Praise the individual?

– *Locating expressions of authority and religion by analyzing the social eras within the Dutch pro-euthanasia community*

Laura Ruohonen
University of Helsinki
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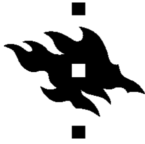

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UNIVERSITY OF HELSINKI

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Tutkielma on uskontososiologiaan paikantuva diskurssianalyysi Alankomaalaisesta pro-eutanasia liikkeestä ja sen parissa toimivista ihmisistä ja järjestöistä. Tutkielma analysoi Nederlandse Vereniging voor een Vrigwillig Levenseide-järjestön, NVVE:n, työntekijöiden ja vapaaehtoisten, sekä eri järjestöjen asiantuntijoiden haastatteluja. Tutkielman tavoitteena on selvittää millaisia diskursseja haastateltavat luovat puhuessaan eutanasiasta: Nostavatko nämä diskurssit esille uskonnon käsitteen, mihin auktoriteetin rooli sijoitetaan, sekä kuinka nämä elementit heijastavat teoriaa kuoleman kulttuurin elpymisestä (tai sen uudesta tulemisesta). Diskurssianalyysi muodostaa työn teoreettisen taustaoletuksen puheen tavoitteellisesta luonteesta ja analyysin metodina toimii Tony Walterin teoria kuoleman kulttuurin siirtymästä modernista neo-moderniin järjestykseen. Durkheimin näkemys uskonnosta yhteisön vaalimien arvojen ja normien kokonaisuutena, yhteisöllisyyden kokemuksena, tarjoaa kehyksen pro-eutanasia yhteisön tarkastelemiselle. Taustaluvuissa tutkielma paneutuu eutanasiaa koskevien sääntöjen muotoutumiseen osana kärsimyksen roolin tulkintaa oikeusjärjestelmän ennakkotapausten kautta: Yhteiskunta joutuu ottamaan kantaa sairaan ruumiin ja mielen, sekä eksistentiaalisen kärsimyksen, asemaan eutanasia-pyynnöissä. Diagnosoidusta sairaudesta tai tilasta johtuva, kestämätön kärsimys ilman realistista mahdollisuutta toipumiselle, muotoutuu yhdeksi ehdoksi eutanasialle, poissulkien eksistentiaalisen kärsimyksen riittävänä perusteena.

Alankomaiden dekriminalisoitua eutanasian, keskustelu itsevalitun kuoleman ympärillä suuntasi huomionsa lääkärin rooliin, kyseenalaistaen tämän auktoriteetin elämän ja kuoleman tuomarina. Järjestönä NVVE pyrkii mahdollistamaan eutanasialla tarkoitetun, lääkärin aiheuttaman kuoleman lisäksi kaksi tästä erillistä väylää toteuttaa itsevalittu kuolema: Avustettu ja autonominen kuolema. Nykyisen järjestelmän salliessa ainoastaan lääkäreiden avustaa kuolemassa, itsen-auktoriteetin kannattajat vierastavat tätä lääkärin kaikkivoipana nähtyä roolia ja kannattavat mahdollisuutta päättää yksilön omasta kuolemasta ilman lääketieteen ammattilaista: Varmojen ja helppojen keinojen ollessa saatavilla, henkilö aiheuttaa kuolemansa joko itse, tai valitsemansa tahon avustamana.

Tutkielman analyysi muodostuu kolmesta osasta. Ensimmäinen näistä käsittelee haastateltavien esiin tuomia myötätunnon diskursseja, jotka painottavat kärsimyksen, armon ja empatian käsitteitä, ajatuksen kärsimyksen tarpeettomuudesta vaikuttaessa taustalla. Analyysin toinen osa keskittyy *itsen* diskurssiin: Tämä muodostuu autonomian ja vapauden; feminismin; kontrollin ja individualismin, diskursseista. Itsen-diskurssi esittää yksilön aseman paikoitellen sakraalina. Diskurssi nostaa myös esille eutanasian taustalla vaikuttavan vaatimuksen korkeasta elintasosta, sekä yksin toteutetun eutanasian, itsen-eutanasian (eng. self-euthanasia), vaihtoehtona itsemurhalle. Analyysin kolmas osa tarkastelee vastareaktioita vallitseville diskursseille. Nämä vastareaktion ilmenevät joko individualismin kyseenalaistamisena sekä eutanasian ja hollantilaisen kulttuurin uhkien käsittelemisenä. Analyysi osoittaa, että myötätunnon diskurssit kumpuavat nimensä mukaisesti tunteesta ja käsittelevät aihetta usein suhteessa ruumiin ja lääketieteen diskursseihin, heijastaen näin kuoleman kulttuurin modernia puolta ja lääketieteen auktoriteettiasemaa. Itsen-diskurssit ilmenevät usein periaatteesta kumpuavia näkemyksiä, joissa keskustelu eutanasian rajanvedosta nähdään itseä rajoittavana ja näin myös epäolennaisena. Näin ollen tunteen ohjatessa mielipidettä, auktoriteetti eutanasian soveltamisesta annettaan luultavammin lääketieteelle.

