counselees (22%) did not involve others in the counselling, nor did they provide openness toward others about the counselling (see Table 7.3).

There were no significant differences between groups of varying underlying primary suffering in the duration, the number of contacts, and content of the counselling. Counselees with psychiatric suffering less often involved others (54%, 95% CI [43, 64]) than counselees with physical suffering (82%, 95% CI [74, 88]). When they involved others, less often it concerned their children (13%, 95% CI [5, 26]) when compared with counselees with physical suffering (39%, 95% CI [29, 51]) or psychological or no suffering at the start of counselling (47%, 95% CI [32, 63]). Counselees with physical suffering more often involved others and/or were open about the counselling they received toward others (90%, 95% CI [84, 95]) than counselees with psychiatric suffering (67%, 95% CI [56, 76]) or psychological or no suffering at the start of counselling (72%, 95% CI [61, 82]; see Table 7.3).

Table 7.3

Characteristics of received counselling of counselees passing away by self-ingesting self-collected lethal medication (MED) divided by primary underlying suffering at start of counselling (according to counsellor) (N=273; missing=2)

Characteristics			Primary underlying suffering					
	All (N=273)		Physical suffering (N=114)		Psychiatric suffering (N=86)		Psychological or no suffering (N=71)	
	N	%	N	% (CI 95%)	N	% (CI 95%)	N	% (CI 95%)
Number of personal consults	N=273		N=114		N=86		N=71	
1	125	46	59	52 (43-71)	38	44 (34-55)	26	37 (26-48)
2	89	33	28	25 (17-33)	32	37 (28-48)	29	41 (30-53)
> 3 (max 14)	59	22	27	24 (17-32)	16	19 (11-28)	16	23 (14-33)
Total number of contacts	N=273		N=114		N=86		N=71	
1	6	2	6	5 (2-11)	0	0 (0-3)	0	0 (0-3)
2-3	39	14	19	17 (11-24)	13	15 (9-24)	7	10 (4-18)
4-6	101	37	44	39 (30-48)	35	41 (31-51)	20	28 (19-39)
> 7 (max 36)	127	47	45	40 (31-49)	38	44 (35-55)	44	62 (50-73)
Duration of counselling	N=267[a]		N=110[a]		N=85[a]		N=70[a]	
< 3 months	123	46	48	44 (35-53)	42	49 (39-60)	33	47 (36-59)
3-12 months	96	36	48	44 (35-53)	28	33 (24-43)	19	27 (18-38)
> 12 months	48	18	14	13 (7-20)	15	18 (11-27)	18	26 (17-37)
Content of counselling[d]	N=251[a]		N=104[a]		N=77[a]		N=68[a]	
General info	248	99	102	98 (94-100)	76	99 (94-100)	68	100 (96-100)
Moral support	250	100	103	99 (96-100)	77	100 (97-100)	68	100 (96-100)
Mental support	230	92	94	90 (84-95)	70	91 (83-96)	64	94 (87-98)
Counselling about others	222	88	99	95 (90-98)	62	81 (71-88)	59	87 (77-93)
Information PAD	176	70	72	69 (60-77)	56	73 (62-82)	47	69 (58-79)
Information preparation MED	247	98	103	99 (96-100)	75	97 (92-99)	68	100 (96-100)
Information perform MED	248	98	103	99 (96-100)	74	96 (90-99)	68	100 (96-100)
Legal information	247	98	103	99 (96-100)	74	96 (90-99)	67	99 (93-100)
Involving others in counselling	N=273		N=114		N=86		N=71	
Yes	186	68	93	82 (74-88)	46	54 (43-64)	46	65 (53-75)
Which others involved	N=148[c]		N=71[c]		N=39[c]		N=38[c]	
Partner	34	23	21	30 (20-41)	7	18 (8-32)	6	16 (7-30)
Children	51	34	28	39 (29-51)	5	13 (5-26)	18	47 (32-63)
Parents	10	7	3	4 (1-11)	6	15 (7-29)	1	3 (0-12)
Other family and/or friends[e]	43	29	18	25 (16-36)	15	39 (24-54)	10	26 (14-42)
Others (professionals)[f]	10	7	3	4 (1-11)	4	10 (4-23)	3	8 (2-20)
Involvement and/or openness	N=262[a]		N=112[a]		N=81[a]		N=68[a]	
Involvement and/or openness	205	78	101	90 (84-95)	54	67 (56-76)	49	72 (61-82)
No involvement nor openness	57	22	11	10 (5-16)	27	33 (24-44)	19	28 (18-39)
Conversations with bereaved	N=257[b]		N=108[b]		N=78[b]		N=69[b]	
Yes	149	55	72	67 (57-75)	39	50 (39-61)	38	55 (43-66)

Note. PAD = Physician Assisted Dying (as under Termination of Life on Request and Assisted Suicide Review Procedures Act. CI = Confidence interval.

[a] Missing less than 5%. [b] Missing 5-10%. [c] Missing > 10%. [d] Category only registered for deaths from 2012 (N=254). [e] Other family and/or friends includes grandchild(ren), brother(s), sister(s), cousin, friend(s), and acquaintance(s). [f] Others (professionals) include physician nurse, psychologist, Right-to-Die-Netherlands volunteer, therapist, legal representative, and documentary maker.

DISCUSSION

Summary

The majority of counselees who have passed away through MED after receiving counselling to be able to self-determine the timing and manner of their end of life have a terminal or serious disease and primarily suffer from physical or psychiatric problems. Almost all have a wish to end life at the start of counselling, and the majority wishes to end life within a year. Help with the wish to self-determine the timing and manner of their end of life has also been sought with other caregivers or organizations by two thirds of the counselees. Half have requested their physician for PAD. Two thirds have involved others in the counselling, while one fifth neither have involved others nor were open toward others about the counselling. Counselees with psychiatric suffering are younger, more often have attempted suicide prior to counselling, and more often have expressed a wish to end life at the start of counselling (although their wish to end life was more often more than 1 year away) than counselees with physical suffering or counselees who mention psychological suffering or do not mention any suffering at the start of counselling.

Strengths and limitations

This is the first quantitative study to include such a large number of people who have passed away through MED after receiving counselling to be able to self-determine the timing and manner of your end of life. Also, it is the first quantitative study to obtain quantitative information from counsellors who counsel counselees who wish to self-determine the timing and manner of their end of life. The results are, however, not generalizable to all people in the Netherlands who have passed away through MED after receiving counselling because there are other organizations in the Netherlands that offer this counselling, which may have different approaches to offering assistance. Furthermore, information about the counselees has been collected through counsellors. The available information is dependent on what counselees share with the counsellor, which can cause an information bias. Furthermore, counsellors have assessed the primary underlying suffering and severity of disease based on this information. The anonymous data provided do not allow to link information to medical files or death registry files.

Who passes away through MED?

This study shows that the majority of the people who have passed away through MED after receiving counselling to self-determine the timing and manner of their end of life have a terminal or serious disease and primarily suffer from physical or psychiatric diseases. In a previous study, we found that 42% of the people seeking this counselling suffer from a terminal or serious disease.[9] In the current study, 65% of the people who ended their life after seeking this counselling had a terminal or serious disease. That seems to suggest that people who seek counselling to prevent possible future suffering less often (or less quickly) reach a situation in which they want to end their life.

Half of the people who have passed away through MED after receiving counselling have requested PAD. Chabot and Goedhart (2009) have also found that about half of the people passing away through MED (and VSED) have requested for PAD.[12] This study shows that some patients do persist in their wish to end life after a denial of their request for PAD and do seek other ways to end life. Research has shown there can be miscommunication about the persistence of a wish to end life after a denied request for PAD.[21]

Furthermore, the results show that half of the counselees with an underlying medical disease have not requested for PAD. While having an underlying medical condition offers the opportunity to request for PAD,[5] this study supports the idea that people do not make use of this possibility. On one hand, this could reflect that there are people who regard ending your own life as their own responsibility instead of asking the physician for help and to take this responsibility.[10] On the other hand, it is also likely there are people who believe that they will not be able to obtain PAD and therefore do not request their physician for assistance.[10] For patients with psychiatric suffering, dementia, or an accumulation of problems of old age, the numbers of granted requests for PAD are low.[22] These patient groups only form a small percentage of patients who receive PAD,[6] while they are well represented among the group of counselees who end life through MED after receiving counselling.

Finally, the study shows that counselees with psychiatric suffering differ from both counselees with physical suffering and counselees with psychological or no suffering at the start of counselling. They are, for example, younger and have attempted suicide more often. Offering

assistance in dying under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act to patients with psychiatric suffering is complex for physicians. Only 3% of the patients receiving PAD have a psychiatric disease.[6] This is a result of matters such as the unpredictable course of psychiatric disorders, the possibility of spontaneous recovery, a large variety of treatment options, and the possibility that the wish to end life may be a symptom of the psychiatric disorder.[5,23-25] These matters will also be apparent in counselling counselees with psychiatric suffering and ask for the necessity to involve knowledgeable professionals. However, the focus on a recovery-oriented approach in mental health care may leave little room for patients with a wish to end life.[24,26,27] This might make it impossible to involve these mental health-care professionals. It might also lead people with psychiatric suffering to contact a counsellor with whom they can discuss the wish to self-determine the timing and manner of your own life in an open manner.[11]

Counselling to self-determine the timing and manner of one's end of life

Regardless of the source of suffering, counselling in a delicate matter such as self-determining the timing and manner of one's end of life asks for carefulness and patience. However, the results seem to suggest that the counselling trajectories are often short and consist of little personal contacts. Almost half of the counselees have only had one personal consult with the counsellor before they passed away. Almost all the personal contacts are complemented with contacts by telephone or email.

The majority of the counselees who passed away through MED suffer from a terminal or serious disease. In certain cases, this might simply leave counselees with little time. It is unclear in which stage the counsellor gets involved, as the counselling is often not the only assistance people seek. About half have requested their physician for assistance in dying, and almost two thirds has also sought help with the wish to self-determine the timing and manner of their end of life from other caregivers or organizations. While for almost half of the counselees the counselling lasts less than 3 months, the data also suggest that the period in which counselees find or receive help with their wish to end life lasts longer for most than is suggested by the time frames in this study.

Findings on the counselling itself show that the counselling exists of more than just providing information on methods to end life in a nonviolent non-mutilating manner. Almost all counselees have received moral and mental support, legal information, and counselling about loved ones surrounding them. However, more detailed information about the content of the counselling and the role of counselling in the decision-making process is not available. This requires further research, for example, in-depth interviews with counselees and counsellors.

About a quarter of the counselees (22%) have not involved others in the counselling and have not provided openness to others about the counselling. This might give cause for concern that these counselees are at risk for a lonely or isolated end of life, although contact with a counsellor itself makes these counselees less isolated. The majority of counselees do involve others in the counselling. In most cases, this concerns family members and/or friends, while physicians are almost never involved in the counselling. This can be cause for concern as physicians can have a very important role in this process, especially concerning assessing competency, diagnosing diseases, and offering (or referring for) treatment.

Conclusion

The majority of people who pass away through MED after receiving counselling to be able to self-determine the timing and manner of their end of life had a terminal or serious disease and primarily physical or psychiatric suffering. Half has requested for PAD, which on the one hand shows not all patients with a medical diagnosis ask for PAD and on the other hand shows that some patients with a denied request for PAD persist in their wish to end life. The physician hardly ever seems to be involved in the counselling, while they could have a valuable role in the process concerning assessing competency, diagnosing diseases, and offering (or referring for) treatment. As people will always keep falling outside the scope of the Dutch PAD law, it remains subject of debate if and which arrangements shall be made for people who still wish to self-determine the timing and manner of their end of life.

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Supplemental Material

See Appendix 6

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8

General discussion

Introduction

This thesis primarily focuses on people who have received counselling to be able to self-determine the time and manner of their own end of life, and on those counselees who have intentionally ended their own life after receiving this counselling.

The aims of this thesis are (1) to estimate the incidence of people in the Netherlands who choose to end life themselves and to describe their characteristics, (2) to gain insight into which people and why these people seek assistance in intentionally ending their own life *outside* the medical practice of the Dutch law on physician assistance in dying (PAD) and how this assistance is experienced, and (3) to describe who passes away in which manner after receiving this assistance, and to describe the characteristics of the counselling they received.

This final chapter highlights the main findings of the former chapters by answering the research questions and interpreting them in relation to the literature. This is preceded by addressing the methodological considerations of the various studies included in this thesis. Furthermore, several overarching themes are discussed: (1) the terminology of assistance in dying, (2) physician involvement in the voluntary termination of life, and (3) the practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD. This thesis concludes with several implications and recommendations for research, practice and policy.

Methodological considerations

Different methods are used in this thesis. Chapter 3 describes findings resulting from a nationwide mortality follow-back study among physicians. Chapter 4 and 7 describe findings from a cross-sectional study among counsellors working with right-to-die organisation Foundation De Einder. Chapter 5 and 6 describe data from a qualitative in-depth interview study with people who sought counselling from counsellors working with right-to-die organisation Foundation De Einder. The methods approach the subject from different perspectives, and all of these methods and perspectives have their strengths and weaknesses, which are described in this paragraph.

Nationwide mortality follow-back study among physicians

The results in Chapter 3 are taken from a nationwide mortality follow-back study that is performed every five years to evaluate the practice of medical end-of-life decision making in the Netherlands.[1] A great strength of this study is its representativeness of all deaths in the Netherlands in 2015 and the generalizability to the population as a whole, as a result of the stratified random sampling techniques. Another strength is the high response rate. The use of a survey is appropriate for the descriptive nature of the study that aims to estimate the frequency of people ending their own life, and to study associations between several characteristics. A limitation of this design for the study into intentionally ending one's own life could be the physician´s perspective. Because the physician often seems to be uninvolved when a patient intentionally ends one´s own life they might be unaware of what happened. Finally, written questionnaires usually contain a predefined set of questions and answering options, which does not allow the researcher to ask for explanations, to check misinterpretations, or to follow-up inconsistencies, contradictions or ambiguous answers. For example, it might be a misinterpretation to infer that the underlying medical conditions contributed to the wish to end life. Other non-medical reasons (e.g. the loss of a partner or financial problems) could also play a role, making the presence or absence of a medical condition less relevant.

Cross-sectional study among counsellors working with Foundation De Einder

The questionnaires used for the cross-sectional study in Chapter 4 and 7 were distributed to the researcher by the board of right-to-die organisation Foundation De Einder, and built upon an already existing practice of registering fitted to the practice of counselling. As the study built upon this already existing practice of registering, the questionnaires were not pilot tested nor validated, and the possibilities to amend the questionnaire were limited. There may also be an information-bias because counselees may not have informed the counsellor correctly or have willingly withheld information about their situation. Furthermore, the counsellor is not a medical professional such as a physician or nurse, which can reduce the trustworthiness of the categorizations of the seriousness of diseases and the primary underlying suffering by the counsellor. However, clear instructions and multiple meetings assisted the counsellors in registering. Furthermore, the initiative for contact lies with the

counselee which may lead to the limitation that the counsellor will not always be informed about proceeding steps of, or the death of the counselee.

Contrary to general limitations of cross-sectional studies, this study showed no non-responders, making the study representative of the counselling offered by Foundation De Einder. Also, the study design made it possible to follow-up on inconsistencies, contradictions or ambiguous answers in the questionnaires, attributing to the validity of the data. The greatest strength of this study is that it is the first quantitative study ever published about counselees that received assistance in intentionally ending one's own life from a right-to-die organisation, and counselees that ended life through self-ingesting self-collected lethal medication (MED) after receiving this counselling. This perspective is valuable as counsellors tend to be involved more often when people intentionally end their own life by MED than professional caregivers, like physicians, are. This study, however, only focusses on the assistance offered by one specific right-to-die organization in the Netherlands, which is Foundation De Einder. Therefore, the results cannot be generalized to assistance offered by other right-to-die organizations, professional caregivers, or significant others.

In-depth interview study among people who sought counselling from Foundation De Einder

The research questions in Chapter 5 and 6 have a more explorative nature. Therefor a qualitative in-depth approach was chosen. A limitation of this interview study was a self-selection bias, because counselees enrolled themselves in the study, often after mediation of the counsellor. This could have led to including more counselees that were very positive about their experiences. Also, counselees that were deceased could not be part of the researched population. This could have biased the results towards a population that only seeks counselling to prevent possible future suffering. Finally, the researcher and author of this thesis previously worked as a counsellor in cooperation with Foundation De Einder which could have led to an interviewer bias. The differences in position and necessary skills for interviewing were addressed within the research team. This prior experience also contributed to more background knowledge about and experience with discussing the subject.

The in-depth interviews allowed to address and overcome several limitations of the cross-sectional research. For example, the quantitative data tells us how many people have or have not requested PAD before seeking counselling and ending their own life. This qualitative study gives an understanding about the motivation of people to have or have not requested for this physician assistance, and how the physician's response to their request has influenced their decision to seek counselling. Furthermore, the cross-sectional studies only allowed for predefined questions and answering options (e.g. whether certain subjects were discussed during the counselling like the involvement of others). The interview study offered the opportunity to extend on these subjects (e.g. the role of others in the counselling). Finally, the perspective of counselees seeking assistance in intentionally ending one's own life complements the perspectives from the physicians and counsellors in the other studies, which led to a greater understanding of the reasons why people seek this counselling and how they have experienced this.

Main findings in relation to the literature

People intentionally ending their own life

Frequency of people intentionally ending their own life

The first aim of this thesis is to give an estimate of the frequency of people who intentionally ended their own life in the Netherlands, and whether this occurred in the context of having a medical condition. Through a nationwide mortality follow-back study into medical end-of-life decision-making in the Netherlands, physicians were asked about their experiences with patients ending their own lives. It is estimated that in 2015, in 0.5% of all annual deaths people ended their own life by voluntarily stopping eating and drinking (VSED), in 0.2% through self-ingesting medication (MED), and in 1.2% by other methods.

This estimate equals the estimate of the numbers by Statistics Netherlands when excluding the number of people intentionally ending their own life by VSED.[2] Whether or not including people ending their own life by VSED is an example of differences in interpretation what is regarded as "suicide". Several authors argue that VSED can be regarded as a (discrete) form of suicide.[3-6] When adding the number of deaths by VSED to the estimate

of Statistics Netherlands, the total number of people intentionally ending their own life rises considerably to a total of around 2,700 people in 2015. It can also be argued whether physician-assisted suicide (PAS) and the physician terminating the life of the patient at the patient's request should be regarded as a patient intentionally ending one's own life.[7] Physician-assisted suicide under the Dutch law on PAD accounts for another 150 people intentionally ending their own life in 2015; the physician terminating the life of the patients on the patient's request under the Dutch law on PAD accounts for another 6,650 people.[1]

Furthermore, estimates of suicide by Statistics Netherlands and of suicide by the death certificate studies rely on how physicians fill out the death registration forms. These estimates are considerably lower than those obtained through a population based study, which estimated deaths by VSED at 2.1% and by MED at 1.1% of all annual deaths.[5,8,9] An explanation for the discrepancy might be a difference in the methods used for estimation, and that physicians are unaware because they are not always involved in nor informed about deaths by VSED or MED.[5,10,11] With careful planning, it might not clearly show someone intentionally ended one's own life. For example, when a person at old age ends life by MED and the physician is unaware of a wish to end life, this might be incorrectly registered as a natural death.[9] It is unknown how often this happens.[12] Finally, anecdotal evidence exists where physicians who are aware of the death wish and the intentional ending of the patient's own life register a natural death to prevent a stigma for bereaved ones or the burden of police involvement.[5,8,12-16] Under-registration of suicide is estimated at about 20-40%.[14]

In conclusion, estimating the number of people intentionally ending their own life is influenced by differences in interpreting which forms of dying are regarded as "suicide" (e.g. VSED and PAS), which sources of information have been used (e.g. physician versus population-based), and the possibilities of incorrectly registering intentionally ending one's own life as natural deaths (e.g. due to unawareness of the reporting person or by intent of the reporting person or deceased).