Taustaluvut ja analyysi muodostavat kuvan yksilöiden vaihtelevasta suhteesta ympäröivään yhteiskuntaan ja ajanjaksoon. Yksilön rooli oman elämän ja kuoleman määrittäjänä on viety äärimmilleen, muistuttaen paikoitellen kuluttajan asemaa kehittyneessä yhteiskunnassa. Käsitys uskonnosta orientoitumisjärjestelmänä esittää pro-eutanasiayhteisöt autonomiaa, itsemääräämisoikeutta ja individualismia vaalivana viitekehyksenä, joka torjumalla yliluonnollisuuteen nojaavan uskonnon muodostuu itsessään sekulaariksi uskonnoksi. Samaan aikaan eri diskurssit osoittavat modernin ja neo-modernin yhteiskunnan elementtien osittaisen päällekkäisyyden tukittavassa yhteisössä.

Avainsanat – Nyckelord – Keywords Diskurssianalyysi, eutanasia, itsemurha, kuolema, individualismi, kärsimys, uskontotiede, uskontososiologia
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1. INTRODUCTION

I have lived most of my life in South Finland and the county's metropolitan area. Considering my upbringing, world view, and values, I would describe myself as a quite liberal person who is open to the possibility of allowing euthanasia practice. Before beginning the research for this work, I saw an attitude against euthanasia being somewhat conservative, and in some cases even cruel. At this point, I was used to following the local discussion[1] focusing on the dying person's right to avoid the painful last moments, which the medicine couldn't alleviate and left the palliative care useless. Thus, in my mind, euthanasia was something associated with a terminal illness and relieving the excruciating physical pain caused by it. During my Erasmus exchange in Holland, I learned more about the Dutch culture – including its Christian background, the pillar society[2], and the contemporary euthanasia practice – and became curious to understand it on a deeper level. Most of all, I wanted to understand the local proponents, who actively promote to further the euthanasia practice to cover non-somatic conditions. Thus, my thesis discusses this Dutch practice, including the different ways it is promoted and the goals and values behind them. As a result, this research combines the studies of intercultural encounters and the study of religions with a sociological approach. Considering the study of religions, this research doesn't result in the most typical outcome. Still, I believe approaching the pro-euthanasia movement, which is strongly irreligious on the surface, can point out how even a secular worldview may not be free from certain sociological aspects present in (religious) communities.

Understanding assisted dying in the Netherlands calls for acknowledging the extent of it. The patient has an option to request euthanasia in case a medical condition, physical or mental, causes unbearable suffering. After decades of discussion, the parliament passed the *Termination of Life on Request and Assisted Suicide Act* in 2002. This act merely legitimized an already existing practice, since the standards of care had been set in the early '90s. Since then, physicians were not prosecuted for actions aiming to end their patients' lives, as long as the doctor had acted according to the requirements of careful practice.[3] Even though the Dutch euthanasia practice has been studied for decades, its lobbyists have received practically no attention in the academic field. Also, the popular culture has published interviews and documentaries about individuals who wish to be euthanized, and the doctors battling with their role

[1] By "local" I refer to the Finnish debate about euthanasia, which includes physically and terminally ill patients in the conversation.

[2] The pillar society or pillarization refers to a Dutch way or organizing society, by segregating different groups, which are often based on religion or political views. This is discussed further in the chapter of *Previous research of euthanasia in the Netherlands.* See de Haan 2014, 33-43.

[3] Van der Heide et al. 2007, 1958.

in this process.[4] I believe the shortage of attention towards the organizations and the ideas directing their actions make my thesis relevant.

The Dutch euthanasia practice doesn't merely exist in the pages of a law book but in the ideas and thoughts people forward and share, sometimes evolving into practice. My work looks into this aspect of euthanasia: The way the respondents address it in speech – either in anonymous interviews or talks with the representatives of different organizations. The majority of my study's primary data consists of the interviews with the employees and volunteers of the biggest pro-euthanasia organization[5] in the Netherlands: the Dutch Association for a Voluntary End of Life, Nederlandse Vereniging voor een Vrigwillig Levenseinde (referred hereafter as the NVVE). Even though 16 out of the 20 interviews were with NVVE's anonymous respondents, I also spoke with four other specialists who work to support the advancements of the practice of self-chosen death[6].

The specialists are:

• Rob Jonquiére, a former director of NVVE, a medical doctor and a member of the World Federation of the Right to Die Societies;

• Ton Vink, a philosopher offering consultation of self-determination;

• Jos van Wijk, one of the founders of the Cooperative Last Will;

• and Jenne Wielenga, a medical doctor and a manager at the End-of-Life-Clinic.

Right at the start of my fieldwork, I was told about the division of the "two camps" within euthanasia's supporters. The respondents explained to me (either during the interviews or stopping me in the office's hallway) how an advocate supports the practice either by emphasizing the role of medicine and suffering or underlining the value of individualism and autonomy. I became curious whether these two camps actually had a component of shared values and ideas, and thus have points of resemblance with sociological approaches to religion. Eventually, curiosity to learn more about these "camps," together with noticing the confluence between them and Tony Walter's ideas of death's revival, helped to form the research question. As mentioned earlier, before euthanasia was decriminalized in the Netherlands, it existed in the discursive reality where it continues to act today.[7] Not every proponent shares the same goals, as the different groups and people working among the organizations are not a uniform and undivided party. This study aims to understand this variety, and my research question is:

[4] The following documentaries give a comprehensive overlook of the Dutch practice and different euthanasia cases: Levenseindekliniek, De Laatste Dagen van Aurelia Brouwers, Global Tourist: Euthanasia in the Netherlands.

[5] I refer to the NVVE both as an organization and association: *Vereniging* translates to an *association*, but the respondents tended to refer to it as an *organization*.

[6] In most cases, this does not refer to being an actor in the actual situation of euthanasia. These specialists and their organizations are discussed in the chapter of *Right to die –movements and "the three routes*".

[7] For example, Jokinen et al examine how discourses construct social reality. See Jokinen et al 1999, 20-32. Currently, the idea of completed life exists in the discursive reality as it isn't legal but pushed by the NVVE. See for example: https://www.nvve.nl/ and https://voltooidleven.nl/.

I. What is the nature of the discourses created to reflect views on authority over dying and do these discourses address religion or indicate the differences in society according to the theory of death's revival?

In all its simplicity, my research question could be reduced to *why euthanasia?* These two words include how the respondents approach the practice and notions they present and repeat. I'm interested in what happens when the respondents describe their thoughts and what kind of discourses – and reality – they create while doing it.[8] If people experience reality through different worlds, then the respondents create discourses to reflect these worlds when sharing their thoughts.[9] After all, how a specific culture approaches death and dying touches something very profound in it. Choosing discourse analysis as the theoretical background gives a front row-seat to examine the process of speech as an action baring the attempt to influence the listener.

1.1 Position as a researcher – Self-reflection and the motivation to conduct the research

It is fair to note that I developed an interest in the topic early in my studies. As a freshman in the study of religions, I participated in a reading circle, organized by the subject's student association. From a list of topics, all the participants selected an article to present to others. Leila Jylhäkangas' study about how Finns write about euthanasia[10] caught my attention, and I have been following the discussion around the topic ever since. When I began my fieldwork in 2017, the topic was very timely in Finland and a question in the county's politics. At the time, one couldn't avoid hearing various opinions and stories of self-chosen death and reasoning why the society should or should not allow this. Finally, the debate even reached the Finnish parliament, and the citizens' initiative was handed to its spokesperson in February of 2017.[11] The topicality of euthanasia in Finland, and the questions and worries it raised motivated me to proceed researching the state of euthanasia in another society.

I believe the fact that I'm not Dutch myself worked both for my benefit and against me while collecting the data. During several interviews I had the impression that the respondents found me to be neutral or an outsider in two different ways: I was a foreigner who didn't work in a pro-euthanasia organization. At the same time, I had lived in the Netherlands shortly before, and knew the basics of the language. I

[8] The concept of discourse and discourse analysis are explained in more detail in this work's methodology chapter.
[9] Paden's idea of reality as different worlds observes religions as existing in their own universes. See Paden 1994, 51-65.
[10] Jylhäkangas 2005, 1-17.
[11] https://www.eduskunta.fi.

had also familiarized myself with the relevant Dutch concepts and main characteristics of the local development in applying the euthanasia-law. This made me someone without ready-made views of the Dutch pro-euthanasia field but also a person who could understand its basis, and thus be talked rather freely. On the other hand, in some instances, being an outsider also meant that the respondents did not expect me to apprehend them. Some pointed out how they experienced parts of the Dutch culture – such as the availability of drugs, prostitution, and euthanasia – being sensationalized outside the Netherlands, and how they were not interested in defending these practices for outsiders. When the respondents asked about my personal view, I always answered that I hope the law allowing euthanasia for the terminally ill people would pass in Finland, but other than that, I'm still forming my opinion. This remains to be my (unclear) position. While writing this research, I caught myself being quite disappointed when the euthanasia law did not pass in Finland in 2017. On the contrary, I was somewhat relieved when the law of Completed Life failed to proceed in the Netherlands the same year.[12] [13]

When I began the writing process, I occasionally found myself worried about the possibility that the interviewees wouldn't like my research or agree with the results. How could I disagree or question the views of the people who gave me their time, welcomed me into their community, and opened up to me? Throughout the process, I had to remind myself of staying as neutral as possible. I wish the outcome of this process manages to contribute in discussing the multifaceted question of euthanasia, by succeeding to understand the different sides of Dutch pro-euthanasia community by giving voice to its proponents. I hope this to shed light into the discourses surrounding the practice in relation to society and consider its commonalities with the cultural factors of the Revivalist Movement. Even though the historical aspect isn't in the center of my focus, it couldn't be avoided, since many of my interviewees strongly emphasized this factor. I also wish to contribute to the tradition of addressing the recognition and use of discourse as a tool to seek impact - such as taking a stand on the limits of dying.

1.2 The structure of the work

The research is constructed as follows: After briefly introducing the research topic and its key concepts I discuss the research material and how it was collected by the thematic and semi-structured interview technics. In the section of previous research, I describe the Dutch euthanasia practice from the sides of the doctor and the patient. After this, I open the theoretical and methodological approach of this work, by discussing the nature of discourse analysis, sociology of religion, and a theory of death's revival according to Tony Walter, its dedicated advocate. As the idea of death's revival as a tool for analysis is in a significant role in this work, I break down its key components. Since the Dutch euthanasia practice

[12] https://www.eduskunta.fi.
[13] https://www.theguardian.com. The issue of completed life is discussed later in this work.

was formed in a courtroom by certain watershed cases, I describe the key points of these trials, such as expanding euthanasia from physical suffering to mental and existential pain. The Dutch right-to-die movement consists of several organizations with a different understanding of how to reach the end of life, which can be mastered by selecting the medical, autonomous, or assisted approach. In the analysis, I apply discourse analysis and Walter's theory of death's revival and the commonalities the result have with the idea of religion, in accordance with thoughts presented in the sociology of religion. I aim to see what kind of forms of society the discourses present as the respondents discuss the topic. I analyze whether the authority over dying is given to doctors or preserved by the self, and what this authority may symbolize. At the end of the study, I draw my conclusions and introduce possible subjects for future research.