Characteristics of people intentionally ending their own life

The nationwide mortality follow-back study into medical end-of-life decision-making in the Netherlands in Chapter 3 also described characteristics of people intentionally ending their

own life. The focus was on the context of having a medical condition when people intentionally ended their own life, because the Dutch Supreme Court decided that a classifiable underlying medical condition is a requirement to obtain PAD.[17]

The majority of the people who ended their own life described in Chapter 3 had a medical diagnosis, but only one quarter had requested PAD. Of those with solely psychiatric diagnoses and those without medical diagnoses only one in twenty had requested PAD. Possible explanations for the low number of requests for PAD are presented in the interviews in Chapter 5. On the one hand, some people value self-determination and independence and wish to assume their own responsibility. On the other hand, requests for PAD might be impeded by a disturbed relationship with one's own physician, fear of provisional detention (especially for those patients with a psychiatric disease), or the conviction that PAD is not possible in their specific situation.

In conclusion, assistance in dying in the Netherlands is primarily embedded in the medical domain as it is currently understood in Dutch law. This raises the question how to address the desire to die from people whose wish to intentionally end their own life is not rooted in a medical condition and therefore falls outside the framework of the medical domain.

People seeking assistance in intentionally ending one's own life outside the Dutch law on PAD

The second aim of this thesis focusses on the people that *seek* assistance in intentionally ending their own life *outside* the Dutch law on PAD. This paragraph is divided in three subsections that focus on the characteristics of the counselees seeking this assistance, how seeking this counselling is related to the availability of PAD, and how counselees experience this counselling.

Characteristics of people seeking assistance in intentionally ending their own life outside the Dutch law on PAD

To study the characteristics of people who seek counselling, in Chapter 3 data was obtained from two consecutive years (2011-2012) of registration by counsellors from the Dutch right-

to-die organisation Foundation De Einder who offer counselling to people who wish to be able to self-determine the time and manner of their own end of life.

A small minority of the counselees seeking assistance in intentionally ending one's own life outside the Dutch law on PAD had a terminal disease, while more than one third had a severe disease. Counselees with a severe or terminal disease differed from counselees without a (severe) disease in underlying source of suffering, age distribution, and the presence and urgency of a wish to end life. Counselees without a (severe) disease were older, had more problems related to old age and existential suffering, and more often wanted to avoid dependency and to be able to self-determine their own end of life. They less often had a wish to end life, and when a wish to end life was present it was less urgent. There are no other studies to compare these findings with because studies that specifically address people that *seek* assistance from right-to-die organisations outside the available legal framework of PAD in the Netherlands are unavailable.

One third of the counselees seeking assistance in intentionally ending one's own life did not have a wish to end life. A distinction was made between counselees who seem to be looking for a peaceful death to escape from current suffering, and counselees who seem to be looking for reassurance to be able to prevent possible prospective suffering. This distinction shows similarities with other studies that distinguish between explicit requests for PAD at a foreseeable term, and request for PAD in due time (for example when the suffering would become too unbearable).[1,11] It has not been explored further if and how these two groups differ and whether seeking reassurance plays a role. The idea that people are looking for reassurance to be able to prevent future (unwanted) situations like dependency, losing mental capacity, and other forms of suffering has been proposed or found in various other publications and studies, for example concerning older people who are weary of life,[18-22] concerning assistance offered by right-to-die organisations,[23,24] and motivations for legalizing assisted suicide.[7] A wish to end life can function as a way to end suffering, prevent future (unwanted) situations, and a means to reclaim a kind of control.[25,26]

In conclusion, people who seek assistance in intentionally ending one's own life outside the Dutch law on PAD have diverse underlying characteristics which can be explained by different

motivations to seek this assistance; either looking for a peaceful death to escape from current suffering, or looking for reassurance to be able to prevent possible prospective suffering.

Relationship between seeking assistance in intentionally ending one's own life under and outside the Dutch law on PAD

To study how seeking assistance in intentionally ending one's own life *outside* the Dutch law on PAD is related to seeking physician assistance in dying *under* that law we used data from the study looking at all counselees seeking this assistance over a two-year period (2011-2012) (Chapter 4) and the qualitative in-depth interviews (Chapter 5).

Two out of five people in Chapter 4 who seek counselling have requested PAD. This percentage is twice as high for those counselees with a severe (or terminal) disease (51%) than for counselees without a (severe) disease (24%). This might partially be explained by the findings that counselees with a severe (or terminal) disease more often have a wish to end life than the counselees without a (severe) disease. For almost two thirds the request was refused. The request for PAD was granted for a small minority (8%). These results show that not everyone with a severe (or terminal) disease and with a wish to end life asks their physician for PAD. As the presence of a medical disease does not initially exclude people from access to PAD, we explored their reasons for seeking assistance *outside* the Dutch law on PAD through qualitative in-depth interviews with counselees.

Three different trajectories described how seeking counselling is related to requesting PAD. The first trajectory consisted of counselees with current suffering who (assumed they) were unable to obtain PAD. Either as a result of a disturbed relationship with their physician, a refused request, or that requesting PAD was impeded by fear of crisis intervention or provisional detention in case of a psychiatric disease. These counselees would have preferred PAD. Counselees in the second trajectory also preferred PAD, but sought counselling as a backup plan for when PAD would not be an option in the future. The counselling offered them an alternative to decide on the time and manner of their own death in the case their prospective suffering would not result in obtaining PAD. Finally, a group of counselees sought counselling without wanting to opt for PAD. As a result of valuing autonomy, self-determination, independence and taking one's own responsibility, they preferred to end

their own life. Seeking counselling helped them to prepare this carefully and to prevent or diminish harm to others.

In two out of three trajectories PAD is the preferred option to end life. PAD would offer more certainty, would feel legitimate and societally accepted, and close ones could be present without worrying about legal issues. Other studies also found a preference for PAD, which would provide the safety of a good judgement of their situation and a painless and societally accepted death.[19] Obtaining PAD is, however, not always possible and remains uncertain for patients who request this. In 2015, 30% of all requests for PAD in the Netherlands were refused because the physician was not convinced that one or more of the criteria of due care laid out in the Dutch law on PAD were met.[1] While the Euthanasia Expertise Centre (initially named the End-of-Life Clinic) offers another option to request PAD when one's own physician refused the request, they also deny one third of the requests.[27-29] A refusal of a request for PAD is more likely for patients who suffer from psychiatric diseases, dementia or completed life. Studies show the conceivability of physicians to provide PAD in these situations is low.[30]

Chapter 3, 4, 5 and 7 show that patients who are confronted with a refusal of their request for PAD can persist in their wish to end life. This has also been confirmed in other studies.[31,32] These PAD "outlaws" can seek other ways to end their own life.[33] Counselees in our study, however, seldom inform their physician about this. The physician´s refusal of or response to enquiries about PAD can be disappointing to patients. Dissatisfaction with the physician–patient communication can motivate patients to exclude physicians in their search for assistance in ending one's own life outside the possibilities of the Dutch law on PAD. Dutch studies into aspects that can complicate physician-patient communication on the subject of PAD and the wish to hasten death show that patients may not want to burden the physician,[31] or that patients or relatives do not understand why PAD is not (yet) an option.[34] Aspects that complicate the communication from the physicians' perspective are that physicians can experience (requests for) PAD as burdensome, emotional and a heavy responsibility.[35,36] Physicians may experience pressure from the patient, relatives or society.[34,36,47] Furthermore, physicians can have multiple concerns, for example about assessing the due care criteria correctly, the time the decision-making process will take, or waiting for the judgment of the review committees.[36] Physicians may also lack skills to

communicate well about wishes to die.[31] Discontinued physician-patient communication on this subject can lead to misunderstandings of the physician that the wish to end life has disappeared.[31] This can lead to sub-optimal care because the physician is not aware (anymore) of the wish to hasten death. Also, when the physician is not involved with the patient acting upon his wish to end life, the physician is unable to diagnose diseases and offer treatment nor offer reassurance that people seem to seek.

In conclusion, not all people seeking assistance in intentionally ending one's own life outside the Dutch law on PAD request PAD; even when medical diseases are present. People can persist in their wish to end life after a refusal of their request for PAD. The physicians refusal of or response to an enquiry about PAD can motivate people to seek assistance outside the framework of the Dutch law on PAD and/or not involve the physician herein.

Experiences with assistance in intentionally ending one's own life outside the Dutch law on PAD

Finally, for studying how the assistance in intentionally ending one's own life outside the Dutch law on PAD is experienced, qualitative in-depth interviews were conducted with people who received non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD from the Dutch right-to-die organisation Foundation De Einder (Chapter 6).

All interviewed counselees in Chapter 6 appreciated the availability of the counsellor, their careful and open attitude, feeling respected and/or being reminded about their own responsibility. Critical notes concerned feeling dependent on the counsellor to provide information on methods to end life, and doubts about the capacity of the counsellor. The counselling and to (be able to) obtain the lethal medication to end their lives, however, offered them reassurance, peace of mind, and less worries about current or prospective suffering. Owning the medication also raised new concerns about proper storage, preventing others taking their medication (and reassurance) away, and what to do when a beloved one asks for the lethal medication you own. Few counselees had a specific moment or time frame to intentionally end their own life, and most mentioned prospective situations like an undignified life, and becoming too dependent. This confirms the idea that some counselees are looking for reassurance to prevent future (unwanted) situations like dependency and

losing mental capacity. Several studies have described the idea that knowing how or being able to end one's own life in a dignified way brings reassurance.[7,18-24]

Concluding, counselees were primarily positive about the availability of the counsellor, their careful and open attitude, feeling respected, being reminded about their own responsibility, and feeling reassured by (being able to) obtain(ing) lethal medication to end their own lives. Some criticized the capacity of and feeling dependent on the counsellor, and mentioned new concerns when lethal medication was collected.

People intentionally ending their own life after receiving assistance in intentionally ending one's own life outside the Dutch law on PAD

The final aim of this study is to describe the incidence and the characteristics of people who have intentionally ended their own life *after receiving* assistance in intentionally ending one's own life *outside* the Dutch Termination of life on request and assisted suicide review procedures Act.

Data from the cross-sectional studies about counselees seeking assistance in intentionally ending one's own life outside the Dutch law on PAD showed one in eight counselees (13%) have intentionally ended their own lives themselves; the majority (90%) by MED. Two thirds of the counselees that have passed away by MED after receiving counselling had a terminal or serious disease, and primarily suffered from physical diseases (42%) or psychiatric diseases (22%). Almost all had a wish to end life at the start of counselling, and three out of four expressed a wish to end life within a year. A quarter had attempted to end their own life before. Help with the wish to self-determine the time and manner of their end-of-life had also been sought with other caregivers or organisations by two thirds of the counselees, and half had requested for PAD.

Several other studies have focussed on intentionally ending one's own life by MED, but several limitations complicate a comparison. The qualitative setting and small numbers of a study that focusses on deaths assisted by volunteers or counsellors related to Dutch right-to-die organisations limit a good comparison with this quantitative study.[15] Another Dutch nationwide quantitative study about the intentional ending of one's own life in consultation with proxies only includes a small minority of people professionally related to right-to-die

organisations.[8,9] The Dutch mortality follow-back studies and Statistics Netherlands do not provide information about whether patients received any counselling from right-to-die organisations.[1,11] Taking these limitations in mind, our study confirms that people who intentionally end life by MED more often have a serious or terminal disease than not having a (serious) disease (65-78% vs 21-35%), and that half requested PAD.[8] Studies from the physician's perspective find a lower percentage of refused requests for PAD amongst patients intentionally ending their lives by MED than our counsellor-based studies (41% vs 10%).[1] Possibly physicians only count the requests at a foreseeable term as an explicit request for PAD, while patients themselves (and their proxies and counselees) also include requests for in due time. Studies have shown that requests for in due time occur about three to four times as much as explicit requests at a foreseeable term.[1,11] Furthermore, the physician-based mortality follow-back study seems to include more psychiatric patients ending life by MED (73% vs 22%/<32%), while people who intentionally ended their own life by MED after having received counselling tend to share more characteristics with patients ending their own life by VSED: more often being over 65 years old, more often having somatic diseases, an accumulation of problems related to old age and dementia, less often having psychiatric problems, and more often having requested PAD.[1]

For about half (46%) of the counselees who intentionally ended life by MED after receiving counselling, the counselling trajectories lasted less than three months, and for about one third (36%) between three to twelve months. One in five (18%) counselling trajectories lasted more than one year. Half (52%) only had one consultation in person with the counsellor, a quarter two consultations, and the remaining quarter three to fourteen. The majority of these consultations in person were complemented by other contacts (e.g. by phone). The counselling trajectories often seem short and seem to consist of few personal contacts. This could raise questions about the carefulness in discussing the many aspects relevant to ending one's own life – like offering moral support, legal information and counselling about (and of) significant others and providing information on methods to end life in a non-violent manner – and achieving Foundation De Einder's aim to "create as much clarity as possible concerning the wish to end one's own life, and realising the best possible preparations for ending one's own life."[38]

The data from this study, however, suggests that people may possibly discuss such matters with others besides the counsellor as well. Two thirds (68%) of the counselees had involved others in the counselling; mainly their partner, children or other family and friends. One in five had neither involved nor were open towards others about the counselling. The physician was almost never involved, contrary to the physician being involved in almost two thirds of the cases of VSED.[10] This can be worrisome when medical conditions play a role in the wish to end life, because of the physician's valuable role in assessing competency, diagnosing diseases and offering (or referring to) treatment. Physicians can have a valuable role in providing reliable information and offering moral support.[39]

In conclusion, one in eight people seeking assistance in intentionally ending one's own life end their own life, mostly through MED. About half have requested PAD, which shows that not all patients with a medical diagnosis request PAD, and that patients can persist in their wish to end life after a refusal of their request for PAD. The physician is often uninvolved when these patients end their own life. It remains a question how to address the wish to end life from people whose wish to intentionally end their own life falls outside the Dutch law on PAD.

Overarching themes

In this section several overarching themes that appear throughout all chapters will be discussed. The first overarching theme will focus on the terminology used in the different chapters and by other researchers. The second overarching theme focusses on physician involvement in the voluntary termination of life. The final overarching theme addresses the practice of non-punishable assistance for people who wish to intentionally end their own life.

Terminology

The use of different terminology in the separate chapters reflects a continuous search of defining the researched matter correctly, in an easy-to-understand manner that also corresponds to the current research field. In this thesis, it is proposed to describe the assistance under research as *non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD* (consisting of having conversations, offering moral support

and providing general information about ways to be able to influence the time and manner of one's own end of life). This description differs from other conceptualisations and asks for clarification.

Suicide

"Suicide" in its ground meaning is regarded as a good description for the subject under study in this thesis because the definition – "the act of intentionally taking one's own life" –[40] does not include a value judgement on the (violence of the) method used or the (quality of the) decision-making process as a defining feature. This thesis uses "the act of intentionally ending one's own life" as an alternative. This choice has been influenced by associated characteristics with "suicide", and the debate about what is or is not regarded as "suicide".

"Suicide" seems to be mostly associated with violent and impulsive deaths occurring in isolation, while this thesis focusses on assistance for those that do not occur in isolation and mostly are not violent nor impulsive. Actually, the public image of "suicide" might be incorrect, because this public image of "suicide" by violent methods is maintained when well prepared "suicides" in consultation with proxies are not always registered as an unnatural death and will not be included in suicide statistics.[5,41] This has also been discussed in Chapter 3. Terms to emphasize these well-prepared "suicides" in consultation with proxies are for example self-deliverance, dignicide, self-euthanasia, and euthanatic suicide.[42-47] As this thesis does not assess the quality of "suicides" but focusses on the assistance offered, using "intentionally ending one's own life" is an attempt to give a factual and neutral description of the behaviour under research.

The preference for "intentionally ending one's own life" is also related to the terminological debate centring around which behaviours are to be regarded as "suicide" and which are not. Using "suicide" to describe VSED – which is also an explicit focus of this thesis – seems to ignore this debate. While "suicide" is an unnatural death, VSED is almost always regarded as a natural death in The Netherlands. This practice has been debated.[3-6,39,48] It is argued that VSED can be regarded as "suicide" because it results from the intention to hasten death, and an action (be it an omission) initiated by the person.[6] VSED can be regarded as a discrete form of "suicide" as it has distinct features from other forms of intentionally

ending one's own life, for example it is not characterized by an invasive or aggressive act, and death follows after at least several days.[6] These characteristics of violence, solitude and impulsiveness are not defining features of "suicide", and therefore do not exclude VSED from the concept of "suicide".[5]

Furthermore, Yuill (2015) argues that people who intentionally end their own life with assistance from a physician may also be regarded as "suicide", as he emphasizes the importance of self-initiating the act that leads to death, not performing the act itself. He argues that while the moral responsibility for the voluntary termination of life on request of the patient lies with the physician – the decision to die is that of the patient who dies.[7] In this thesis the focus is on the self-performance of the act of ending one's own life, but this choice can be debated. In the Dutch statistics of causes of death, PAD (including physician assisted suicide) is not classified as "suicide", but as a person dying as a result of their underlying medical condition.[1,2,11] This is partly because the World Health Organisation's International Classification of Diseases does not provide in a registration code for PAD, and to allow for comparisons of causes of death between countries.[8,49] Underneath the practice of registering the underlying disease as cause of death in the case of PAD lies the assumption that the patient would have died from this underlying disease anyway.[50] The great majority of people receiving PAD do have an underlying serious medical condition, like cancer, heart and vascular diseases, pulmonary diseases and diseases in the nervous system that will likely lead to an imminent death.[1,51] In three out of four cases life shortening is less than one month.[1] However, life shortening of more than six months by PAD under the Dutch law has risen from 0% in 2005 to 8% in 2015.[1] Also, there is a rise in granted requests for people with other or unknown diagnosis from 2% in 2005 to 13% in 2015.[1] Amongst these other diagnoses, early stage dementia has risen to 170 cases in 2020 and psychiatric diseases to 88 in 2020.[51] To still adhere to the practice to register these patients as passing away from their underlying disease may not always be an accurate representation of reality.

In conclusion, the act of "intentionally ending one's own life" has been proposed to describe the topic of this thesis because of associations with "suicide" as a violent and impulsive act, and the debate about what is or is not regarded as "suicide".

Assistance

The other terminological matter concerns the description of the assistance provided which has to inform about what kind of assistance is provided, by whom the assistance is provided and the legal status of that assistance. To describe this in a brief, compact, straightforward manner has been challenging.

There are different terms to explain who provides assistance in intentionally ending one's own life; the most well-known being Physician Assisted Suicide (PAS) or Physician Assisted Dying (PAD). This terminology refers to assistance that is offered by a physician under PAD legislation, like the Dutch law on PAD.[52] Examples of terminology for assistors who are not physicians are Lay Assisted Death (LAD),[53], Relative Assisted Death (RAD), Relative Assisted Suicide (RAS), Family Assisted Suicide (FAS),[33,53-56] and Non-Physician Assisted Suicide (Non-PAS),[57-60]. The term Non-Physician Assisted Suicide (Non-PAS) not only describes who offers assistance (anyone but physicians), but can also distinguish assistance from physician assistance in suicide (PAS) under a legislation on PAD.

As shown in Chapter 4, 5, 6 and 7 in this thesis and in other studies, physicians can also offer assistance to a patient intentionally ending their own life outside the Dutch law on PAD; be it a different form of assistance than stipulated under that specific law. To remove the focus from the person providing the assistance Demedicalised Assistance in Suicide (DAS) has been termed as an alternative. This term emphasizes the fact that the assistance under study falls outside the judicial model of assistance in dying that is embedded in the medical domain as currently understood by Dutch law. The position paper of the Royal Dutch Medical Association on the role of the physician in the voluntary termination of life by the patient, however, addresses how physicians can assist outside the Dutch law on PAD.[39] The involvement of a physician can be regarded as an aspect of medicalisation or embedding this assistance in the medical domain.[61] Therefor in hindsight, "demedicalised" is not seen as an accurate description.

Finally, neither the terms "non-physician" nor "demedicalised" give information about the legal status of this assistance. This thesis focuses on *non-punishable* assistance offered to someone intentionally ending one's own life outside the Dutch law on PAD. The non-

punishable character is related to case law concerning Article 294 of the Dutch Penal Code, which has been described more thoroughly in Chapter 2.[62] This case law has clarified that having conversations about the wish to end life, offering moral support (also in the form of being present on the condition that no active assistance has been offered) and providing general information on methods to end your own life are non-punishable forms of assistance in intentionally ending one's own life.[63-67]

Concluding, the term *non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD* (consisting of having conversations, offering moral support and providing general information about ways to be able to influence the time and manner of one's own end of life) has been proposed to describe the topic of this thesis. In Chapter 4 it has been shown that not everyone that seeks this assistance has a (current) wish to end life, and necessarily wishes to end life oneself. A more accurate description of the assistance under research might therefor be *'non-punishable assistance in enabling a person to influence the time and manner of one's own end of life'*. The assistance can either be offered by personally related people like relatives and friends (referred to as significant others) or professionally related people; either a medical professional (like a physician) or a professional acting on behalf of a professional organisation (like volunteers or employees from a right-to-die organization). This thesis focusses on the last group.

Physician involvement in the voluntary termination of life

The second overarching theme is related to physician involvement in the voluntary termination of life. While this thesis has shown that physicians are often not involved when someone intentionally ends one's own life by MED (Chapter 7), other studies have shown that physicians are more often involved when a patient intentionally ends one's own life by VSED.[10] Furthermore, physician involvement in the voluntary termination of life under the Dutch law on PAD has been addressed in every single chapter, for example in the presence or absence of a request for PAD (Chapter 3,4,5,6 and 7), the reasons for not requesting PAD (Chapter 5), and the preference of counselees to be able to receive PAD (Chapter 5).

Counselees in Chapter 5 and 6 preferred physician involvement under the Dutch law on PAD because the distribution of means by the physician was regarded as trustworthy. The physician´s legal access to lethal medications to end life also offered reassurance for the successful enactment of the death. Furthermore, family can be present without the threat of police involvement or prosecution. The presence of the physician during the termination of life also contributes to a careful (and certain) performance of death. This preference also resonates in the accounts of the people who intentionally ended their own life by MED in the interview study in Chapter 4 and 5. The ones who collected their lethal medication through the Dutch black market and in pharmacies abroad or online regarded these methods as dubious which amounted to (their concerns for) extra risks of failure.

The involvement of the physician under the Dutch law on PAD also seems to be preferred for other reasons than a trustworthy, safe and successful performance of death. Counselees in Chapter 5 preferred PAD because this would feel more legitimate and societally acceptable, while intentionally ending your own life without physician involvement carried a negative connotation. The Dutch law on PAD requires the physician to assess competency, unbearableness and hopelessness. Physicians are regarded to be the appropriate people to make these assessments and to safely and responsibly perform the act, because of their (medical) expertise, independence, emotional and professional distance, and the safeguard of the medical disciplinary law.[68,69] The involvement of a physician also reflects the involvement of the society concerning the protection of life.[68] When performed, the physician legitimates the death as not irrational, and therefore not wrong.[7] This can contribute to the patients' feeling of the safety of a good judgment, and a societally accepted death.[19]

Despite the preference for PAD, only a minority of the people in Chapter 3 and 7 who have ended their own life, had requested their physician for PAD under the Dutch law on PAD. Possible explanations for not requesting PAD are offered in Chapter 4 where counselees' requests for PAD were impeded by a disturbed relationship with one's own physician, by the fear of provisional detention (especially for those patients with a psychiatric disease who the physician judges to be a risk to themselves), or by the conviction that PAD is not possible in their specific situation. It is important to emphasize that the physician will only be exempted from prosecution under the Dutch law on PAD when all criteria of due care

are met,[52] and when the unbearable and hopeless suffering *primarily* results from a medically classified disease or condition.[17] In Chapter 3 it has been shown that especially people who have ended their own life in the absence of a medical diagnoses or with solely psychiatric diagnoses had hardly requested for PAD under the Dutch law on PAD. This could reflect awareness of patients that the conceivability of physicians to provide PAD for people with psychiatric problems is low,[1,30] or that they are aware their suffering has to primarily result from a medical condition.[17]

Furthermore, this thesis has shown that some people who ended their own life (in Chapter 7) and about a quarter of people who seek counselling to be able to intentionally end their own life (Chapter 4) did not have a medical disease. This confirms that the wish to end life or the wish to seek assistance to intentionally end one's own life does not necessarily originate from a medical condition.[26,70,71]

That not all patients who wish to end life can be assisted under the Dutch law on PAD has been acknowledged by the RDMA with the publication of their position paper about the role of the physician in the voluntary termination of life by the patient.[39] Also, the Advisory Committee Completed Life mentions intentionally ending one's own life by VSED and MED as alternatives for those people who cannot be assisted under the Dutch law on PAD.[68] Concerning assistance, the RDMA position paper describes what the physician can and can't do, while the Advisory Committee Completed Life states that physicians (and other caregivers or intimate ones for that matter) can provide assistance as long as this is limited to offering moral support and providing general information.[68]

In conclusion, physician involvement in the voluntary termination of life of the patient under the Dutch law on PAD is appreciated because of the reassurance of a trustworthy, safe and successful performance of death, the unproblematic presence of others, and of the legitimate and societally acceptable feeling. People whose wish to die does not primarily results from a medical condition or people who cannot find a physician to grant their request cannot be assisted under the medical framework of the Dutch law on PAD. In those situations, the physician can assist in the voluntary termination of life by the patient by VSED or MED. This, however, hardly happens for those who choose to intentionally end life by MED.

The practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD

The final overarching theme discusses the core theme of this thesis: the practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD. Chapters 4, 5, 6 and 7 all focus on counselees who have received such assistance in intentionally ending one's own life. This thesis demonstrates that non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD (in the form of offering moral support and providing general information) is currently already an option. This practice is not a well-known practice, and is met with criticism.

First, publications providing general information about intentionally ending one's own life by right-to-die organisations throughout history have led to criticism and political questioning. Examples are publications published by the Voluntary Euthanasia Information Centre,[72] by Foundation De Einder,[38,73,74] by Right-to-Die Netherlands,[75-81] by Foundation Scientific Research for Dignified Dying,[82,83] by Foundation Dignified End-of-Life [84], by Exit International.[85], and most recently by Cooperation Last Will.[86-90]

Furthermore, assisting someone who wishes to intentionally end one's own life has led to political questioning.[74,83,86,89-99] Offering this assistance can result in prosecution by the Public Prosecutor. People who have offered assistance that goes beyond having conversations, offering moral support and providing general information have been sentenced, although this is not always the case (see Appendix 4 and 5). Assistance by significant others may face a more sympathetic response from prosecuting authorities than professionals or volunteers related to right-to-die organizations.[33] Judges seem to have an implicit tendency that friends and family members are grosso modo more punishable than partners, because friends and family members are more distanced from the suffering than partners and should therefore withdraw oneself easier from person's the wish to die.[69]

The Advisory Committee Completed Life regards the consequences of the already available option of offering non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD as limited, but fears that more attention to this possibility could lead to "erosion of the necessary reluctance concerning decisions about the end of life".[68]

While this Committee has not evaluated the currently available practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD, their concerns about abolishing article 294 sub 2 of the Penal Code – concerning allowing non-physicians to assist in suicide – and about providing or owning a last-will pill are related to this currently available practice. The current practice involves non-physicians who give information about how to obtain a last-will pill. Amongst the concerns from the Committee are the risks to owning one's own lethal medication, the current lack of a normative framework, the current existence of a non-transparent non-reviewable practice, and that non-physicians lack (medical) expertise.[68] Some of these concerns are also addressed in this thesis, for example in Chapter 5 when counselees worry about the illegality and dubiousness of collecting lethal medication, in Chapter 6 when the competency of a counsellor is questioned, and in Chapter 7 where those people who intentionally ended their own life through MED had relatively few personal contacts with the counsellor and the counselling lasted relatively short. In addition, new concerns about possessing lethal medication are brought up in Chapter 6, like worries about preserving lethal medication, preventing it being taken away, and dilemmas when someone close asks for the lethal medication they possess. The currently available practice of non-punishable assistance in intentionally ending one´s own life outside the Dutch law on PAD is characterized by a non-transparent, and non-reviewable practice. It is pulled into an atmosphere of taboo because people wish to prevent their significant others a criminal investigation into the possibility of punishable assistance by the Public Prosecutor. This situation resembles the practice of PAD from decades ago when it was not yet legally regulated, and that also used to be a hidden death of which no one really knew what and how often this happened.[13]

Despite that the practice of non-punishable assistance in intentionally ending one's own life is acknowledged by the Royal Dutch Medical Association and the Advisory Committee Completed Life, its existence is ignored in the law proposal for an integral approach for suicide prevention, and the zero-suicide approach of the Dutch State Secretary for Health, Welfare and Sport.[100,101] The ultimate goal of the law proposal is to lower the number of suicide attempts in the Netherlands, and primarily of suicides that are lonely and desperate.[101] The focus on people who end life in desperation and under lonely circumstances does not seem to characterize the people who wish to intentionally end their own life that are included in this thesis. Several counselees in Chapter 4 who wish to intentionally end their

own life seek assistance in their emotional and psychological preparation to address the considerations of their decision, and the majority of counselees in Chapter 4, 6 and 7 have involved others. Furthermore, the law proposal does not specify how "suicides" that are not lonely and desperate should be treated, other than those deaths that can be performed under the Dutch law on PAD. One answer to the question how to address the desire to die from people whose wish to end life falls outside the medical framework of the Dutch law on PAD – and also a possible solution to the downsides of the zero-suicide approach – has been addressed in Chapter 4: "suicide-attempt prevention". This approach aims to prevent lonely and desperate suicides, but instead of aiming for zero suicides it aims for zero suicide attempts.[102] At the same time, this approach allows for suicides that are well-considered and do not occur in forced solitariness. It is aimed at openly talking about the wish to end life, and where possible searching for sensible and attainable solutions for unbearable situations. When attainable solutions are not possible, also assistance in suicide can be discussed.

Concluding, this thesis shows that besides a practice based on the law on PAD in the Netherlands, there is also a practice of assistance in intentionally ending one's own life outside this medical practice. There will always be people that fall outside the medical framework of PAD. Suicide prevention is the first response to people who wish to intentionally end their own life with the aim to diminish suicide attempts and suicides that are solitary and desperate. For people who wish to intentionally end their own life well-considered and with openness towards significant others the proposed approach of suicide-attempt prevention could be appropriate. This assistance in intentionally ending one's own life outside the Dutch law on PAD is not punishable when this assistance is limited to providing moral support and general information. This assistance is, however, met with criticism because it currently consists of a non-transparent and non-reviewable practice.

Implications and recommendations for further research, practice, and policy

Research

This thesis only forms a small step into an understudied research area where further research is required. This further research is also an important aspect for the recommendations and implications for practice and for policy.

a. The intentionally ending of one's own life that is the focus of this thesis seems to be largely unnoticed in the research field of "suicidology". Their focus is mainly on the standard picture of "suicide" that is impulsive, executed by violent means, and without any communication with family or friends. It is necessary to also broaden that view with those intentional deaths that are not violent and do not occur in isolation. To be able to characterize these intentional deaths (for example to distinguish between 'good' or 'bad' deaths, or to be able to distinguish intentional deaths a society wishes to prevent or assist) it might prove helpful to incorporate certain characteristics in research. Proposals for such characteristics could be whether or not the death is mutilating, considered dignified, impulsive, chosen after clear and careful consideration, preceded by a durable longing for death, occurs in forced isolation or with prior openness to others about the reasons to end life and considerations for such methods, and whether or not the person wishing to end life has accepted death.[8,45,47]

b. An accurate estimation of all people who have intentionally ended their own life is important for monitoring developments in its occurrence. With the current use of definitions of intentionally ending one's own life and the current system of registering causes of death, it is not possible to obtain this estimation from Statistics Netherlands. The quinquennial evaluation of medical end-of-life decision making in the Netherlands is able to offer an estimation which includes intentionally ending one´s own life through PAD, VSED and other methods. It is worthwhile to complement this estimation through a survey study amongst counsellors and volunteers related to right-to-die organizations, and other caregivers who are involved with someone intentionally ending one's own life. Through these informants an estimate on the amount of deaths that are incorrectly registered as a natural death can be obtained.

c. In addition to obtaining an accurate estimation of the number of people that intentionally end their own life, it is also important to obtain insight into the (medical) situations and reasons why people intentionally end their own life. This can help ameliorate care to prevent someone ending one's own life. Yuill (2015,p100) points out that the exact reasons why someone intentionally ends one's own life remain a mystery.[7] Studies into the reasons or motives are always indirectly inferred, for example through studying associated factors (not allowing causal inferences) or studies involving bereaved intimates or proxies (who are prone to information, interpretation and recall bias). Perhaps this can only be overcome by creating

a more open, less stigmatising approach to people intentionally ending their own life so physicians, caregivers, and significant others can become involved before a person actually intentionally ends one's own life, and become familiar with the reasons leading to the wish to intentionally end one's own life. Recommendations under practice and policy can contribute to this more open and less stigmatising approach.

d. This thesis has included multiple sources of information about assistance in intentionally ending one's own life: physicians, counsellors, and people receiving counselling. The perspective of significant others and bereaved ones of people who intentionally ended their own life, however, is missing. Further research should include this source of information to obtain information about for example whether they were present at the counselling, their experiences with this assistance and their grief process. Furthermore, this thesis has addressed multiple perspectives on intentionally ending one's own life, but the perspectives of people offering this assistance (for example physicians, counsellors, and significant others) are missing. Further research could address the perspective of the physicians providing non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD. This could be explored through surveys and in-depth interviews in the quinquennial evaluation of this Act. For example, the physicians' knowledge about the RDMA position paper concerning their role in the voluntary termination of life by the patient, their conceivability to assist a patient in that manner, and their experiences with it. As physicians are currently often uninvolved in the deaths under research in this thesis, the quinquennial evaluation could be complemented by a survey study and in-depth interviews amongst counsellors and volunteers related to right-to-die organizations and other caregivers and significant offering assistance to someone who intentionally wishes to end one's own life.

Practice

The results from this thesis can be translated into several recommendations for practice.

a. This thesis has shown that not everyone who wishes to end one´s own life can be assisted under the Dutch law on PAD. The first recommendation would be to ameliorate assisting people who wish to intentionally end their own life and fall within the current possibilities of the medical domain. In the past few years several ameliorations have started. For example,

with the founding of the Euthanasia Expertise Centre (originally founded as the End-of-life Clinic) an alternative has become available for patients whose requests are impeded by a bad relationship with their own physician, and a place to turn to when confronted with a refused request by their own physician. Furthermore, several education and support initiatives to ameliorate the practice of physician assistance in dying have come into existence. For example, the Platform Euthanasia and Psychiatry published a guideline to inform psychiatrists (and patients) about all aspects concerning PAD for patients with a psychiatric disorder.[103] An education program for physicians concerning the subject remains necessary.

b. This thesis has also emphasized the importance of physician-patient communication concerning the subject of intentionally ending one's own life. First of all, many of the counselees seeking assistance did not have a current wish to end life but were looking for reassurance. Communication with the physician about future possibilities for the patient concerning the time and manner of their own end of life may satisfy this need for reassurance. Furthermore, how physicians react to enquiries about and requests for PAD can influence patients to seek assistance in intentionally ending one's own life outside the medical practice, and often without further involvement of the physician. Discontinued physician-patient communication on this matter can lead to misunderstandings of physicians that the wish to end life has disappeared and to sub-optimal care because physicians might become uninvolved and are unable to diagnose diseases and offer treatment. Therefore, there is a need for more mutual understanding, respect and empathy for the limitations and possibilities of the position of both the physician and patient in discussing assistance in dying. Initiatives to address this issue have been launched. For example, the KNMG published a brochure for physicians about a timely discussion of the end of life of the patient, which is available as an e-book.[104] Together with several patient's interests advocacy organisations, the RDMA also published a patient version of this brochure to assist patients in discussing the subject of their own end of life.[105,106] Furthermore, the Federation of Medical Specialist has published a guideline about the termination of life on request of patients with a psychiatric disorder which describes how a physician can discuss and judge the wish to end life in a careful manner, but also informs patients about the legal necessities the physician has to fulfil.[103] The RDMA also published guidelines for physicians about their role in the voluntary termination of life of the patient, with specific attention to the importance of keeping the conversation going, and informing the patient.[39,48] This information

contributes to creating a better understanding about the way the legislation is designed and what the physician is and is not able and allowed to do. Still, patients could incorrectly have the conviction they are entitled to PAD, which may cause that physicians feel they are under pressure and patients feel disappointed. Therefore, the need to bring abovementioned brochures to the attention of physicians and patients remains important, for example by displaying them in the physicians´ practice and advising patients to read these brochures. Furthermore, it may be helpful for physicians to realize that patients are often looking for reassurance by having (knowledge about) an option to humanely end life. Incorporating this knowledge in the physicians training program can contribute to this.

c. Studies have shown that physicians are often involved when it concerns the voluntary termination of life by VSED, but this thesis has shown that physicians are often not involved in the voluntary termination of life by MED. When physicians are willing to offer non-punishable assistance to patients who wish to intentionally end their own life outside the Dutch law on PAD, the RDMA position paper on the role of the physician in the voluntary termination of life of the patient offers guidelines.[39] The physician can have conversations about the wish to end life, can offer moral support and can provide general information about methods to end life. As physicians perform a counselling role in these situations, it is worthwhile to inform physicians about positively valued characteristics of this counselling: a careful and open attitude, feeling respected and/or being reminded about one's own responsibility, and having time available. A training and intervention programme to educate physicians in these matters can be helpful.

d. Another option for physicians who are confronted with patients wishing to end life outside the possibilities of the Dutch law on PAD, is to refer patients to organisations that offer non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD. The existence of this practice, however, is under critical review from parliament (which at multiple occasions in history questioned the existence of such assistance and information brochures on the voluntary termination of one´s own life), and the Public Prosecutor (who prosecutes people offering such assistance). A reason for this critical standpoint might be the non-transparent and non-reviewable practice. Referral to or better access to right-to-die organisations like Foundation De Einder should be accompanied by a professionalisation that addresses the issues of the non-transparent and non-reviewable practice, for example

concerning the expertise of assistants involved and the procedures of assisting. Concerning the expertise and review issues of assistants, proposals have been made to educate non-physicians to become involved in end-of-life matters.[21,107] It has been proposed to register these assistants under the law on professions in the individual healthcare. The applicability of the medical disciplinary law would offer an important safeguard.[21,108]

e. Suicide prevention and the zero-suicide approach could be complemented with a suicide-attempt prevention approach from a harm-reduction philosophy. Suicide-attempt prevention agrees upon preventing lonely and desperate suicides, but instead of aiming for zero suicides it aims for zero suicide attempts.[102] This view allows for suicides that are well-considered and do not occur in forced solitariness. It is aimed at openly talking about the wish to end life, and where possible searching for sensible and attainable solutions for unbearable situations. When this is not possible, assistance in suicide can be discussed as well. This suicide-attempt approach could be considered from a harm-reduction point of view. The harm-reduction approach is borrowed from the substance abuse field which recognises that an illegal (or undesired) behaviour exists but cannot be eliminated by legal prohibitions. While not condoning that behaviour outright, these programs seek to provide the means to minimize adverse consequences of that behaviour.[109-111] So when an undesirable behaviour – in this case intentionally ending one's own life – cannot be prevented, it is conducted in a manner that reduces as much harm as possible. This harm can be viewed from three perspectives: the perspective of the person ending one's own life, significant others and involuntarily involved persons. For the person ending one's own life harm can be reduced by being available for conversations to clarify the wish to end life and to help searching for sensible and attainable solutions for unbearable situations. When solutions are not attainable, the focus is on reducing harm and preventing the death occurring in a violent manner, in forced solitariness, impulsively, and without prior openness towards significant others. Secondly, for these significant others harm can be reduced by involving them before the person has intentionally ended his or her own life, so bereaved persons have received the opportunity to understand the situation of the person wishing to end one's own life, share experiences while the person is still alive, and offer the opportunity to say goodbye. Thirdly, providing information on nonviolent ways to end life in consultation with and preferably in

presence of others may prevent that people will choose methods that enhance the number of involuntarily involved people. For example, reducing people witnessing somebody jumping of high buildings or in front of moving objects. Perhaps this suicide-attempt approach could encompass the currently divided fields of suicide prevention, PAD and non-punishable assistance in intentionally ending one's own life outside the practice of PAD.