2. THEORETICAL FRAMEWORK AND METHODOLOGICAL ORIENTATION

This interdisciplinary research locates simultaneously in the fields of intercultural encounters and sociology of religions. The theoretical approach of this study is sociological and manner of data collection ethnographically-based. As a theoretical frame, the sociology of religion can look into the shared values within various groups and communities, whether they are at first glance seen as secular or religious. Thus, religion is examined as a social organization or ideology: Durkheim presents that religion is the whole of different values, ideals, and norms that are collectively shared and maintained by the society.[14] Erickson Nepstad and Williams interpret his theory by stating, *"religion is the articulation of a social connection and collective identification."*[15] On the other hand, Waardenburg's definition presents religion as an orientation system, which shows the individuals a framework to follow and find a way to be oriented towards life, society, and the world.[16] In a similar manner, Geertz presents that all relations, such as the meaningful relation between the human and the world, (whether the world is understood as divine or natural) other humans and the community, all happen and become understandable by religion that can also be viewed as a shared cultural system.[17]

According to Demerath, until the late '70s, the notion of non-religious views pushing traditional religions aside received a fair amount of attention among scholars, and irreligious thinkers welcomed the weakening position of organized religion. Surprisingly, in recent decades, the understanding of the secularization process has been questioned, and some critics call it a false hypothesis. For some,

[14] Laitila 2007, 17; Durkheim 1980.
[15] Erickson Nepstad & Williams 2007, 420.
[16] Waardenburg 1986, 31.
[17] Geertz 1973, 3-10, 40-41; Erickson Nepstad & Williams 2007, 420.

secularization merges with sacralization by forming a continuum that keeps relocating the idea of sacred.[18] Demerath proposes that the secularization and sacralization converge, and are to some extent, *"linked to insure some constant level of sacredness in an individual or social unit*.[19]" In this study, the social unit or community is the Dutch pro-euthanasia field and the profound or fundamental ideas they hold: The shared and not shared points of culture. This research approaches the presence of religion on two separate levels. Firstly, if religion is understood as a collection of ideas, or orientation systems, this study pays attention whether the non-religious pro-euthanasia group itself possesses elements of a religious community. Secondly, attention is paid in if and how the respondents directly address religion. Consistent with sociological research, an essential part of the process is collecting and creating the new data in the present, in this case, by carrying out interviews.[20] In this chapter, I present the theoretical framework, the research data, and questions concerning the methodological aspect.

Before proceeding, it is necessary to underline how euthanasia laws are not introduced randomly in different societies, but how all of these countries have gone through a particular cultural and societal transition. Rietjens argues that three changes in society are linked with euthanasia's legalization: Increasing individualism combined with diminishing taboos around death and questioning the meaningfulness of prolonging life. Even though these changes have taken place in many western societies, only a few countries have actually legalized euthanasia.[21] Demerath links increasing individualism with the process of the converging secularization and sacralization. By introducing the pieces of this study's framework – key concepts, theoretical ideas, and previous research – I hope to make some of euthanasia's social aspects comprehensible to support the later analyses.[22]

2.1 Key concepts

In this sub-chapter, I open briefly the meaning of the relevant concepts used in this work. Some of these concepts are best understood as parts of the historical contexts that initially brought them up and introduced in more detail in the chapters of *Euthanasia's history in the Netherlands* and *Right-to-die movements and the three routes.*

Three routes

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[18] In itself secularization as a term covers a wide range of meaning and defining them goes beyond this research. See Demerath (2007, 57) about the responses to secularization. He also defines the process of sacralization (66) as: *"the process by which the secular becomes sacred or other new forms of the sacred emerge, whether in matters of personal faith, institutional practice or political power. And sacralization may also 'occur gradually or suddently, and it may be sometimes temporary and occasionally reversible.'"*

[19] Demerath 2007, 67.

[20] Laitila 2011, 96-97.

[21] Rietjens et al. 2009, 274.

[22] Pihlaja (2004, 106) discusses the role of different components of the theoretical framework.

The NVVE introduced me to one of their goals: Making *the three routes* an accessible reality. These routes are called the medical -, autonomous -, and assisted route. The routes are used to describe the different options to choose from when ending one's life: Whether the person assisting is a doctor who administers the drug (medical), or only prescribes it without being part of the process (autonomous), or somebody else of the patient's choosing assists with the technicalities (assisted). The routes refer to technical notions of the dying process and methods: Who helped the dying person or whether the person ended his or her life without assistance. Strictly speaking, the current Dutch system allows only the medical route, as the doctor is the one performing the euthanasia.[23] The familiarity with the concept of three routes helps to understand how, and in which form, the respondents of this study support the practice.

Euthanasia

The Greek word *euthanasia* has its roots in antiquity: *eu* translates to *good* and *thanos* to death. Thus euthanasia literally means good death. Originally the word referred to a death which occurred peacefully by itself and without any assistance. Only in the 19th century, the doctor's actions began to be associated with the term.[24] In most cases, the word is used when a physician knowingly carries out the final act that occurs only when a legally competent patient repeatedly requests to die.[25] [26] The Dutch define euthanasia as *"intentionally taking the life of another person upon his or her explicit request.[27]"* In a case of physician-assisted suicide (PAS) the doctor provides the patient with the lethal substance, which the patient himself takes. Strictly speaking, euthanasia only refers to a situation where the life of another person is terminated after an explicit request.[28] Euthanasia and assisted suicide differ only in technical detail.[29] Since in the Netherlands doctor is always involved in euthanasia and physician-assisted suicide, these both go under the category of *the medical route*. In the interview data and the general conversation euthanasia and the doctor-assisted suicide are practically used as synonyms. Even though in academic publications commonly referred with the abbreviation *EAS*.[30] [31] In the sake of the readability of this research, I do the same unless otherwise specified. Underlining all the technical details might appear as

[23] The three routes were brought up by most respondents and discussed in one form or another in every interview. The routes are also introduced in a separate document available on NVVE's website (see bibliography for the full link).
[24] Pöysti 2009, 7.
[25] Jylhäkangas 2005, 2.
[26] Pöysti 2009, 7.
[27] Thomasma et al. 1998, 3.
[28] Weyers 2006, 802.
[29] Jonquiére 2006, 172.
[30] For example, it is common to use the word *euthanasia* when referring to cases of physician-assisted suicide, such as the laws in Switzerland or certain states in the United States of America, even though these are cases of physician-assisted suicide. Samia A. Hurst and Alex Mauron (2003, 271) discuss the role of physician and non-physicians in euthanasia and assisted suicide in Switzerland, Holland, Belgium, and Oregon.
[31] EAS comes from combining the two terms: euthanasia & physician-assisted suicide. Van der Weide, et al. 2005, 1698.

hair-splitting precision, but it is relevant since the organizations have it on their agenda to change or extend these technicalities. The examples described above are occasionally referred to as *active euthanasia.* The rarely used term of *passive euthanasia* means the withdrawal from any available treatment, thus lacking any concrete action to end a life.[32]

Completed Life and the Last Will Pill: Drion's pill

In 1991 Huib Drion, a former Supreme Court judge, argued that a doctor should provide people of 75 years or older with the means to end their lives if they so wished. According to Drion, this way the elderly could have the feeling of not having to experience dependency and decline. The press began to call this idea, "*the autonomy from any real medical involvement*[33]*"* as Pil van Drion[34]. After the decriminalization of euthanasia, the NVVE began to promote the discussion on *the last will pill*.[35] In a more recent development, the debate has followed Drion's ideas and proposed to extend the euthanasia law to older people, calling this the case of a *completed life*.[36] Another conversation has taken a step forward from the issue of age and suggests that any adult person should be provided the means to kill him- or herself if one so requests, thus completely erasing the doctor's role from the self-chosen death.[37]

Pro-euthanasia and the Right to Die Movements

In the global context, several organizations and groups together have formed *The World Federation of the Right to Die Societies (WFRtDS)*.[38] In this study, I talk about the Dutch pro-euthanasia movement and organizations linked to it, whether or not they are members of the World Federation. Each of the organizations that took part in this study has a different focus but loosely defined the unifying factor shared by them all is to ensure a person's possibility for self-determination at the end of their lives. [39] Even though some of the respondents in this study may have contradictory values and objectives, I refer to them all as pro-euthanasia.

Revivalist Movement

In the turn of the 19th century, scholars began writing about the *dying of death* and how the end of life had become a taboo and something to be hidden.[40] [41] *Death's revival* refers to the end of hiding death, and the assumed return of it as a topic of discussion, and the increased attention it attracts in the current

[32] Breck 2008, 389-390.
[33] Sheldon 2004, 1204.
[34] In English *Drion's pill.*
[35] Sheldon 2004, 1204.
[36] Kessler 2018, 231-234
[37] See Attachment 2: The press release by the Cooperative Last Will – legal last aid available**.**
[38] More information about the World Federation of the Right to Die Societies: https://www.worldrtd.net/
[39] The organizations are discussed in more detail in the chapter of *Right to die movements and the three routes.*
[40] Kübler-Ross 1970, 7.
[41] Joseph Jacobs 1899, 264.

society. Possibilities offered by modern medicine, and the lost authority of the religion telling people how to die, have strengthened *the letting go of life* as something to be done *my own way*.[42] Kübler-Ross claims that as medical science improves, so does the fear towards death grow. As medical development has wiped out many diseases in the Western world, it has also contributed to dying becoming more lonely and technical. Unlike dying at home in a familiar environment, without the efforts of trying to prevent death, the patient is rushed into an emergency room. When great measures are taken to keep the person technically alive, the end of life is impersonalized.[43] According to Gittings, in an individualistic society religion has lost (some) of its power of dictating how to deal with death and dying. Despite the lost authority of religion, the rational role of science hasn't been able to compensate for the fear left behind, making the new direction of dying in one's own way a consistent outcome of the Western individualism.[44] Today the hospital staff is encouraged to treat the dying patients as individuals, combining the personal aspect with the expertise of advanced medicine.[45] As medical discourse could not satisfy the personal needs, the individuals began the process of taking back the control of dying. Although this time with the expectation of having access to the relief offered by modern medicine, without returning the control to it.[46]

2.2 The thematic and semi-structured interview as a research tool

The primary data of this study consists of twenty interviews. Out of this total, nine respondents were employed by the NVVE, seven volunteered for the association, and four of the interviewees were representatives of the different sectors of Dutch pro-euthanasia field. I refer to the last group as the *specialist interviews,* and only these interviews were not anonymous.