Policy

The results from this thesis can be translated in several recommendations for policy.

a. Results from this thesis confirm that patients are sometimes confronted with a refusal of their requests for PAD. Requesting PAD might be impeded for various reasons. It also emphasizes that the Dutch law on PAD concerns assistance in dying *in the medical domain*. The conclusions of the quinquennial reports on Dutch medical end-of-life decision making and the Advisory Committee Completed Life state the PAD law functions well, and recommend to hold on to those facets of the well-established practice of the Dutch law on PAD that allows patients to die a "good" death.

b. This thesis showed that very few people without a medical condition who ended their own life were over 80 years old. This seems to confirm the statement from the Advisory Committee Completed Life that the group of older people without an accumulation of problems of old age and without a medical diagnosis who end their own life seems small. [68]. This also questions the necessity for the recent law proposal that would make it possible for people over 70 years old who are tired of life or regard their life to be completed to obtain legal assistance in dying and means to perform their death.[112] Despite the involvement of an end-of-life caregiver and removing the requirement of a medical condition, the proposed law still remains partially in the medical domain as the physician still needs to be involved for distributing the lethal medication. As an alternative, the Advisory Committee Completed Life suggests these people have the option of intentionally ending their own life by VSED or MED. This thesis shows that assistance in the form of moral support and general information about methods to intentionally end one's own life is available for people who wish to intentionally end their own life. While this assistance currently needs professionalisation to address the non-transparent and non-reviewable practice, it does not need any law

reform because it can make use of current case law. However, openness and acceptance are necessary to develop guidelines on how to guarantee the safety, carefulness, transparency and reviewability of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD. This shows parallels with the coming into existence of the Dutch law on PAD where physicians were able to report openly on their assistance in dying when they met requirements that were proposed in jurisdiction. Therefore, it is recommended that the Public Prosecutor refrains from prosecution when assistants have limited their assistance to offering moral support and providing general information, and to create a policy on how to diminish the burden for assistants when the Public Prosecutor has to establish this.

c. The final recommendation for policy resulting from this thesis concerns the recent law proposal to strengthen the approach of suicide prevention.[100] The people who have intentionally ended their own life in this thesis have sought assistance with their intention to end life, have discussed their considerations, and often involved significant others in this process. It is recommended that the Proposal Law for Integral Suicide Prevention also addresses people that intentionally end their own life well-considered and with openness towards and in presence of others. A harm-reduction approach like suicide-attempt prevention could prevent suicide attempts and suicides that are solitary and desperate, but could also provide a good death for people who intentionally wish to end their own life after thorough consideration and in consultation with others.

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Summaries

SUMMARY

The first chapter provides a general introduction to the topic of this thesis: non-punishable assistance in intentionally ending one's own life outside the Dutch Termination of life on request and assisted suicide review procedures Act. The second chapter offers a more detailed introduction of the historical and legal background of assisting someone who intentionally ends one's own life in the Netherlands.

The introduction of Article 294 of the Penal Code in 1886 penalized assistance in suicide, but there are several exceptions to this criminalization. The most well-known exception is the Dutch Termination of life on request and assisted suicide review procedures Act, which excludes physicians from prosecution when they meet all criteria of due care as laid down in the Act. Next, assistance offered during voluntary stopping eating and drinking (VSED) is not regarded as a criminal offence. Last, case law clarified assistance in intentionally ending one's own life is not punishable when this assistance limits itself to having conversations about the wish to end life, offering moral support (including being present on the condition that no active assistance has been offered), and providing general information about methods to end one's own life. Several Dutch right-to-die organisation offer this non-punishable assistance in the form of non-directive counselling.

This thesis aims to (1) clarify which people seek such non-punishable assistance, (2) clarify how seeking such assistance is related to seeking physician assistance in dying (PAD) under the Dutch law on PAD, (3) clarify how counselees experience the assistance they received, (4) describe the incidence and the characteristics of people who have intentionally ended their own life after receiving such assistance, and (5) describe the characteristics of the counselling they received. This thesis also gives an estimate of the number of people who intentionally ended their own life in the Netherlands, and describes their characteristics.

The third chapter provides an estimate of the number of people in the Netherlands that ended their own life through VSED, self-ingesting self-collected medication (MED), and other non-mutilating and mutilating methods. Through a nationwide mortality follow-back study into medical end-of-life decision-making in the Netherlands it is estimated that in 2015, in 0.5% of all annual deaths people ended their own life by VSED, in 0.2% through MED, and in

1.2% by other methods. Estimating the number of people intentionally ending their own life is influenced by differences in interpreting which forms of dying are regarded as “suicide”, which sources of information have been used, and the possibilities of incorrectly registering intentionally ending one’s own life as natural deaths. The third chapter also describes the characteristics of people intentionally ending their own life, based on over 500 cases reported by physicians. Few people who intentionally ended their own life requested PAD, especially those who suffered from solely psychiatric diseases and those without a medical condition. PAD in the Netherlands is primarily embedded in the medical domain as it is currently understood by Dutch law. This raises the question how to address the desire to die from people whose wish to intentionally end their own life is not rooted in a medical condition and therefore fall outside this medical framework of assistance in dying.

The fourth chapter shows the characteristics of people that seek assistance in intentionally ending one’s own life outside the Dutch law on PAD. This chapter presents the results from the cross-sectional questionnaire study of counsellors working with Foundation De Einder on almost 600 counselees they had consulted. Differences in age, underlying suffering, severity of the disease, and the presence and urgency of a wish to end life between counselees are explained by distinguishing two groups of counselees. One group of people were seeking a peaceful death from current suffering. They more often had a severe or terminal disease, were under 65 years old, and had a(n urgent) wish to end life. Another group of people were looking for reassurance to prevent possible future suffering. They more often had no (severe) disease, were over 65 years old, had no wish to end life, and less often had requested for PAD.

The fifth chapter explores the reasons for seeking assistance in intentionally ending one’s own life outside the Dutch law on PAD, and how this is related to seeking physician assistance in dying under this law. This chapter draws data from in-depth interviews with people who received counselling from a counsellor facilitated by Foundation De Einder. It distinguishes three different trajectories that lead people to seek assistance in intentionally ending one’s own life. In the first trajectory, counselees with current suffering (assumed they) were unable to obtain PAD. Either as a result of a refused request, or that requesting PAD was impeded by a disturbed relationship with their physician or by fear of crisis intervention in case of a psychiatric disease. Counselees in the second trajectory sought counselling

as a backup plan for when PAD would not be an option in the case of future prospective suffering. Finally, a group of counselees sought counselling without wanting to opt for PAD – contrary to the counselees in the other two trajectories. As a result of valuing autonomy, self-determination, independence and taking one's own responsibility, they preferred to end their own life. Seeking counselling helped them to prepare this carefully and to prevent or diminish harm to others. Dissatisfaction with physician–patient communication – especially concerning requests for PAD – can result in the physician not being involved in assistance offered by right-to-die foundations, being unable to diagnose diseases, refer to treatment nor offer reassurance that people seem to seek. In general, however, counselees prefer physician involvement under the Dutch law on PAD. This involvement gives the reassurance of a trustworthy, safe and successful performance of death, the unproblematic presence of others, and because of the legitimate and societally acceptable feeling.

The sixth chapter focuses on the content of the assistance, and how counselees experience this assistance. This chapter also uses data from the in-depth interview study. 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, which 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.

The seventh chapter focuses on counselees who have ended their own life after having received non-punishable assistance in intentionally ending one's own life. This chapter draws data from the cross-sectional questionnaire study of counsellors working with Foundation De Einder on almost 300 counselees they had consulted, and who passed away by MED. It is estimated that about one in eight people who seek this non-punishable assistance had intentionally ended their own life. The majority of these counselees had a serious disease, and physical or psychiatric suffering. For the majority the counselling trajectory consisted of one or two face-to-face consultations in addition to several consultations by phone in a period of under one year. The majority involved significant others in the counselling. About two

thirds of the counselees previously sought help with their current wish to end life, primarily with a physician, Right-to-Die Netherlands or a psychiatrist, and half of them had requested PAD. These results show that patients with a denied request for PAD can persist in their wish to end life. It also shows that not all people with an underlying medical disease request PAD. Physicians and psychiatrist are often uninvolved in these self-chosen deaths while they could have a valuable role in the process concerning assessing competency, diagnosing diseases, and offering (or referring to) treatment.

Chapter eight, the general discussion, summarizes the results of the studies and addresses the methodological considerations of the research presented in this thesis. It relates the findings to the overarching themes of the terminology for assistance in dying, physician involvement with people intentionally ending their own life, and the practice of assistance in intentionally ending one's own life outside the Dutch law on PAD. The chapter concludes with implications and recommendations for further research, practice, and policy. Amongst others, it is recommended to further investigate the knowledge of physicians about the Royal Dutch Medical Association (RDMA) position paper concerning their role in the voluntary termination of life by the patient through VSED and MED, their conceivability to assist a patient in that manner, and their experiences with it. Furthermore, an accurate estimation of all people who have intentionally ended their own life is important for monitoring developments in its occurrence. It is therefore suggested to complement the estimation from the quinquennial evaluation of medical end-of-life decision making in the Netherlands with a survey study amongst counsellors and volunteers related to right-to-die organizations, other caregivers and significant others who are involved with someone intentionally ending one's own life. Finally, insight into the (medical) situation of and reasons why people voluntarily end their own life offers valuable information about possibities to ameliorate care to prevent someone ending one's own life. This insight can perhaps only be obtained by creating a more open, less stigmatised approach to people who wish to intentionally end their own life, for example by complementing suicide prevention and the zero-suicide approach – which are aimed at diminishing intentional deaths that are solitary and desperate – with the suicide-attempt prevention approach from a harm-reduction philosophy. This approach allows for those intentionally deaths that are well-considered and with openness towards significant others. While such assistance currently needs professionalisation to address the non-transparent and non-reviewable practice, it does not need any law reform because it meets the criteria of

the current case law. A guideline to contribute to a safe, careful, transparent and reviewable practice of non-punishable assistance in intentionally ending one's own life outside the Dutch law on PAD seems warranted.

SAMENVATTING

Het eerste hoofdstuk introduceert het onderwerp van dit proefschrift: niet-strafbare hulp bij zelfdoding buiten de Wet Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Wtlh). Het tweede hoofdstuk geeft een gedetailleerdere introductie van de geschiedenis en wettelijke achtergrond van hulp bij zelfdoding in Nederland.

De introductie van artikel 294 in het Wetboek van Strafrecht in 1886 heeft hulp bij zelfdoding strafbaar gesteld. Inmiddels zijn er diverse uitzonderingen op deze strafbaarheid. De bekendste uitzondering is de Wet Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Wtlh) welke artsen uitsluit van strafvervolging indien zij voldoen aan alle zorgvuldigheidseisen uit de wet. Ten tweede, is hulp bij het vrijwillig stoppen met eten en drinken (VSED) niet strafbaar. Ten slotte is hulp bij zelfdoding die zich beperkt tot het voeren van gesprekken, het bieden van morele steun (inclusief het aanwezig zijn bij een zelfdoding op de voorwaarde dat er geen actieve hulp wordt geboden) en het verstrekken van algemene informatie niet strafbaar. Verschillende recht-op-waardig-sterven verenigingen bieden dergelijke niet-strafbare hulp bij zelfdoding in de vorm van non-directieve counseling.

De onderzoeksdoelen van dit proefschrift zijn (1) inzicht geven in welke mensen deze niet-strafbare hulp bij zelfdoding buiten de Wtlh zoeken, (2) inzicht geven hoe het zoeken van dergelijke hulp gerelateerd is aan het zoeken naar hulp onder de Wtlh, (3) inzicht geven hoe counselees de ontvangen hulp ervaren, (4) het omschrijven van het aantal mensen en de kenmerken van de mensen die hun leven beëindigd hebben na het ontvangen van dergelijke hulp en (5) het beschrijven van de kenmerken van de counseling die zij ontvangen hebben. Dit proefschrift geeft ook een schatting van het aantal mensen in Nederland die zelf het leven beëindigd hebben en beschrijft hun kenmerken.

Het derde hoofdstuk geeft een schatting van het aantal mensen in Nederland die zelf hun leven beëindigd hebben door middel van VSED, MED en andere niet-verminkende en verminkende methoden. Middels het landelijke sterfgevallenonderzoek naar medische besluitvorming rondom het levenseinde wordt geschat dat in 2015 in 0,5% van de jaarlijkse sterfgevallen mensen hun leven beëindigen via VSED, in 0,2% via MED en in 1,2% via andere methoden. Het schatten van het aantal mensen dat zelf hun leven beëindigt, wordt

beïnvloed door verschillende interpretaties over wat wordt beschouwd als “suïcide”, welke informatiebronnen worden gebruikt en de mogelijkheden voor het incorrect registreren van zelfdodingen als een natuurlijk overlijden. Het derde hoofdstuk beschrijft eveneens de kenmerken van mensen die zelf het leven hebben beëindigd, gebaseerd op meer dan 500 door artsen beschreven gevalsbeschrijvingen. Het blijkt dat weinig mensen die zelf het leven hebben beëindigd hun arts hebben verzocht om hulp bij zelfdoding of levensbeëindiging op verzoek onder de Wtlh. Dit geldt vooral voor mensen met alleen psychiatrisch lijden en mensen zonder een medische aandoening. Hulp onder de Wtlh is voornamelijk ingebed in het medisch domein zoals dat momenteel door de Nederlandse wet en rechtspraak wordt begrepen. Dit roept de vraag op hoe om te gaan met de doodswens van mensen wiens wens het leven te willen beëindigen niet voornamelijk voortkomt uit een medische conditie en daarom buiten het medische raamwerk van de Wtlh vallen.

Het vierde hoofdstuk toont de kenmerken van mensen die niet-strafbare hulp bij zelfdoding buiten de Wtlh zoeken. Het presenteert de resultaten van het transversale vragenlijstonderzoek van counselors die samenwerkten met Stichting de Einder over bijna 600 hulpvragers die de counselors begeleid hebben. De verschillen in leeftijd, onderliggend lijden, de ernst van de ziekte en de aanwezigheid en urgentie van de doodswens tussen hulpvragers wordt verklaard door twee groepen hulpvragers te onderscheiden. De eerste groep is op zoek naar een humane dood om te ontsnappen aan hun huidige lijden. Zij waren vaker jonger dan 65 jaar, hadden vaker een ernstige of dodelijke ziekte en een (urgente) doodswens. De andere groep is op zoek naar geruststelling om mogelijk toekomstig lijden te voorkomen. Zij waren vaker boven de 65 jaar en hadden vaker geen (ernstige) ziekte en geen doodswens en hadden minder vaak hun arts om hulp binnen de Wtlh verzocht.

Het vijfde hoofdstuk beschrijft de redenen voor het zoeken van niet-strafbare hulp bij zelfdoding buiten de Wtlh en hoe dit gerelateerd is aan het verzoeken om hulp binnen de Wtlh. Dit hoofdstuk beschrijft gegevens uit diepte-interviews met mensen die niet-strafbare hulp bij zelfdoding ontvingen van counselors die samenwerkten met Stichting de Einder. Het hoofdstuk onderscheidt drie wegen die ertoe leidden dat mensen hulp bij zelfdoding buiten de Wtlh zoeken. In het eerste traject slaagden mensen met huidig lijden er niet in om hulp onder de Wtlh te verkrijgen, of dachten dit niet te kunnen verkrijgen. Dit was het gevolg van een geweigerd verzoek om hulp onder de Wtlh, of omdat het doen van een verzoek

werd bemoeilijkt door of een slechte relatie met de arts of de angst voor crisisinterventie in het geval van psychiatrische aandoeningen. Mensen in het tweede traject zochten een back-up plan voor wanneer hulp onder de Wtlh niet mogelijk zou blijken in geval van mogelijk toekomstig lijden. Ten slotte zocht een andere groep mensen met prospectief lijden de niet-strafbare hulp bij zelfdoding zonder een voorkeur voor hulp onder de Wtlh – in tegenstelling tot de mensen in de andere twee groepen. Naar aanleiding van het gehechte belang aan autonomie, zelfbeschikking, onafhankelijkheid en het nemen van iemands eigen verantwoordelijkheid, gaven zij de voorkeur aan zelf hun leven te willen beëindigen. De counseling bood hun de mogelijkheid dit zorgvuldig voor te bereiden en schade voor anderen te beperken. Ontevredenheid met de communicatie tussen arts en patiënt – vooral met betrekking tot een verzoek om hulp onder de Wtlh – kan ertoe leiden dat de arts niet betrokken is bij de niet-strafbare hulp bij zelfdoding die wordt geboden door recht-op-waardig-sterven organisaties. Dit leidt ertoe dat zij geen diagnoses kunnen stellen, geen behandeling kunnen voorstellen, noch de geruststelling kunnen bieden die mensen lijken te zoeken. In het algemeen hebben counselees echter een voorkeur voor de betrokkenheid van de arts binnen de mogelijkheden van de Wtlh. Dit biedt de geruststelling van een betrouwbare, veilige en zekere uitvoering van het sterven, de aanwezigheid van naasten zonder juridische problemen en een rechtmatig en sociaal geaccepteerd gevoel.