As a tool for collecting data, the advantage of using the semi-structured interview is its flexibility to allow the researcher to attend exact areas and details of the research question, at the same time enabling the respondents to present new ideas and meanings. According to Galette, the semi-structured interview, *"responds to an imperative for fine-grained qualitative analyses in order to open up new possibilities in understanding complicated phenomena often accepted as unproblematic.[47]"* It appears the semi-structured interview does not only allow to examine the specific question, perhaps previously viewed as a simple matter, now as something multifaceted, but it allows the interviewees to be more than just

[42] Walter 1994, 2-3.
[43] Kübler-Ross 1970, 1-2, 7-8.
[44] Gittings 1984, 188, 211-213.
[45] Walter 1994, 3, 9, 26-27.
[46] Ibid., 139-141.
[47] Galette 2013, 2.

respondents, but active participants offering new meanings to consider.[48] The semi-structured method can be used to navigate the interview from open-ended questions to more detailed and specific matters. Due to its adaptability, this interview technique can be used in various ways: It can appear either as the only method or one of many. Its focus combines the theoretical curiosity with what Galette calls *"the lived experience.*[49]*"* Since the semi-structured interview presents the same themes to every respondent, just as the thematic interview, this approach may be referred to with both terms.[50] When preparing the questions for the interview, I wanted to form them in a way that would leave space for the respondents to bring out and discuss the points and ideas that matter to them. At the same time, I needed the data to address the research question: What is the nature of the discourses created to reflect views on authority over dying, where do these discourses place religion, and do they indicate the differences in society according to the theory of death's revival? In itself, the research question appears as one that requires a group of smaller questions to gain any results and findings. I chose to seek the answer to this by forming a set of open-ended questions addressing the respondents' personal views and thoughts about different dimensions and controversial issues. I expected this to indicate the respondents' values and core notions for advocating the possibility of a self-chosen death. Importantly, I never asked directly about religion but paid attention to when the topic was brought up and how it was discussed. Even though I had presumptions about the themes that would likely to be brought up, I wanted to find out what type of expressions the respondents would use. In other words, how they support the practice. Therefore, when outlining the interview frame, I already had begun to turn over different possibilities for the analysis in my mind.

Occasionally I found myself overwhelmed with the amplitude of new aspects and the countless possibilities for further research questions opening up in front of me when using the semi-structured interview method. According to Hurme, interviewing is generally, but incorrectly, viewed as an uncomplicated tool to collect data. Interviewing somebody is a situation of social interaction, an exchange between the researcher and the participant, where the message received is never without errors. At the same time, this method gives both the respondent and the interviewee the possibility to clarify meanings.[51] Interviewing people also incorporates an element of unpredictability, which requires reflexivity from the interviewer's part.[52] In the case of this study, during one interview, the respondent burst into tears, and in another instance, the interviewee told me how she actually was not pro-euthanasia. In these situations, I needed to adapt to what had happened and diverge from the original order of the interview frame by giving the respondent the much-needed space. I had a checklist of the questions with me in every interview, but since every encounter was different, I did not follow the list

[48] Galette 2013, 24.
[49] Ibid.
[50] Galette 2013, 24, 45; Hirsijärvi & Hurme 2001, 48.
[51] Galette 2013, 2, 24, 75; Hirsijärvi & Hurme 2001, 34-35, 41, 49.
[52] Galette 2013, 104.

religiously. Often the respondent covered a question I had in mind even before I even asked it, and occasionally, the interview took a surprising turn, and I came up with new questions. For example, I spoke with seven of the NVVE's consultants, whose volunteer work takes them to visit the people that wish to die. Understandably an interview such as this may raise different questions than an interview with a person working at the organization's administration. All the anonymously interviewed respondents signed informed consent, and they had the opportunity to read the transcript of the interview.[53]

Picture 1: NVVE's office, interview room with the class wall and blue carpet on the right. Picture taken by the author.

Picture 2: Interview room at the NVVE's office. Picture taken by the author.

2.2.1 Research materials and ethical questions

In the original plan, the interviews were not supposed to play the central role, as I had planned to conduct a more ethnographical study, consisting mainly field journal notes and observations of participating in the everyday chores at the office. After my arrival in Amsterdam, the circumstances had somewhat changed, and the interviews turned out to be the main source for data. Before I began the interviews, I was worried if I would have enough participants, but the challenge ended up being quite the contrary as

[53] Informed consent in the attachments.

over twenty people were willing to be interviewed. I attempted to schedule as many interviews as possible since I was constantly afraid that the participants would cancel the appointments.

All the interviews were carried out during the two and half month period I stayed in Amsterdam. The first interview took place in late May in 2017 at the NVVE's office in Amsterdam and the last one in mid-August in 2017 in the province of Gelderland. I was able to interview almost every person that expressed their willingness to meet with me. When looking for people to interview, my contact person at the NVVE assisted me in the beginning, to get in contact with the potential respondents. First, I focused on interviewing NVVE's employees by providing my contact person with a short, written description of the interview and my research. Based on this description, she sent a group email to her colleagues at the office.[54] Nine members of the staff volunteered to be interviewed, and I scheduled the appointments either via email or face-to-face at the association's office, where all the staff-interviews were held. After being nearly finished interviewing the staff members, I began to prepare to find theorganization's volunteers to interview. Again, my contact person made it possible for me the get in touch with the potential respondents, by including a short description of my study in the NVVE's email-newsletter. Based on this description, ten volunteers expressed their interest to participate in my study, but out of this number, I was able to arrange seven appointments. In two instances I was not able to travel to meet the volunteers at their place of stay, and at the end of my stay in Holland, I had to cancel an already scheduled interview due to becoming ill. The interviews were scheduled with email and one over the phone. I emailed the participants the informed consent before the scheduled interview and brought two copies with me to for them to sign before the interview. In a few instances, emailing the informed consent was not possible, and the respondents were able to read the copy only right before the interview. In order to protect the respondents' anonymity, I won't mention the exact town where the interviews took place, unless in the association's office in Amsterdam. Three of the volunteer-interviews were carried out at the Amsterdam office, one at a Café in South Holland and three at the participants' homes across the Netherlands in the provinces of Gelderland, South Holland, and North-Brabant. Five of these interviewees were currently staying in the provinces of North and South Holland.

The interviews lasted from 43 minutes to almost two hours. The youngest person I interviewed was in his or her early twenties, and the oldest over 80 years old. The members of the staff participating in my study were from various age groups, but apart from a few exceptions, all the volunteers were pensioners. I did not enquire the respondents' background or education. Equally, men and women participated in my study, as I interviewed ten women and ten men. This even gender distribution was not planned, but I believe it benefits the data's credibility and its generalizability. Considering the data's credibility, it would have been ideal to interview people evenly in every province. Unfortunately, this wasn't possible,

[54] Copy of the email in attachments.

since the people willing to participate in my study were mostly concentrated in Amsterdam and having no funding for the research set limitations for travelling. One possible explanation for why such a high percentage of the participants were concentrated in the capital is the language. The volunteers were informed that the interviews will be done in English, and potentially living close to the capital makes people more used to using English with foreigners, such as myself. When transcribing the data or quoting a respondent in this study, I chose to translate the possible Dutch words in the footnotes but use the original expressions in the text itself. The same applies to any occasional English errors. Because my research is about *how* the respondents support the euthanasia practice, and the analysis relies to a great extent on the specific words they use while creating discourses, I saw it best to refer to the material with the precise words used. Then again, I made a choice to not to include pauses and tones, because I didn't find them to contribute to the research agenda.

When referring to the anonymous staff interviews in this work, I don't mention the respondents' profession or other information revealing the person's identity. This is crucial as the office has about thirty members of the staff and mentioning a person's profession or occupational title would easily uncover his or her identity.[55] In the case of volunteer interviews, I may refer to the type of volunteer work the respondent does – whether he or she is a consultant that visits the members in their homes to discuss their wishes and answer any questions, or gives presentations at the association's events, or assists the members to draw their advanced directive-documents – in case it contributes to the reading of the analysis or examining a specific quote. The NVVE has approximately 160 volunteers across the country, thus making the identification less likely.[56] In the case of all the interview quotes, I use the respondents' pseudonyms and when needed the letters 'L' for the interviewer and 'R' for the respondent.

The specialist interviews cover a significant part of the different aspects of the local pro-euthanasia field. The appointments were arranged by email and one over the phone. The time I scheduled the interview with Rob Jonquiére, he was – for the third time – the director of the NVVE, but at the time of the interview, he had retired, though still working with the World Federation for the Right to Die Societies. The interview with Jenne Wielenga, a doctor, and the medical manager of the Levenseindekliniek took place at the Clinic's office in The Hague. The interview with Jos van Wijk took place at a café in the province of Gelderland. I interviewed Ton Vink at his practice, also in the province of Gelderland. Only Ton Vink required to read and comment on the transcript before agreeing to participate in my study. After I send him the transcript, he wished to erase one of his responses from it, explaining it was not right in terms of his clients' privacy. The other three experts I interviewed did not wish to see the transcripts.

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[55] www.nvve.nl.
[56] Ibid.

2.3 Previous research of euthanasia in the Netherlands

There is an extensive amount of previous research about euthanasia in the Netherlands, covering different aspects of the practice with the focus on the physicians and the patients. Discussing a few of these previous studies introduces some of the field's core questions and the surrounding debate. As these studies do not focus around the organizations, looking into them means looking into the widely studied aspects of the Dutch euthanasia practice: The reasons why doctors agree or refuse to assist with dying, the end-of-life practices and the impact this has had on the Dutch society.

One ingredient for the explanation of the Dutch euthanasia practice is in the way the local health care is organized: Practically everyone in the Netherlands is covered by health insurance and has his or her primary care physician. The patients have a long-lasting relationship with their doctor, and end-of-life care is often provided at home.[57] Besides health care, Dutch culture has other values that contribute to enabling the practice. Principles such as candor, directness, and open discussion together with welcoming new ideas are greatly valued. The heritage of the *pillarization,* referring to the social segregation of different groups by providing each of them with their channels for social reality, still affects the contemporary Dutch society and the way other groups are viewed and allowed to act.[58] Also, the role of political decision making is seen as *directing* the change instead of *preventing* it.[59] Instead of prohibiting the doctors' involvement in hastening the death of patients requesting so, the authorities began to monitor the practice.