Het zesde hoofdstuk richt zich op de inhoud van de niet-strafbare hulp bij zelfdoding buiten de Wtlh en hoe counselees deze hulp ervaren. Dit hoofdstuk maakt ook gebruik van gegevens uit de diepte-interviews. De counseling varieerde van het alleen ontvangen van informatie over dodelijke medicatie tot het combineren hiervan met psychologische counseling over leven en dood en de gevolgen voor naasten. Counselees waardeerden de beschikbaarheid van de counselor, hun zorgvuldige en open houding, het gevoel gerespecteerde te worden en herinnerd te worden aan hun eigen verantwoordelijkheid. Sommige counselees voelden zich afhankelijk van de consulent of stelden vraagtekens bij hun competentie. De meeste mensen hadden dodelijke middelen verzameld. Dit gaf hun een gevoel van geruststelling en vergrootte de kwaliteit van hun leven. Het leidde echter ook tot nieuwe zorgen. Weinig mensen hadden de intentie hun zelf verzamelde dodelijke middelen te gebruiken. De begeleiding droeg bij aan het denken over of, wanneer en hoe mensen hun leven zouden willen beëindigen.

Het zevende hoofdstuk richt zich specifiek op mensen die hun leven daadwerkelijk beëindigd hebben na het ontvangen van niet-strafbare hulp bij zelfdoding buiten de Wtlh. Het hoofdstuk maakt gebruik van gegevens uit het transversale onderzoek van counselors die samenwerkten met Stichting de Einder over bijna 300 mensen die de counselors begeleid hebben en die hun leven beëindigden door MED. Naar schatting beëindigde één op de acht counselees zelf hun eigen leven. De meerderheid van deze mensen hadden een ernstige ziekte en fysiek of psychiatrisch lijden. De begeleiding bestond meestal uit één tot twee persoonlijke gesprekken aangevuld met meerdere (telefonische) contacten binnen een periode van minder dan een jaar. De meerderheid had naasten betrokken. Tweederde van de counselees hadden eerder hulp gezocht met betrekking tot hun huidige doodswens, voornamelijk bij een arts, de NVVE of een psychiater. De helft had hun arts verzocht om hulp binnen de Wtlh. Deze resultaten tonen aan dat mensen met een afgewezen verzoek om hulp binnen de Wtlh kunnen blijven persisteren in hun doodswens. Artsen en psychiaters zijn vaak niet betrokken in deze zelfgekozen dood, terwijl zij een belangrijke en waardevolle rol hebben in het proces met betrekking tot het vaststellen van de wilsbekwaamheid, het diagnosticeren en het bieden van (of doorverwijzen naar) behandeling.

Het achtste hoofdstuk, de algemene discussie, vat de resultaten samen, bespreekt de methodologische overwegingen van de in dit proefschrift gepresenteerde onderzoeken en relateert deze resultaten aan de overkoepelende thema's van de terminologie voor hulp bij zelfdoding, de betrokkenheid van artsen bij het zelfgekozen levenseinde en de praktijk van niet-strafbare hulp bij zelfdoding buiten de Wtlh. Het hoofdstuk eindigt met verscheidene implicaties en aanbevelingen voor toekomstig onderzoek, de praktijk en beleid. Onder andere wordt voorgesteld om onderzoek uit te voeren naar de kennis van artsen over het KNMG-standpunt met betrekking tot niet-strafbare hulp bij zelfdoding buiten de Wtlh, hun bereidheid om deze hulp aan patiënten te bieden en hun ervaringen met dergelijke hulpverlening. Verder is het belangrijk een accurate schatting te hebben van mensen die zelf het leven beëindigen om zodoende ontwikkelingen in het voorkomen in kaart te kunnen brengen. Daarom wordt voorgesteld om de schattingen uit het vijfjaarlijkse evaluatieonderzoek naar medische besluitvorming rondom het levenseinde onder artsen uit te breiden met een onderzoek onder betrokkenen bij een zelfgekozen levenseinde, waaronder counselors, consulenten en vrijwilligers die betrokken zijn bij recht-op-waardig-sterven verenigingen, andere zorgverleners en naasten. Ten slotte is het van belang inzicht

te verkrijgen in de onderliggende (medische) situatie en de redenen waarom mensen hun eigen leven beëindigen. Dit biedt de mogelijkheid zorg te verbeteren om te voorkomen dat mensen hun leven willen beëindigen. Dit inzicht kan misschien alleen worden verkregen door een meer open en minder gestigmatiseerde benadering voor mensen die zelf het leven willen beëindigen. Bijvoorbeeld door de suïcidepreventie en de "zero-suicide" benadering – gericht op het verminderen van eenzame en wanhopige zelfdodingen – aan te vullen met de suïcide*pogingen*preventie vanuit een "harm-reduction" filosofie. Deze benadering biedt ruimte voor weloverwogen zelfdodingen in openheid naar anderen. Alhoewel de huidige hulpverlening vraagt om professionalisering van deze niet-transparante en niet-toetsbare praktijk vereist het geen wetswijzigingen, omdat dergelijke hulpverlening valt binnen de huidige jurisprudentie. Een richtlijn om bij te dragen aan een veilige, zorgvuldige, transparante en toetsbare praktijk van niet-strafbare hulp bij zelfdoding buiten de Wtlh lijkt daarvoor nodig.

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Besides all the support from this more professional side, writing a thesis also requires a lot of support in personal life. As remarked upon in the prologue, writing this thesis formed quite an essential part of my life for the past ten years. Although I've always strived not to let work take priority over those aspects in life that are most precious to me: my family, my friends, my dearest ones. I am thankful for the special moments I have shared with you, especially those completely unrelated to this thesis: thank you for your being, and your presence in my life. I'd like to thank those people for their support, their interest in the subject of my work (even after all these years) and their inspiration: Denise (for your greatest inspiration, energy, enthusiasm, and love…true love), Jack (for your appreciation and precious conversations and questions during beautiful walks), Shirley (for all your support and care, food, money, baby/toddler-sitting time that enabled me to finish this thesis), Bas (for your love and support, and our impressive teamwork to form our lives the way we do, the cups of tea, scones and lunches to revive me and keep me focussed), Sanne (for creating a love I never knew, and making me realize to remain marvelled and amazed), Alvaro (para tu amistad y que soy capaz de explicar muchas cosas de mi vida en Español, incluido el tema de este tesis), Gerard (for providing me with the best holiday and writing location in the Netherlands besides home), Mathieu and Brenda (for providing me with the best holiday and writing location abroad, and your always warm and kind hospitality), Meine Willem and Martien (for that welcoming stepping stone), Russel and Sylvan (for good company during conferences, and inspiring me to continue in this research field), and all those I have not mentioned personally by name here but whose interest, whose questions, whose conversations, whose discussions, and whose appreciation stimulated me to continue.

About the author

Martijn Hagens (1978) graduated in Developmental and Social Psychology from the University of Amsterdam with specialisations in Clinical Neuropsychology, Psychogerontology, Social psychology, and Behavioral Science Training. He has worked as a Clinical Neuropsychologist in a nursing home, as a trainer in Professional and Personal Communication Skills at the University of Amsterdam, and as a trainer for volunteers at the Academy for Volunteers in Amsterdam before starting his own company The Good Life's End (TGLE). TGLE specialises in training, counselling and research with a focus on matters related to life's end. For several years, TGLE worked in cooperation with Foundation De Einder to counsel people who seek assistance in their wish to self-determine the time and manner of their own death, and to offer training to counsellors. From 2012 to 2020 he was part-time employed at the VU Medical Center (Amsterdam UMC) as a junior researcher to work on this parttime PhD project that focusses on non-punishable assistance in intentionally ending one's own life outside the Dutch Termination of life on request and assisted suicide review procedures Act. He combined these professional endeavours with personal ones that over the past ten years included being a proud stay-at-home-as-much-as-possible father, raising a beautiful daughter, organising an amazingly beautiful wedding, being a loving partner, being an involved parent for his children, taking part in many primary school activities, creating film projects, renovating houses, combining walks with the dogs with icemannic challenges, organising memorable dance parties, proudly assisting in the organisation of the first Pride family boat, being available for precious beloved ones, raising six puppie dogs, travelling the world, enjoying the beauties that Mother Nature has to offer, and taking efforts to take good care of her.

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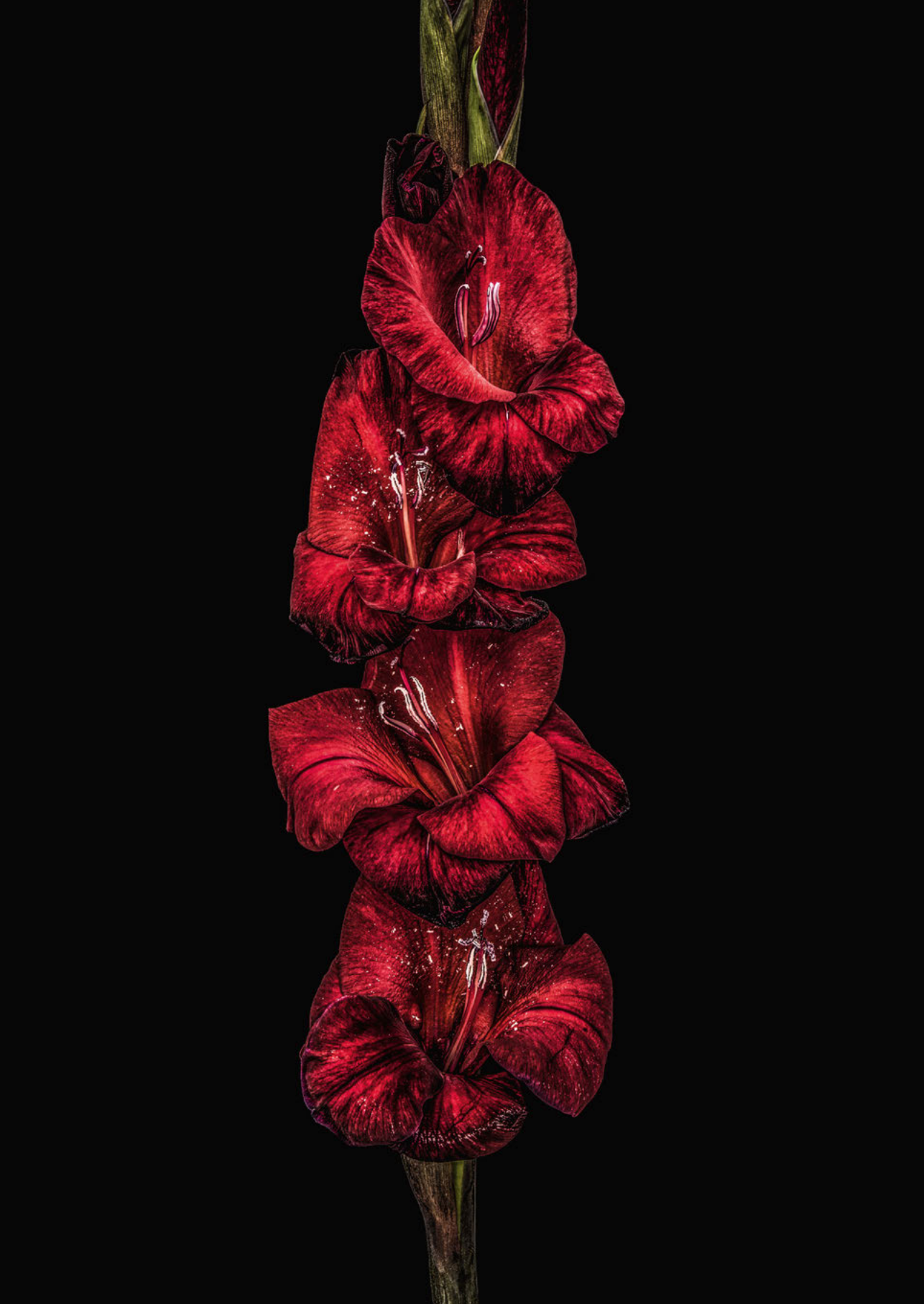

Appendices and supplementary files

APPENDIX 1

Description of and terminology for intentionally ending one's own life

Intentionally ending one's own life is usually referred to as suicide. Suicide is generally believed to come from the Latin *suicidium* (from *sui* = oneself and *cidere* = killing).[1,2] However, other sources believe the word "suicide" is a modern Latin formation on an English neologism (from self-homicide), which only came in use in the 17th century. It originated under the influence of Enlightenment when denunciation of the deed gradually gave way to empathy for the doer; as a term that does not initially imply a negative evaluation. [1-5]

The definitions of suicide usually do not refer to a certain method nor any distortions in thinking or the decision-making process. Amongst the many definitions for suicide are shorter ones like "the act of intentionally causing one's own death",[6], "the act of killing yourself intentionally, or a person who has done this",[7] and "the act of intentionally taking one's own life".[8] More elaborate definitions are "an act with fatal outcome, initiated by the deceased, resulting in death in the expectation of a fatal or possibly fatal outcome, with the intention to achieve desired changes",[9,10] "intentionally ending one's own life, irrespective of circumstances, intentions or causal manners to reach that goal",[3] and "the deliberate termination of one's own life by self-initiated, potentially injurious behaviour; with the intent to die; with a fatal outcome resulting in death".[11]

Over the years, in general opinion and in scientific research, suicide is often characterized as a symptom of depression, insanity or psychiatric disorders, and associated with violent methods, like hanging oneself or jumping from great heights or in front of moving objects. This can be regarded as the public image of paradigmatic cases of suicide.[12] Other terminology to describe intentionally ending one's own life exists, and this terminology often emphasizes some of the features that became associated with suicide, for example how the intention to end life evolved or which method of bringing about death is used, as well as which assistance preceded death and who offered this assistance. Several examples in alphabetical order are:

Auto-euthanasia is described by Glaser & Strauss in 1965 as "to die 'gracefully' […] to manage his own death, to arrange a painless, easy departure".[13] The word *autothanasia* and *autothanatos* can be traced back to the first century A.D.[1] Van Tol (1977) refers to it as 'choosing a well-considered (peaceful) death over a (cruel) life or life's end" and also distinguishes "passive auto-euthanasia" when someone refuses to eat.[14] In later works he regards it as synonymous to "balance suicide".[15]. Chabot (2007) defines auto-euthanasia by four characteristics: (1) the deceased has had conversations with at least one confidant about the why, when and how of the wish to end life and the method of ending one's own life, (2) the deceased was – according to the confidant – able to make decisions (decisive and competent) and was able to understand that death would be the result of performing the decision, (3) the deceased passed away through a method which did not mutilate the body, and (4) the deceased had the control over ending one's own life.[16]

Balance(-sheet) suicide focusses on the decision-making part. It is first coined by Hoche (1918) as a suicide resulting from "a cool and clear deliberation of the pros and cons in the absence of a psychic disorder".[17,18] Van Tol (1986) defines it as "the well-considered ending of an unacceptable and as meaningless experienced life by the autonomous human being; the human being who in terms of their mental state of mind is considered to be fully able to oversee their own psychic and social situation, and the societal consequences of their intended death".[18] Kerkhof & Van Luyn (2010) define a balance suicide (1) of which the intention to suicide developed in a long-lasting process of positive and negative evaluations of one's own existence, (2) being convinced in all reasonability no amelioration of the situation is to be expected, (3) consultation with a physician, psychologist, psychiatrist or confidant, and (4) possible bereaved ones are prepared for or protected against possible negative effects.[10]

Dignicide refers to the dignified self-taking of life that is (1) quiet and peaceful, (2) accomplished with the family aware, often in support and present, (3) thoughtfully planned, usually with the help of others and (4) the result of a rational logical plan.[19]

Dysthanatic suicide concerns a death (1) that is an escape from a pressing situation, (2) that is (also) the clear result of disfunctioning of others or institutions related to person ending his or her life (3) where the person ending his or her life shows an ambivalence towards death and suicide, changing as a result of circumstances, (4) where alternatives for suicide have not been explored and discussed extensively and repeatedly with relevant others, (5) where relevant others or institutions knew or should have known that suicide was a repetitively considered option.[20] "*Eu thanatos*" is seen as a value judgment that refers to the quality of death, and hence can also be applied to suicide, which can be considered "good" or "bad".[20]

Euthanasia literally means a "good death", from the Latin "*eu*" (good) and "*thanatos*" (death). It is most often used to describe "the termination of life by the physician on the request of the patient". It is included in this overview of intentionally ending one's own life, as in the Netherlands physician assistance in dying (PAD) under the Dutch Termination of life on request and assisted suicide review procedures Act is often referred to as the "Euthanasia Law". This law also includes physician assistance in suicide.[21] Furthermore, it is argued that because the intention to end one's own life lies with the patient, the termination of life by the physician *on the request of the patient* might as well be regarded as suicide.[22]

Euthanatic suicide is a death (1) that is desired and carried out by the person oneself, (2) that is not the result of disfunctioning of persons or institutions the persons dealt with in the period prior to the suicide, (3) for which the person has a durable wish to end life (4) for which the alternatives for suicide have repetitively and extensively been the subject of discussions between the person and relevant others, (5) performed in a desired manner and safe for others.[20] "*Eu thanatos*" is seen as a value judgment that refers to the quality of death, and hence can also be applied to suicide, which can be considered "good" or "bad".[20]

Family (or Relative) assisted suicide refers to a suicide in which family members or relatives have assisted.[23-27]

Lay assisted suicide refers to suicides where assistance is offered by non-medical professionals (lay persons). This terminology also includes the situation where a member, volunteer or employee from a right-to-die organisation is the assistor.[23] Also referred to as *laicide*.[28]

Medicide is defined as a death after a medical decision. It not only refers to physician assisted suicide but to all decisions in which physicians are involved that have the effect of a shortening of life. The term emphasizes the responsibility of the actor.[28,29]

Mutilating suicides are suicides that mutilate or pain the body as a consequence of the method used, e.g. jumping from high buildings or in front of moving objects, hanging, shooting, drowning or swallowing (agricultural) poison. Often these methods occur in solitariness or pose a threat to bystanders or people present.[16] In combination with impulsivity these deaths influence the public image (paradigmatic cases) of suicide.[12]

Non-mutilating suicides are suicides that leave the body physically intact, and lead to death after an intermediate phase of deep sleep. Examples may be voluntary stopping eating and drinking with appropriate palliative care, self-ingesting self-collected lethal medication (e.g. barbiturates), inhalation of inert gases, sleeping pills in combination with a plastic bag (suffocation).[16]

Non-physician-assisted suicide refers to a suicide which is assisted by someone other than a physician (for example a relative or right-to-die activist).[30-33] It also distinguishes it from physician-assisted suicide conforming to a legal regulation. In this latter sense, the term can be rather confusing because physicians can also assist in a suicide outside legal regulations (becoming non-physician assisted suicide by physicians).

Non-violent suicides are suicides that use a non-violent method – which contrary to violent methods – results in less visible and external damage to the body.[34] This generally concerns the following codes from the International Statistical Classification of Diseases and Related Health Problems ICD-10 of the World Health Organization: poisoning (X60-65), and inhalation of gases and vapours (X66-67).[34-36] This is, however, rather arbitrarily chosen,[37] as some authors include only poisoning,[38,39] and others also include drowning.[37,40-42]

Physician-supported accompanied suicide refers to an assisted suicide in Switzerland whereby a physician assesses the competency of the patient who wishes to intentionally end life, and provides the lethal medication. The accompaniment refers to the role of the employees of right-to-die organisations that accompany and support rather than assist the patient.[43]

Physician-assisted suicide (or *doctor-assisted suicide*) refers to the voluntary termination of one's own life by self-administering of a lethal substance with the assistance of a physician. Usually it describes the practice under a legislation that allows a physician to assist in suicide by legally prescribing and/or providing lethal medication, e.g. the Dutch Termination of life on request and assisted suicide review procedures Act.[21] However, theoretically it can also refer to the voluntary termination of one's own life by a patient facilitated by information (such as an indication of a lethal dosage) provided by a physician aware of the patient's intent.[44].

Rational suicide focuses on the rationality of the decision instead of the suicide being impulsive, hastily and not carefully thought through. A rational suicide results from a rational decision to terminate one's life based on a realistic assessment of one's own situation, which is unimpaired by psychological illness or severe emotional distress.[45] Werth (1999) describes it as "that following a sound decision-making process, a person has decided, without being coerced by others, to end his or her life because of unbearable suffering associated with terminal illness".[46] According to Battin (1999) there are five crucial criteria to determine whether a suicide might be rational: (1) ability to reason, (2) realistic world view, (3) adequacy of information, (4) avoidance of harm, and (5) in accordance with fundamental interest.[47] Opponents to the term rational suicide sometimes regard the combination of suicide and rational as an oxymoron, because suicide is regarded as an immoral act, a behaviour performed by a mentally ill individual or a tragedy for the survivors and society.[46]

Self-chosen death (or *self-determined or self-directed death*) refers to an intentional choice to end life at a self-appointed time.[48,49] In the Dutch debate, it not only refers to the voluntary termination of one's own life (the autonomous route; also referred to as self-euthanasia), but also to the voluntary termination of life under the Dutch Termination of life on request and assisted suicide review procedures Act (the medical route) and the voluntary termination of one's own life with dying assistance performed by so-called counsellors in dying (the caregivers route), which is not permitted in the Netherlands.[50]

*Self-directed dying in dignit*y refers to the intentional act of a person independently ending one's own life in a humane way outside the medical domain.[51]

Self-euthanasia is termed to make an explicit distinction with euthanasia (voluntary termination of the life of the patient by the physician) and a suicide that is associated with self-harm and/or incapacity in the sense of lacking decision-making capacity. It is defined as a dignified, careful or humane end of life after consultation with others, which is self-chosen, results from an effective method without adding pain or suffocation, and preferably with others present.[52] According to Vink (2013,2016) it refers to "the deliberate termination of one's own life by the person himself, under his own control, after clear and careful consideration, and carried out with due care." Vital constituents are that the death is self-performed and self-determined.[53,54] This self-requested, self-performed and self-determined death can be regarded as a good death when the death is (a) decidedly self-chosen after clear and careful consideration (b) in which the individual's role is as large as possible (c) carried out with the utmost care and without adding pain or suffering (d) not executed in forced loneliness, (e) if at all possible, prepared in contact with loved ones (f) considered (given the circumstances) as dignified, and (g) accepted by the individual in peace and quiet.[53,54].

Self-homicide is a term used by John Donne to refer to "a suicide that is not regarded as intrinsically morally abject".[1,3]

Self-killing (in Dutch: *zelfdoding*) is coined to remove the judgmental element that is inherent to self-murder.[3] Also described as "to remove oneself hastily from life" and to replace the rigid "self-murder".[1]

Self-murder (in Dutch: *zelfmoord*) refers to a suicide that is regarded as morally reprehensible, that a suicide is condemnable.[1] It contains a negative judgement and a condemnation, and is only useful in a community where both hearer and speaker share this negative evaluation of the voluntary termination of one's own life. [3] According to Chabot (2019) it is popular use for a bad suicide which is usually characterized by impulsivity, loneliness, mutilating methods, and a disaster for bereaved and involuntarily involved (e.g. train drivers).[52] The use of self-murder is discouraged because of the strong negative moral judgement, and the differences in circumstances, precursors and psychological motives between murder and suicide.[10] According to Vink the

term is intrinsically contradictory as “murder” refers to taking a life that is not yours, so you can only murder another, not yourself.[55]

Violent suicides are suicides that use a violent method which results in (more) visible and external damage to the body.[34]. In general, this concerns deaths as a result of the codes X60-X84 of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) of the World Health Organization: hanging, strangulation and suffocation (X70), submersion and drowning (X71), firearms guns and explosives (X72-75), smoke, fire or hot objects (X76-X77), cutting and piercing (X78), stomp object (X79), jumping from great height (X80), jumping or lying in front of a moving object (X81), intentional accident with a motor vehicle (X82), and other or unspecified methods (X83-X84).[34-36,38] Some researchers exclude drowning.[40-42], and some include gas poisoning.[39]

APPENDIX 2

Right-to-die organisations in the Netherlands

In the past decades, several Right-to-Die organisations have come into existence in the Netherlands. These organisations have in common that they work for the right to die in a dignified, peaceful or humane way at a time of one's own choice.

Right-to-Die Netherlands (Nederlandse Vereniging voor een Vrijwillig Levenseinde; NVVE)

In 1972, the prosecution of general practitioner Postma-van Boven moved several of her patients to found a "pro-euthanasia task force", the Dutch Task Force Voluntary Euthanasia.[56] The task force continued as Right-to-Die-Netherlands (NVVE). The aim of this foundation was "social acceptance and legalization of voluntary euthanasia".[56,57] They primarily acted as a patients' interest organisation, with a great influence in the public and political debate through lobbying.[57] Furthermore, the foundation supported physicians, while their Member Support Service (later Advisory Centre) supported people who experienced problems concerning the voluntary ending of their own life. They primarily regarded it as their task to provide a listening ear, to mediate between patients and physicians, provide models of living wills and refer to physicians willing to terminate the life of the patient at the patients request when the patients' own physician was unwilling.[57] This resulted in several court cases by Right-to-Die Netherlands-mediated physicians, for example Mulder-Meiss (1992-1995) and Chabot (1993-1995) (see Appendix 5).[57] Since 1991, they added the societal acceptance and legalisation of assistance in suicide to their aims.[57] Initially with reluctance, they also provided practical assistance in suicide according to the principle to mediate in obtaining a "peaceful death", but not providing the actual means thereto. This also led to court cases involving Right-to-Die Netherlands consultants, for example Cornelisse (2002) (see Appendix 5). Currently, besides the possibility to speak to a volunteer (consultant) according to a member-to-member principle, they also provide a member-only-access website with information on methods to end life that are quick, free of pain, non-mutilating and with as little burden for others.[58] Currently, it is the largest right-to-die organisation in the Netherlands and worldwide with over 170,000 members.[59].

Foundation Voluntary Euthanasia (Stichting Vrijwillige Euthanasie, SVE)

In 1973, just prior to the start of Right-to-Die-Netherlands, Foundation Voluntary Euthanasia (Stichting Vrijwillige Euthanasie; SVE) was founded. An old gentleman raised a fund to enable people to "deal with the euthanasia problem".[57] SVE can be regarded more as a conversation centre.[56] Contrary to the Right-to-Die Netherlands, they are not in favour of legal changes. To their opinion a solution had to be found by the judicature and not the legislator.[57] After the acquittal in the Schoonheim court case, their goal had been reached and the foundation was disincorporated.[57]

Voluntary Euthanasia Information Centre (Informatiecentrum Vrijwillige Euthanasie)

In 1976, the couple Sybrandy left Right-to-Die Netherlands and founded a new organisation: the Voluntary Euthanasia Information Centre. Besides striving for societal acceptance and legalizing euthanasia, they also openly provided information to people about the way they could end their own life themselves.[56,57] For example about the "plastic-bag-method", which gained publicity through their book "Will you take care I won't wake up anymore? Voluntary euthanasia in practice".[60] A judicial investigation was started after providing information on medication to end life in the Centre's news bulletin (*Euthanatos*) and two complaints by bereaved family members. The case was subpoenaed as the couple Sybrandy sufficiently warned about the consequences before offering information on intentionally ending one's own life, and only providing general information was not enough for a punishable offence.[56,57,61]

Foundation De Einder (Stichting de Einder, SDE)

In 1995, Foundation De Einder was founded with the aim to help people with a wish to end life by referring them to independent consultants who provide counselling to be able to self-determine the time and manner of ending one's own life.[62] Foundation De Einder-Noord was a split-off foundation that focussed on requests for help in the Northern part of the Netherlands. It only existed briefly between 1999 and 2001 and was disincorporated as a result of the Muns court case. Foundation De Einder describes the work of the consultants they work with as non-directive counselling. This counselling consists of having conversations, offering emotional and psychological support and providing general information on non-mutilating methods to end life. The counselling is aimed at creating as much clarity as possible regarding the wish to end one's own life and possible self-directed death. This covers the psychological process of decision-making and might include matters like considering alternatives, time of death, and consideration of others. In the situation the counselee decides to act upon the wish to end life, the counselling is aimed at realising the best possible preparations for the self-directed death. This covers information about the practical preparation and might include information about gathering means for and the effectuation of the self-directed death. The counselling is not aimed at a specific choice or outcome, 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 life. In this aspect, it differs from suicide prevention organisations that aim to prevent a suicide instead of regarding it as a possible outcome of the intervention.[55,62] The founder and several counsellors have been brought to court: Muns (2002-2005), Hilarius (2005-2008) and Vink (2007) (see Appendix 5).

Foundation for Voluntary Life (Stichting Vrijwillig Leven, SVL)

In 1996 Foundation for Voluntary Life (Stichting Vrijwillig Leven – SVL) was founded as a split-off foundation of Right-to-Die Netherlands. It aimed for legal recognition for the right to a self-chosen end-of-life and to obtain means to make this possible in a dignified way. It strived to establish support centres where people could receive advice, assistance and means to self-determine their own end-of-life, and where physicians could turn to for advice, consultation from other physicians and referral of their patients.[57,63] A court case against the chairman of the foundation, Schellekens, and the foundation itself resulted in the abolishment of the organisations in 2015 (see Appendix 5).

Exit International

Exit International was founded in 1997 by the Australian physician Philip Nitschke. Currently, it has offices in Australia (head office), the United States, Ireland and the Netherlands. Their mission is to inform members and support them in their end-of-life decision making from the perspective that it is a fundamental human right for every adult of sound mind to be able to plan for the end of their life in a way that is reliable, peaceful and at a time of their choosing. They first published The Peaceful Pill (e)Handbook in 2006, which was translated into Dutch in 2018. They do not offer individual counselling, but do offer workshops for those aged over 50 years old, who are of sound mind and/or who are seriously ill. These workshops are based on their published book and discuss the more practical aspects of end-of-life choices.[64]

Foundation for Research into a Humane Self-chosen Death (Wetenschappelijk onderzoek naar zorgvuldige zelfdoding; WOZZ Foundation)

In 2000, this foundation was founded with the central aim "to promote scientific research into a humane self-chosen death, planned and carried out in a careful manner by the individual without substantial help from others".[65] Amongst the founders was Piet Admiraal, the publisher of the first Dutch guide on methods for a self-chosen death in 1980, "Responsible euthanasia. A guide for doctors."[66] In 2001, the foundation established a research committee with the task to "draw up a concise overview of drugs suitable for humane self-chosen death and describe the necessary steps to ensure a humane death with these drugs. This information must be scientifically based and make full use of the present state of toxicological and pharmaceutical knowledge." It resulted in the publication of a Dutch and English guide to a humane self-chosen death that described several methods to end life.[65,67] The information was primarily intended for physicians, and for professional assistors or volunteers of right-to-die societies who are consulted by people wishing to end their lives in a humane and careful way.

Foundation Dignified Dying (Stichting Waardig Sterven, SWS)

Foundation Dignified Dying was founded in 2011 by Boudewijn Chabot and Stella Braam, the authors of the book "A way out. A dignified end-of-life under own autonomy."[68] This book describes several methods to intentionally end one's own life. The aim of the foundation is "to distribute reliable and accessible information about a humane end-of-life under own autonomy and in conversation with others."[69] Besides the book, the foundation also produced a movie about the Helium method.[70]

Cooperation Last Will (Coöperatie Laatste Wil, CLW)

Cooperation Last Will (CLW) was founded in 2013 after an idea from a task force within Right-to-Die Netherlands (NVVE). CLW focusses on the so-called "autonomous route" which allows people to choose for a self-chosen death under own autonomy through a humane last-will remedy that can be obtained legally. Instead of being a foundation, the cooperation is focussed "to provide in the material needs of her members". The aim is to distribute a last-will pill (or powder) to her members.[71] They sought publicity with practical plans to do so. A criminal investigation by the public prosecutor into the activities of the foundation resulted in a warning that while striving for legalising a last-will means is not forbidden, they act in a grey area with their published guide (see Appendix 5). For individual counselling they refer to other right-to-die organizations in the Netherlands. In 2021, they started a lawsuit (together with thirty-three citizens) against the Dutch state to legalise assistance in suicide following recent German and Austrian verdicts that acknowledge the right to self-determination of the European Convention on Human Rights.[72] In 2021, the Dutch Public Prosecutor started an investigation into the deliverance of a powder to intentionally end one's own life by a member of CLW.[73] In 2021, the chairman of Cooperation Last Will was arrested on suspicion of participating in a criminal organisation that has the objective to commit and/or plan the crime of assistance in suicide.[74]

Foundation End-of-Life Counselling (Stichting LevenseindeCounselling, SLC)

Foundation End-of-Life Counselling was founded in 2015 by several counsellors formerly working in cooperation with Foundation De Einder. The aim of the foundation is (1) to discuss or perform a careful and well-considered humane end-of-life which is complementary to or an alternative for medically organised end-of-life counselling, and (2) support the discourse in society about self-euthanasia (a careful and well-considered humane end-of-life under own responsibility and own autonomy).[75] People seeking for assistance can contact a professionally skilled end-of-life counsellor who offers non-directive, clarifying and (general) informative conversations.[76]

APPENDIX 3

Overview of "key judgments" contributing to the forming of (the practice of) the Termination of life on request and assisted suicide review procedures Act

Postma-Boven (1973)
A 78-year-old nursing home occupant who was physically seriously ill and suffered amongst other ailments from a half-sided paralysis, incontinence, and pneumonia expressed her wish to end her life to her treating physician and family members. The treating physician was not willing to help, after which her daughter, Mrs Postma-Boven, a physician, ended her mother's life by injecting a lethal dose of morphine. The physician was sentenced to one-week imprisonment with a probation period of one year seen the "purity of her motives". Contrary to the judgment of the court in 1952 – when a Dutch physician appeared before court for the first time for violating Article 293 of the Penal Code and it was decided not to be the task to create grounds for a legal exclusion – in the Postma court case the judge formulated conditions about in which circumstances it could be justified to terminate life on request of the patient.[77,78] These conditions were (a) the patient was sick because of an incurable illness or disease, (b) the physical or mental suffering was subjectively serious and unbearable for the patient, (c) the patient had clearly expressed the wish to end life or be relieved from his or her suffering, and (d) the treating physician (or another physician in consultation with the patient) had ended the life of the patient.[79] The Lower Court had specifically not mentioned the necessity of the dying phase of the patient, so non-terminal patients could also obtain this assistance from a physician.[50,57,80]

Wertheim (1981)
While this case did not concern a physician (and is described in more detail in Appendix 4 on assistance by significant others), it is important to mention in this section because the Lower Court of Rotterdam ruled with general guidelines that in exceptional cases assisted suicide should not necessarily be unacceptable. The Court also held that for the person wishing to end one's life (as well as for their significant others) it is important that there are possibilities to intentionally end life in a non-violent way. In general, this presupposes help of another person. Therefore, the court added the following requirements to the Postma verdict: (1) the decision to assist should not be taken by one person, (b) the lethal drugs should always and only be described by a physician, (c) the physician should make a good prognosis and adequately inform the patient about alternatives.[50,57,80,81,82]

Schoonheim (1983-1986)
A 95-year-old disabled and bedridden woman had repetitively, during a decade, requested her physician, Mr. Schoonheim, to end her suffering. The week preceding her death her situation deteriorated. After pronouncing again she did not wish to experience such a situation, her physician granted her wish and ended her life. The physician reported the termination of life on request of the patient. Initially, he was dismissed from prosecution in Lower Court but found guilty without punishment in Higher Court.[83,84] The Supreme Court held that the invocation of a situation of "force majeure" (or necessity) – resulting from a conflict of duties – was justifiable when the physician (a) carefully balanced the duty to alleviate hopeless suffering and the duty to preserve the patient's life, (b) acted according to the norms of medical ethics and medical-professional standards, and (c) made a decision that objectively seen was justified, taking into account the exceptional circumstances of the case. Factors that could play a role were further decline of already unbearable suffering, not being able to die in a dignified manner and possibilities to alleviate the suffering.[85] The Higher Court of The Hague concluded that Schoonheim had reasonably come to the conclusion the suffering of the patient was unbearable, that no other possibilities were available to relief her suffering, that he acted in a situation of "force majeure", and he therefor was acquitted.[50,57,80,86]

Chabot (1993-1994)
A 50-year-old woman lived a life full of sad and traumatic events, amongst others an unhappy and violent marriage, and the deaths of both her sons of whom one intentionally ended his own life. After many years of psychiatric help and several attempts to end her own life, another attempt was to be foreseen. The psychiatrist Chabot – involved through Right-to-Die Netherlands – determined she suffered intensely, that her suffering was durable, unbearable and hopeless. After he consulted seven experts in writing and concluded that through her objection to further treatment a "realistic perspective" was not available, he assisted in her suicide by providing the lethal medication. Both the Lower and Higher Court honoured his appeal for "force majeure".[87,88] The Supreme Court, however, ruled guilty without punishment. The major criticism was that he did not consult experts who met the patient in person. Beforehand the requirement for consultation was less stringent.[89] Essentials from the verdict were that it was not the source of the suffering (either being psychiatric, somatic or otherwise) but the unbearableness and hopelessness of it. This implied that suffering from a psychiatric disease could also be ground for assistance in dying from a physician, and that psychiatric patients also had a free and autonomous will.[50,57,80]

Brongersma (2000-2002)
The 86-year-old former Dutch senate member Brongersma primarily suffered – beside several problems related to old age – from his physical and social deterioration, the loneliness, dependency and feelings of uselessness. His physician established his unbearable and hopeless suffering, his voluntary and well-considered request and consulted another physician after which the physician provided Brongersma with lethal medication to intentionally end his own life. Initially, the Lower Court of Haarlem acquitted him as a result of conflict of duties ("force majeure"), and the Higher Court of Amsterdam guilty without punishment.[90,91] Interestingly, contrary to the former court cases concerning physicians assisting in dying, the High Court of Amsterdam did not take a casuistic approach but looked for more general norms. Finally, the Supreme Court held that questions about life and existential suffering (such as hopelessness, despair, loneliness and existential suffering caused by the inability to adapt to a new situation) were beyond the doctor's professional competence. They further specified that unbearable suffering should originate from a medically classifiable condition, either somatic or psychiatric. [50,57,80,92]

Advanced dementia case (2019-2020)
A nursing home physician ended the life of a 74-year-old deeply demented woman based on her advance directive. Her written advance directive was drafted after she received the diagnosis for dementia in 2012. She re-confirmed the written advance directive in 2015, and at a regular basis during several years confirmed her wish she did not want to live deeply demented in a nursing home. When she was transferred to a nursing home in 2016, the nursing home physician read her medical file, talked to and observed the patient, talked to her former treating physician, her husband and daughter, consulted the treatment team of the nursing home, the psychologist of the patient, a consultant from the Euthanasia Expertise Centre and two independent physicians who both judged the nursing home physician met all criteria of due care. After ending the life of the patient, the Regional Disciplinary Board of The Hague and the Central Disciplinary Board judged that the nursing home physician did not meet the criteria of due care laid out in the Termination of life on request and assisted suicide review procedures Act, and received a formal warning.[93,94] The following court case was aimed at answering the question if a physician had the duty to confirm the current wish to live or die from a deeply demented incompetent patient. The Court of The Hague judged the physician did not need to verify the current wish to die of a deeply demented and completely incompetent patient, that the nursing home physician had met all criteria of due care in the situation of a deeply demented incompetent patient, and therefor was acquitted.[95] The Supreme Court confirmed that the advance directive was clear, and also reversed the judgement of the Central Disciplinary Board.[96,97,98] Nevertheless, the Supreme Court did not judge about the need for the physician to consult with the patient.[99]

Note. Only the key judgements in forming (the practice of) the Termination of Life on Request and Assisted Suicide review procedures Act have been discussed in this overview. For information on other court cases concerning physicians assisting in dying see Weyers (2004) and Pans (2006).[57,80]

APPENDIX 4

Overview of cases (subpoenaed and brought to court) involving significant others who assisted people who intentionally ended their own life

Before introduction of Penal Code 1886

Dettemeijer (1858)
When a couple decided to end their lives themselves together, this only resulted in the death of the woman. The man, who had assisted in ending the woman´s life by providing the means to end life, was then charged for complicity with murder. The High Court, however, acquitted the man, because according to the then current law neither suicide nor assistance in suicide were a punishable offence. This court case was used as an argument by the minister of Justice, Modderman, to introduce article 294 of the Dutch Penal Code in 1886.[55,57,82]

After introduction of Penal Code 1886

'Mastervoordt' (1980-1981)
A husband bought and installed attributes to enable his wife to end her life through the inhalation of gas. Initially, he was sentenced to one months' conditional imprisonment with a probation period of one year because of the relationship, the foresight of a forced admission to a psychiatric hospital and the multiple unsuccessful treatments. The High Court of The Hague, however, sentenced him to six months' unconditional imprisonments less pretrial detention. This sentence was considered important by the court "to offer clarity in these times of discussion on euthanasia and assistance in suicide". The sentence was the result of "not just violating the respect for human life, but also falling short of carefulness and respect for his wife's life".[15,56,82]

Wertheim-Elink Schuurman (1981)
Mrs Wertheim-Elink Schuurman helped an acquaintance by supplying a lethal medication, mixing the medication with chocolate custard, feeding it to the acquaintance and offering alcohol to enhance the lethal effect. She did not inform the authorities. Something she had done before in 1974 when she assisted an aunt, something which did not result in any juridical consequences. This time she was sentenced to a half-year suspended sentence with a one-year probation period and two weeks of house-arrest. While the way she assisted was judged uncareful on all criteria the judge formulated (for example not involving a physician), she did not have to go to prison due to the physical and psychological burden as a result of her old age.[82] Note: Mrs Wertheim-Elink Schuurmans' husband and a friend were also present at the assisted suicide and were not prosecuted. This indicates that that being present at an assisted suicide is neither punishable nor that there is a duty to intervene, in the sense to prevent a suicide. Also, the option of non-physicians being able to assist was judged permissible as long as a physician was involved.[15,57,81,82]

'Plachman' (1982)
The husband of a woman who suffered from trigeminal neuralgia bought lethal medication in Switzerland and offered assistance when his wife took this medication. While the court believed in the husband's good intentions, they blamed him for not consulting a physician for psychological treatment. Prosecution was regarded necessary for general prevention and resulted in a six months' suspended sentence with a one-day probation period. Especially the one-day probation period seems a – for that time – very positive approach to express sympathy for the situation the husband was in.[52,57,80, 82,99]

Dystrophy case (1989)
A woman suffered from dystrophy. Her husband and a female friend (the latter related to Right-to-Die Netherlands) assisted the woman by helping her with ingesting the medication that led to her death. Both were sentenced to six months' suspended sentence with a two-year probation period. This punishment was motivated by the fact the decision to assist in her death was not taken by a physician in the context of careful medical practice. Especially the friend was considered more reprehensible because of her knowledge and relationship with Right-to-Die Netherlands.[57,80,100]

Muns (2003-2005)
This case is described in more detail in Appendix 5 as a counsellor working in cooperation with Foundation De Einder(-Noord) was convicted. Initially, this court case was declared inadmissable. Several other persons were present – of which at least one person had a greater role in the actions which finally led to death than the counsellor – but only the counsellor was prosecuted.[57,101] The other persons who were present offered practical assistance, namely placing bowls with medicine in the vicinity of deceased, getting bottles of alcohol from the cupboard, getting and placing water, yoghurt and jam for the intake of the medication to end one's own life in the vicinity of the deceased, and donning the plastic bag around the deceased's neck.[102] These actions of the "co-perpetrators" are punishable assistance according to article 294 of the Penal Code as the character of their presence was not just passive moral support. Only the counsellor was convicted as he was held accountable for the actions of all persons involved, as he was the most knowledgeable person present. According to the Court of Groningen it is not a requirement for co-perpetrating that all co-perpetrators are prosecuted.[103]

Methadone case (2006)
A friend helped a man with psychiatric problems after an earlier suicide attempt failed. He provided him with methadone and a heroine injection needle. He was sentenced to a fifteen-month sentence of which five months suspended sentence.[104] The person providing the methadone was acquitted because – at the time of distributing the means – he did not know about the suicide plans (no deliberation).[105]

Oxycodon case (2006)
A man personally related to a 30-year-old woman bought medication at the woman's request. After a prevented attempt to jump from the window, she died one week later with a great amount of pills in her stomach. The man got acquitted for assistance in suicide because at the time the pills were bought there were no indications for her serious attempt to end life. The man did act reprehensible for not contacting the health carer or her family after she wished to jump from the window, while the judicial authorisation she was under required this. While an autopsy could not conclusively find the cause of death, the Court of Assen deemed it plausible that the woman intentionally ended her own life. The man did get a sentence for buying, transporting, owning and providing medication under the Dutch Pharmaceuticals Act and displacing and concealing the corpse under the Dutch Burial and Cremation Act.[82,106,107,108]

Piek case (2006)
This case shows parallels with the Dettemeijer case from 1858. A couple decided to intentionally end their own lives together. In this case the woman survived the attempt, and the man died after one week in coma. The woman was charged – amongst many other things – with assistance in suicide. Eventually, she was acquitted, after which she intentionally ended her own life.[109,110]

Gun case (2006)
A man provided cash and a debit card which enabled his girlfriend to buy a gun and ammunition. He loaded the gun for her with the ammunition, and answered her question about how many bullets she had to use with "one would probably be enough". After this she shot herself. According to the judge he did not seek enough alternatives (e.g. no other experts than a physician, other family or friends), and only knew about his girlfriend's death wish for three weeks. The pressure he experienced and the personal grief resulting from his girlfriend's death motivated an entirely conditional sentence of six months imprisonment with a probation period of two years. The imprisonment primarily emphasized the absolute character of the violated standard (the prohibition of assistance in suicide).[111]

Vink (2007)
This case is described in more detail in Appendix 5 as it concerned a counsellor of Foundation De Einder. The counsellor was not present, but two friends of the deceased were. These friends were not prosecuted.[109,112]

Family drama (2007)
A couple decided to end their own and their children's lives. The husband also assisted in his wife's suicide by buying custard (which she ingested together with an overdose of medication) and holding skin folds of her upper legs so she could inject insulin. The Lower Court of Zutphen did not regard this as punishable assistance in suicide. The husband did receive a sentence of 18 years imprisonment for ending the lives of their children.[113]

Schellekens (2009-2012)
This case is described in more detail in Appendix 5 as it concerns assistance by the chairman of the right-to-die organisation Foundation Voluntary Life (SVL). The three children of the deceased woman received the lethal medication from the chairman and also were present at the assisted suicide. The chairman and children all spent a night in prison. The children were not prosecuted. This was motivated by the difference in position: the chairman having a more directing and facilitating role in the punishable offences than the children, and the public prosecutor taking into account the emotional engagement of the children in the death wish and the death of their mother.[114]

Attempted suicide (2012)
A woman who suffered from tinnitus and social isolation was faced with a denied request for physician assistance in dying. After two failed suicide attempts, she asked her husband for help, who prepared water with paracetamol dissolved in it and added morphine to her dessert. When she did not die from ingesting the medications, he placed a pillow over her face out of despair. When the woman said she did not wish to die this way, he stopped and called a psychiatrist for help. The Court of Lelystad acquitted the husband as he stopped carrying out the assistance out of free will, and the woman had wilfully taken the pills. Also, preparing and handing over were not regarded as a punishable offence. Eventually, half a year later, the woman intentionally ended her own life without her husband's knowledge.[115]

Heringa (2013-2018)
Albert Heringa had conversations with his 99-years old (step)mother (Mrs. Moek) about her wish to end life, and eventually provided her the lethal medication to take her own life. He filmed the suicide. This film was aired as a documentary after which Heringa was prosecuted. The Lower Court of Gelderland ruled guilty without punishment, motivated by the long trial period and the intimate bond between son and mother, and despite the absence of "medical or mental force majeure" and acting in uncareful ways.[116] In appeal, the Higher Court of Arnhem applied the criteria of due care from the Termination of life on request and assisted suicide review procedures Act to the assistance he offered. The Court came to the conclusion that the request of the mother was well-considered and voluntary, that she was informed about her situation, that she did not have reasonable alternatives at that time, and that the son had carefully acted during her ingesting the lethal medication as far as his position as non-physician allowed for. He even was acquitted due to acknowledging a conflict of duties ("force majeure") between adhering to Article 294 and the unwritten moral duty to help his mother with realising her wish to end life in a peaceful and dignified manner.[117] However, in 2017 the Supreme Court overruled this verdict by stating that the criteria of due care from the Termination of life on request and assisted suicide review procedures Act were incorrectly applied to a non-physician, as they were specifically designed for physicians.[118] In 2018, the Higher Court of 's Hertogenbosch sentenced him to a six months' conditional imprisonment with a two year probation period. Despite acknowledging that the son had acted out of compassion, and the long duration of the trial, several aspects of the case negatively influenced the sentence: not enough efforts to change his mother's mind, being motivated by his conviction that the law on assistance in dying should be changed, leaving his mother alone after she fell asleep but before she passed away (and not recognizing the possibilities of complications), and not being transparent about his role in his mother's death in the years before the airing of the documentary.[119] In 2019, the Supreme Court upheld this judgement.[120]

Helium case (2019)
A 48-year-old son was sentenced to a three-month imprisonment with a two-year probation period for providing the means to end life (several necessities for inhaling inert gas) and constructing the installation which his father used to intentionally end his own life. To the disadvantage of the son, he did neither explore enough alternatives for help, despite his belief to be of assistance to his father, nor did he consult other family members or a physician. The sentence has a generic preventive goal to clarify that offering assisted suicide outside the legal boundaries will be punished, even if it is carried out with the best intentions.[121]

Powder X case (2021)
Currently, the Dutch Public Prosecutor is investigating the case of man who has sold a powder to intentionally end one's own life to hundreds of people of which at least six people died by ingesting the powder.[73]

Subpoenaed cases of Article 294 of the Dutch Penal Code

Between 1952 and 1983 there were 21 subpoenaed cases concerning Article 294 of the Dutch Penal Code. In the majority of these cases this concerned physicians who distributed (sleeping) medication with which the patients took their own life (after the patient collected a sufficient amount of medication).[15]

Between 2015 and 2020 there have been 13 cases related to Article 294 of the Dutch Penal Code that have been subpoenaed. In the majority of the researched cases (n=9) this involved significant others, like a partner or a friend. Two cases are current affairs. In three cases, the involved persons were wrongly accused as suspects because the facts and circumstances unequivocally showed their innocence (subpoena code 01). Four cases were subpoenaed due to insufficient proof (subpoena code 02), and two cases were subpoenaed because the involved persons acted out of (psychological) force majeure (subpoena code 06). In two other cases, significant others had offered punishable assistance in suicide according to article 294 of the Dutch Penal Code. The severe condition of the person who intentionally ended one's own life motivated the significant other to offer assistance in the payment for lethal medication. This case has been subpoenaed because of the low criminality of the offence (subpoena code 42). The prosecution of a significant other who gave instructions how to open a helium bottle and tightened a loosened bag filled with helium was subpoenaed. This decision was motivated by the small role of the punishable offences in the complete fact (subpoena code 41), by the suspect being negatively affected by the consequences (subpoena code 52), by the continued resistance of the suspect to the plans of the other to end one's own life, and – after giving up this resistance – by remaining present when the other ended one's own life and acting transparently.

Note. All cases where relatives (also) violated article 293 of the Dutch Criminal Code (Termination of life on request of the deceased) have not been included in this overview, for example: Partner (1812); Slotboom (hired acquaintance) (1852); Helmsman (fiancee) (1908); Warehouse clerk (friend/partner) (1910), Boeken (1916); Ter Braak (brother and physician) (1940); Office clerk (friend/partner) (1944); Eindhoven physician (brother and physician) (1952); Barkeeper (partner) (1969); Postma-Boven (daughter and physician) (1973); Nameless (stepson) (1978); Pols (friend and psychiatrist) (1984); 'Hofland' (acquaintance) (1985). For more information on these case see Enthoven (1984) and Weyers (2004).[57,82]

APPENDIX 5

Overview of court cases of professionally involved people related to Dutch right-to-die organisations who offered assistance to people who intentionally ended their own life outside the Dutch Termination of life on request and assisted suicide review procedures Act

Sybrandy—Alberda (Voluntary Euthanasia Information Centre) (1980)
A judicial investigation was started after the couple Sybrandy-Alberda provided information on lethal medication to end life in the organisation's news bulletin (*Euthanatos*) and two complaints by bereaved family members about the death of their loved ones. They made use of this information by obtaining lethal medication abroad and ended their own lives with it. The public prosecutor subpoenaed the case because the couple Sybrandy sufficiently warned about the consequences before providing information about intentionally ending one's own life, and providing general information is insufficient reason to presume punishable assistance as meant in article 294 of the Dutch Penal Code.[56,57,61,122]

Wertheim (Right-to-Die Netherlands) (1981)
The Wertheim court case was important in formulating the criteria for the Dutch law on PAD (see Appendix 3). However, it concerned an activist of Right-to-Die Netherlands, Wertheim-Elink Schuurman, who founded a Voluntary Euthanasia Task force in her domicile. She distributed lethal medication to an acquaintance. She was sentenced to a half-year suspended sentence with a one-year probation period and a two-week house arrest for distributing lethal medication and offering practical assistance during the suicide. It is not specified how her relation to Right-to-Die Netherlands influenced the prosecution or verdict, but her husband and a friend who were also present were not prosecuted (see Appendix 4).[56,81]

Dystrophy case (Right-to-Die Netherlands) (1989)
A woman suffered from dystrophy. Her husband and a female friend (the latter related to Right-to-Die Netherlands) assisted in the woman's suicide by helping her ingesting the medication that led to her death. Both were sentenced to six months' suspended sentence with a two-year probation period. This punishment was motivated by the fact that the decision to assist in her suicide was not taken by a physician in the context of careful medical practice. Especially the friend was considered more reprehensible because of her knowledge and relationship with Right-to-Die Netherlands.[57,80,100]

Mulder-Meiss (Right-to-Die Netherlands) (1992-1995)
A physician, Mrs. Mulder-Meiss, was present at the suicide of a 73-year old man as a by Right-to-Die Netherlands mediated confidential physician, although she always said not to have acted in her quality as physician. She was punished for giving instructions about when he had to pull a plastic bag over his head. This verdict was the first to explicate that "having conversations, offering moral support and providing information" are not punishable forms of assistance in suicide as meant under article 294 of the Penal Code. However, giving instructions is punishable. Initially, the Lower Court of Rotterdam sentenced her to a ten-months' imprisonment with a two-year probation.[123] The Higher Court of The Hague reduced this to one month with a two-year probation. According to the Court, giving the instructions in this specific case did not concern a gross infringement of the Penal Code, and Mulder-Meiss acted out of a caregivers' motive.[124] An appeal by the suspect failed.[125] Mulder-Meiss was also involved in another case of assistance in suicide – in which she was present together with a nurse – when an old woman ingested lethal medication. This case was subpoenaed.[57]

Chabot (Right-to-Die Netherlands) (1993-1994)
The psychiatrist Chabot became involved in this case after mediation of Right-to-Die Netherlands. As it concerned physician assistance in suicide, it is described in Appendix 3.[87-89].

Cornelisse (Right-to-Die Netherlands) (2001-2003)
A 43-year-old woman with psychiatric suffering for which she was being treated had a well-considered and persistent wish to end life. She had expressed this wish to her physician and the mental health care staff, and had also tried to intentionally end her own life on multiple occasions. A health psychologist of Right-to-Die

Netherlands provided her with information about a do-it-yourself guide with information on methods to end one's own life (the so called "Scottish booklet" published by Right-to-Die Netherlands; a Dutch translation of Chris Docker's "Departing drugs").[126,127] The psychologist also provided information about which medication, the necessary quantity, the manner of ingestion and how to obtain this medication to end one's own life. The psychologist was not present at the suicide, but had contact by telephone just before and after the woman ingested the lethal medication. Something she had done twice before. Initially, this case was subpoenaed, but after a formal complaint from the deceased's brother, the case was brought to court.[128] The right of non-disclosure under the Law on the professions in the individual health care was denied as the activities of the health psychologist were primarily informative and advisory and did not have the character of a therapeutic relationship.[129,130] The psychologist was acquitted as her assistance only existed of providing information and moral support. With this verdict, the Court of 's Hertogenbosch confirmed non-punishable assistance in intentionally ending one's own life from the Mulder-Meiss court case.[125] Neither did she have a duty to intervene as the deceased was not in a situation she did not want to be in and would have made her struggle with death, and the psychologist was aware of and reminded her about the advance directive for non-treatment.[131]

Muns (Foundation De Einder) (2003-2005)
A counsellor of Foundation De Einder(-Noord) was present – together with another representant of this organisation and a befriended couple of the deceased – when an 81-year-old woman intentionally ended her own life. The counsellor was charged for the practical assistance he provided (namely preparing and providing a list of necessities to end one's own life, opening a jar of jam, placing a bottle of alcohol in the vicinity of the deceased or perhaps giving it to the deceased, placing the plastic bag in the vicinity of the deceased and giving it to the deceased, and tightening the elastic band after it was donned) and the practical assistance offered by the other persons present (namely placing bowls with medicine in the vicinity of deceased, getting bottles of alcohol from the cupboard, getting and placing water, yoghurt and jam for the intake of the medication to end one's own life in the vicinity of the deceased, donning the plastic bag around the deceased's neck). The assistance did not limit itself to the non-punishable assistance of having conversations, providing moral support and information. The counsellor provided practical help and took control over the situation. His advice, given in his professional capacity of counsellor, were considered to be instructions. Instructions and practical acts – not just during the intentional ending of one's own life but also beforehand – are punishable offences under article 294 of the Penal Code. The counsellor was sentenced to twelve months' imprisonment of which eight months' suspended with a two-year probation period.[101-103]

Hilarius (Foundation De Einder) (2005-2006)
A 25-year-old woman with psychiatric suffering contacted Foundation De Einder for assistance with her intention to end her own life. Founder and counsellor of Foundation De Einder, Mr. Hilarius, provided her with instructions and information in writing about which combinations of lethal medication could end her life and how to obtain this medication. He was actively involved in her actually obtaining the medication by trading her sleeping medication for lethal medication. He was sentenced to a one-year imprisonment of which eight months' suspended with a two-year probation period. Providing the lethal medication is an offence under article 294 of the Penal Code and under article 2, section 3 of the Pharmaceuticals Act.[107,132] Furthermore, Hilarius did not limit himself to "providing information and offering moral support", but he gave her instructions. Through this act he made it possible and easier for the woman to end her life. Furthermore, he was uncareful in not seeking contact with her family, physician or treating psychiatrist to get a better view on the seriousness and durableness of her wish to end life.[133,134,135]

Vink (Foundation De Einder) (2007)
A counsellor working with Foundation De Einder, Vink, provided information about lethal medication based on a publication.[67] With this information a 50-year-old woman obtained such medication by herself and intentionally ended her own life in the presence of two friends. It could not be clarified whether the information given by the counsellor had the character of an instruction by which he took control. Because his assistance in suicide was limited to "having conversations, offering moral support, and providing general information", he was acquitted. The two friends who were present at the suicide were not prosecuted.[112]

Schellekens (Foundation for Voluntary Life; SVL) (2009-2012)
An 80-year-old woman suffered from Parkinson's disease and was bedridden. Her nursing home physician did not wish to facilitate her wish to end life. The woman's children contacted Foundation Voluntary Life (SVL). The woman and the children personally met with the chairman, Mr. Schellekens, and two other board members of Foundation Voluntary Life, to discuss about methods to end life, providing medication to end life, and the shared responsibility of the children by preparing the medication. Schellekens provided the lethal medication. After carefully reconsidering her wish to end life and saying goodbye, the woman died in her own bed in the presence of Schellekens and her children. The children were not prosecuted (see Appendix 4), and Schellekens was sentenced to twelve months' imprisonment, which was completely suspended due to his deteriorating physical condition. Providing lethal medication was an offence under article 294 of the Penal Code and article 2, section 3 of the Pharmaceuticals Act.[107] Furthermore, Schellekens was blamed for not sufficiently having explored other options, to have advised to antedate a letter signed by the woman to make her death wish look more well-considered and to not have acted in an transparent way by advising to remove the bottles and a cup with medication.[114,136] Also, the Foundation itself was brought to court as there was no distinction between Schellekens acting as chairman or as a private person, two other board members were involved, and there was a deliberate deviation from the Foundation's own (regular) procedures. The Foundation received a fine of 25,000 euros, of which 20,000 euro on a conditional basis with a two-year probation period.[137]

Vink (Foundation De Einder) (2016)
In 2016, the Public Prosecutor investigated the work of a counsellor working in cooperation with Foundation De Einder after an undercover television program secretly filmed the counsellor at work. For assistance under article 294 of the Penal Code to be criminal, a suicide has to actually follow, that is has to happen. As the television program staged a fake client who did not end one's own life, the criminal investigation was based on a suspsicion of violating article 96 of the Individual Health Care Professions Act.[128] The Public Prosecutor came to the conclusion the broadcasted material was not a correct representation of the activities of the counsellor who did not offer punishable assistance. The counsellor also informed about alternatives to ending one's own life and urged to take advantage of treatment options in regular health care. The case has been subpoenaed. [138,139]

Cooperation Last Will (CLW) (2018)
There has been an investigation by the public prosecutor into the guidebook published by Cooperation Last Will. The guide itself did not constitute an illegal activity. For assistance under article 294 of the Penal Code to be criminal, a suicide has to actually follow. Furthermore, jurisprudence is on a "casuistic" base, but in essence stated that providing general (non-committal) advice was not punishable. Only instructions and practical actions or skills prior to the suicide were criminal offenses, and these acts must have made the suicide possible or easier.[140] The public prosecutor sent a letter to the Cooperation Last Will to warn that with their guide the Cooperation entered a grey area. Also, prosecution under article 2:20 of the Civil Code – stating it is a crime to act in conflict with the public order – was not a sufficient ground to prosecute as it is not illegal to wish to legalize a means through which people can decide the time and manner of their own end of life.[140]

Powder X case (2021)
Currently, the Dutch Public Prosecutor is investigating the case of man who sold a powder by which someone can intentionally end one's own life to hundreds of people, of which at least six people have died by making use of it.[141] Although the man is not a representant of a Right-to-Die organisation, the case is mentioned here as he is actively involved with the Australian Voluntary Euthanasia Party, with Philip Nitschke from Exit International and a member of Cooperation Last Will.[142,143]

Note. Several cases concerning confidant-physicians mediated by Right-to-Die Netherlands and nurses have not been included in this overview because they concern the termination of life on request (Article 293 of the Dutch Penal Code), for example: Nurse from De Terp (1985), Physician Cohen (1994), Nurse Leeuwarden (1995), Nurse van der Weerd (1995), Physician Postma (1996). For more information on these cases see Weyers (2004).[57]

APPENDIX 6

Additional files Chapters 4 and 7

Additional file 1

Registration form version 2012 and version 2015

Item	Selected option
1. Personal characteristics of the client / counselee	
Postal Code	4 digits of Dutch postal code; Name of country, if abroad; Unknown
Gender	Male; Female; Unknown
Year of birth	4 digits; Unknown
2. Overview of the situation of the client / counselee prior to start of counselling	
Current disease(s), diagnosis or situation	Open-ended questions. More than one answer possible. Several examples preselected: Physical: E.g. cancer, problems of old age, dementia, heart problems. Psychiatric: E.g. depression, personality disorders, fear disorder. Psychological: E.g. existential suffering, loneliness, youth trauma. No current suffering: E.g. wanting autonomy, completed life. Unknown
Main motivation to request counselling	Physical suffering; Psychiatric suffering; Psychological suffering; No suffering at present; Unknown
Severity of disease	Terminal disease; Severe disease; No severe disease; No disease/not applicable; Unknown
Presence and urgency of death wish at start of counselling	No death wish present Death wish present, wants to end life within three months Death wish present, wants to end life between 3 to 12 months Death wish present, wants to end life more than one year away Unknown
Request for assistance in dying to a physician	No request for PAD; Request for PAD denied; Request for PAD pending; Request for PAD granted; Unknown
Explication on request	Open-ended question. More than one answer possible. Several examples preselected: No request: E.g. staying autonomous, not wanting to burden the physician. Request denied: E.g. not meeting legal criteria of due care. Request pending: E.g. physician has to think about it Request granted: E.g. granted for near future, granted for in due time. Unknown; Not applicable
Situation of request for assistance in dying to a physician[b]	Not applicable; Request for PAD for current situation; Request for PAD for future situation; Unknown
Moment of request for assistance in dying to a physician[b]	Not applicable; Request for PAD before start counselling; Request for PAD before and during counselling; Request for PAD during counselling; Unknown
Prior suicide attempt[b]	Yes; No; Unknown
Prior sought help at other organisation or caregivers related to current request for help[b]	No; Yes, at physician; Yes, at psychiatrist; Yes, at Right to Die Netherlands / SVL (Foundation Voluntary Life); Yes, at End-of-Life Clinic; Yes, at other …; Unknown

Additional file 1. *Registration form version 2012 and version 2015 (continued)*

3a. Characteristics of the counselling process (number of contacts)	
Number of face-to-face contacts in 2012[a]/2015[b]	Any number; Unknown
Number of other contacts in 2012[a]/2015[b]	Any number; Unknown
Total number of contacts in 2012[a]/2015[b]	Calculated automatically from two prior columns
Month of first contact	Jan – Dec; Unknown
Year of first contact	1995-2012[a]/1995-2015[b]; Unknown
Number of face-to-face contacts since start of counselling	Any number ; Unknown
Number of other contacts since start of counselling	Any number; Unknown
Total number of contacts since start of counselling	Calculated automatically from two prior columns
3b. Characteristics of the counselling process (content)	
Character of counselling[a]	Open-ended question. More than one answer possible. Several examples preselected: Referral: E.g. referral to physician, suicide prevention, End of Life Clinic General information: E.g. about goals foundation, about euthanasia law. Mental counselling: E.g. motivation, emotional, role of others. Practical counselling: E.g. explicit information on methods, preparing, Counselling ended: E.g. deceased, treatment elsewhere, continue living
Content: Moral support[b]	Yes; No
Content: General information[b]	Yes; No
Content: Mental preparation / decision making[b]	Yes; No
Content: PAD[b]	Yes; No
Content: Practical preparation information methods[b]	Yes; No
Content: Practical preparation performance methods[b]	Yes; No
Content: Close ones[b]	Yes; No
Content: Juridical information[b]	Yes; No
Status of counselling	Counselling on-going; Counselling (ready) on hold; Referral to …; Passed away through..

Additional file 1. *Registration form version 2012 and version 2015 (continued)*

3c. Characteristics of the counselling process (client/counselee system)	
Involvement of others during counselling	Yes; No
Reason for no others involved	Open-ended question. Several examples preselected: No social network/ Alone; Fear of reactions; Regarded as a private matter; Unknown; Not applicable
Relationship of others involved	Open-ended question. More than one answer possible. Several examples preselected: E.g. partner; (grand)child(ren); parents; siblings; friends; Not applicable
Number of others involved	Any number; Not applicable
Attitude of involved others	Positive/Supportive; Negative/Critical; Mixed/Ambiguous; Unknown; Not applicable
Openness about counselling towards others	Yes; No; Unknown
Reason for no openness towards others	Open-ended question. Several examples preselected: No social network/ Alone; Fear of reactions; Regarded as a private matter; Unknown; Not applicable
Relationship of other towards whom clients is open	Open-ended question. More than one answer possible. Several examples preselected: E.g. partner; (grand)child(ren); parents; siblings; friends; Not applicable
Number of other towards whom client is open	Any number; Unknown; Not applicable
Attitude of others towards whom client is open	Positive/Supportive; Negative/Critical; Mixed/Ambiguous; Unknown; Not applicable
4. Outcome of the counselling process	
See also character of counselling at 3.	See also character of counselling at 3.
Manner of death, if client deceased.	Not deceased; Unknown if deceased; Natural death; Physician-assisted dying; Lethal medication; Voluntary refusing food and fluid; Helium; Dignitas; Hanging/Choking; Jumping train; Jumping height; Drowning; Unknown manner of death
When deceased: month	Jan – Dec; Unknown; Not applicable
When deceased: year	2011, 2012; 2013[b]; 2014[b]; 2015[b]; Not applicable
Follow up counselling with bereaved ones	Yes; No
Other information on follow up counselling	Open- ended question.
5. Other	
Additional remarks about whatever deemed relevant	Open-ended question

Note. This registration file was previously used by the board of Foundation De Einder for their annual reports and—in consultation with counsellors—adapted for this study. The registration form underwent minor changes and expansions as a result of feedback from counsellors and the wish to collect more information. This additional file shows the items for the version of 2012 and 2015; [a] item only for 2012; [b] item only for 2015.

Additional file 2

Table Severity of illness (N=595)

	Frequency	Percentage
Terminal disease	30	5
Severe disease	225	38
No (severe) disease	280	47
Unknown	60	10
Total	595	100

Additional file 3

Table Distinction between no disease and no severe disease (N = 310; Only for data 2012)

	Frequency	Percentage of total (N=310)	Percentage of no (severe) disease (N=166)
Terminal disease	12	4	-
Severe disease	107	35	-
No (severe) disease	166	54	-
No severe disease	*89*	*29*	*54*
No disease	*77*	*25*	*46*
Unknown	25	8	-
Total	310	100	*100*

Additional File 4

Table Reasons for not requesting Physician assistance in dying (PAD) (N = 187; Only for data 2012 and if no request for PAD)

	Frequency	Percentage
Client judges PAD not possible	41	22
Client wishes to stay autonomous	39	21
Other reasons	12	6
Clients doesn't want to burden physician	11	6
PAD not discussable with physician / moral objections	11	6
Client has fear of being sectioned	7	4
Unknown / Missing	66	35
Total	187	100

Additional File 5

Reasons for denial of request for Physician assistance in dying (PAD) (N= 71; Only for data 2012, and if request for PAD denied)

	Frequency	Percentage
Patient doesn't meet criteria of due care	46	65
Moral objections	9	13
Other reasons	12	17
Unknown / Missing	4	6
Total	71	100

Additional File 6

Reasons for not involving others in counselling (N = 162; Only for data 2012 and if others not involved)

		Frequency	Percentage
Regarded as a private matter		55	34
Fear of reactions of other		43	27
No social network or alone		41	25
Other reasons		8	5
Unknown		15	9
	Total	162	100

Additional File 7

Methods of Non-Physician Assisted Suicide (N = 76; Only if passed away through Non-PAS)

		Frequency	Percentage
Lethal medication		68	89
Voluntary refusal of food and fluid		4	5
Oxygen deprivation by inhalation of inert gas		4	5
	Total	76	100

APPENDIX 7

Supplementary files Chaptes 5 and 6

Supplementary file 1

Topic list for in-depth interview

Introduction
Information on goal of study, informed consent and recording of interview

Opening question
What has been the motivation to contact foundation De Einder?

Personal characteristics
Factual background information, and the evaluation by participant
(e.g. age, gender, family situation, social network, work, hobbies)

Motivation to choose for counselling for Non-PAS
Motivation to contact counsellor
Experiences, beliefs, opinions, values relating to contacting the counsellor
Communication with general practitioner (GP) about death wish and/or request PAD

Health situation
Current health situation and experienced seriousness,
Prior and available treatments for (current) health problems
Mastery: Experience of influence over own situation (current health)
and prospective death
Suicidal thoughts (current and past) and suicidal attempts

Counselling
Expectations, evaluation, and result of counselling
Content of counselling (duration, frequency, involvement of others)

Judicial situation
Effects of Article 294 Penal Code, PAD law, law on narcotics.

Possible death
Plans for / opinion about timing and manner of own death

Supplementary file 2
Analysis code list Chapter 5

Codes that were made in the analysis of motives and experiences leading to seek DAS from a counsellor facilitated by De Einder, and content of and experiences with counselling.

Supercodes	Codes	Subcodes
A Personal characteristics		Gender, age, marital status, family situation, social contacts, ADL, character, religion, membership right-to-die organisations
B Current Health situation		Current health problems (physical, psychiatric, psychological), and evaluation by client, treatment history, available treatment options
C Motivation to contact counsellor	00 Dignity	Dignified life, dignified death
	10 Self determination	Self determination, responsibility, need for security / reassurance, fear of losing control, need for being independent / self-reliant
	20 Social motivation	Loss, aging, accepting end of life, completed life, decreased satisfaction with ADL, feeling useless, loneliness, no/ small social network, not burdening others, not being remembered as decayed
	40 Health	Currently healthy, current problems (physical, memory, no more treatments, suicidal thoughts, completed life), prospective suffering, experiences with health situation of others
	50 Health care	Received health care by themselves (temporary admittance, problems mental health care, inability to discuss death wish), received health care by others (wishes not respected or granted, inability to offer help, observed health care), opinions on health care (palliative care, costs of care, bureaucracy and targets), experiences with suicide.
	60 Contact physician	PAD not discussed and reasons, PAD discussed and result, counselling not discussed and reasons, counselling discussed and result.
	70 Law	Opinion about PAD law (not used to full extent, obligation to refer, dependence on physician), opinion about 294 Penal Code (illegal assistance others, inability to be present at suicide, negative action of police and justice), opinion about relevant organisations.
	80 Other motivations	Earlier experiences with other Dutch right-to-die organisation
D Content of counselling	00 Form	Period, number of personal consults and other contacts, involved others, status
	10 Expectations / Goal	Creating clarity death wish (moral aspects, alternative to live, checking seriousness), responsible enactment, finding reassurance, not wanting to die alone, support with involving others, practical information on suicide, acquiring means

	20 Mental preparation	Motives wish to end life, effects of ending life, emotions
	30 Living wills	Living wills, contact with physician
	40 Juridical	Punishable actions involved others, acting of police and justice
	50 Others	Involvement of others (and reason therefor), openness towards others (and reasons therefor), meaning for others, carefulness towards others, presence of others, saying goodbye of others
	60 Medication method	Which medication, dosage, acquiring, interactions, shelf life, intake
	70 VRFF	
	80 Inert gas	
	90 Enactment suicide	Location, role counsellor, characteristics death, being found, acting of police and justice, arrangements after death (will, science, funeral)
E Result of counselling	10 Positive aspects	Personal approach, support, acceptation, reassurance, relief, non-violent death, no worries failure, quality of life, rational, information
	30 Negative aspects	Secrecy, worries failure, dependence on counsellor, option PAD not discussed enough.
	60 Timing of death	Wish to live, unknown, with more loss of quality of life
	70 Preference of manner of death	Natural death, PAD and advantages, DAS, disadvantages DAS, doubt suicide

Supplementary file 3
Analysis code list Chapter 6

Codes that were made in the analysis of the content of and experiences with the counselling from a counsellor facilitated by De Einder.

Supercodes	Codes	Subcodes
V Expectations about counselling	V10 Practical design counselling	
	V20 Counsellor	Knowledge, character, position, relation
	V30 Counselling	
	V40 Mental processes	Self determination, researching death wish, seeking reassurance
	V50 Practical self-ethanasia general	
	V51 Practical self-euthanasia medication	
	V60 Juridical	
	V70 Close ones / Others involved	Prevent burdening close ones, physician
	V80 Medical assistance	
	V90 Other expectations	
E Content of counselling	E10 Practical design counselling	Period, frequency, duration, means of communication, content, costs, location, involvement others, initiative, reports, assignments
	E20 Counsellor	
	E30 Counselling	Focus medication, focus mental counselling, listening no taboo
	E40 Mental processes	Death wish, help in life
	E50 Practical self-ethanasia general	Methods, preparation, performance
	E51 Practical self-euthanasia medication	Which medication, efficacy, dosage, intake, interaction, obtaining, quality and shelf life, performance
	E55 Practical self-euthanasia STED	
	E56 Practical self-euthanasia plastic bag	
	E57 Practical self-euthanasia helium	
	E58 Practical self-euthanasia after death	
	E60 Juridical	Assistance from others, safeguarding others
	E70 Close ones / Others involved	About others (psychological), about others (juridical), counselling of others
	E80 Medical assistance	PAD, living wills
	E90 Other content	

R Results after counselling	R10 Practical design counselling	
	R20 Counsellor	Listening ear, respect, count on, trust, relation, other positive results, other negative results.
	R30 Counselling	Listening without taboo, appointments design, attitude, other positive, other negative
	R40 Mental processes	Process: if ending own life, Process: when ending own life, Process: ending life together
	R50 Practical self-ethanasia general	Preference method
	R51 Practical self-euthanasia medication	Info medication, stage obtaining, manner obtaining, period owning medication, worry effectiveness
	R55 Practical self-euthanasia owning	Independence, certainty, relieve, worry effectiveness
	R55 Practical self-euthanasia STED	
	R56 Practical self-euthanasia plastic bag	
	R57 Practical self-euthanasia helium	
	R58 Practical self-euthanasia after death	
	R60 Juridical	Safeguarding others, worry others
	R70 Close ones / Others involved	Preparing farewell, openness, informing others, worry about others
	R80 Medical assistance	PAD, living wills
	R90 Other content	

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