Rietjens paints an overview of the euthanasia research over the past two decades. The study points out how euthanasia is debated in many countries, and usually, the arguments are based on personal feeling and understanding of moral. Thus, empirical research based on facts helps to have a more fruitful discussion.[60] Van Marwijk and Haverkate have researched the impact euthanasia has on general practitioners in the Netherlands. They point out how the Dutch GPs[61] have traditionally enjoyed great freedom in their decision making over life and death, and that patients rarely change their physician,

[57] Cohen et al. 2008, 703-709. See also van der Heide 2007, 1957-1965.
[58] The pillar society or pillarization refers to a Dutch way of organizing society, by segregating different groups, which are often based on religion or political views. Even though different groups are often concentrated in their own areas, the segregation refers mostly to the different social reality among the groups: Every pillar may have their own newspapers, tv-channels, schools, and various clubs. This politico-denominational form of society may result in preventing contact with people from another pillar. The pillarization was strongest from the nineteenth century till the 1060s, though it still influences the society. See de Haan 2014, 33-43.
[59] Rietjens et al. 2009, 274.
[60] Rietjens et al. 2009, 271.
[61] GP = general practitioner.

contributing to the trust between both parties. The physicians described emotions from feeling touched by the trust and commitment to feeling traumatized and even suicidal, expressing feelings of anger, frustration, or unfairness for being expected to perform euthanasia.[62]

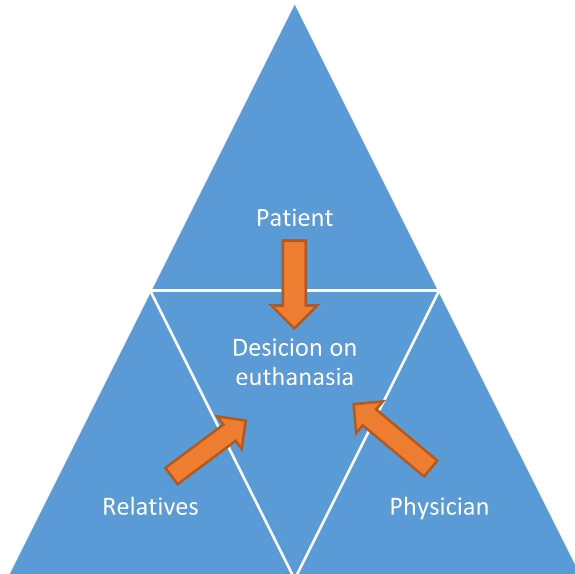
In their study of physicians' decisions concerning euthanasia requests, Van der Weide et al. concluded that the most common reasons for uncertainty from the physicians' side were doubts about the hopeless and unbearable nature of the suffering and availability of other treatment. When the request was refused or when a patient changed his mind, the physicians often doubted how well considered the requests were in the first place, and the role of depression influencing them. The doctors also mentioned the *pressure of next-of-kin* more often in the cases where the patient died before the final decision was made.[63] When the patients brought up the fear of suffocation, pointless suffering, or the loss of dignity, the doctor was less likely to refuse the request. On the contrary, when the doctor doubted the patient's competence, the lesser extent of unbearably or hopelessness of the suffering, the euthanasia was more likely denied. Patients were also found to hide their depression from the physician, fearing it would cause the request to be rejected. In 44% of the cases when euthanasia was explicitly requested, it was also granted and performed.[64] The study concludes that the patients assume that the nature of suffering matters and fear the mental suffering would prevent the fulfillment of the euthanasia request, even when it was based on suffering from a physical origin.[65]

Snijdwind examines the complexities of euthanasia and physician-assisted suicide as perceived by Dutch physicians and patients' relatives.[66] The research categorized the complexities into those arising from unexpected situations or relational difficulties, such as the sometimes invisible nature of the suffering, miscommunication, and the absence of growth towards euthanasia.[67] Another research by Snijdwind examined how much the relationship between people involved in the process affected whether euthanasia was performed or not. The study suggests that euthanasia should be seen as a process of a triangle between the physician, patient, and relatives: Even when doctors expressed having a sole focus on the patient, they might refuse to perform euthanasia if they felt the next of kind couldn't handle it. Also, if the physicians did not know the patient, the process of growth was missing. In such cases, doctors were more likely to turn them down even in case of severe conditions. It is easy to assume that

[62] Van Marwijk et al. 2007, 609-612.
[63] Van der Weide et al. 2005, 1701.
[64] For comparison, when one in eight requests was refused in the Netherlands, in Oregon, this number is one in two. In the Netherlands, 12% of the physicians would never be willing to prescribe their patient the lethal medicine, when this percentage is 37 among the doctors in Oregon. Van der Weide et al. 2005, 1702-1704.
[65] Van der Weide et al. 2005, 1704.
[66] Snijdewind et al. 2014.
[67] Ibid., 1125.

euthanasia is an isolated event involving only the patient and the physician, but the research shows a bigger circle of people the decision involves in different phases of the process.[68]

Figure 1: Process of the euthanasia decision



The figure is made by the author. Snijdewind suggests that even though the patient requests to be euthanized, the reality as to whether this happens should be seen as a triangle that also includes the physician and the patient's relatives. Also, Van der Weide et al. mention "the pressure of next-of-kin" as one factor influencing the physician's decision of euthanasia. [69]

2.3.1 Measuring the unbearability of suffering – The role of empathy

Any debate, lecture, or academic article aiming to discuss euthanasia cannot avoid including the role of suffering. One of the requirements of the Dutch *Law on Termination of Life on Request* is that the physician believes the patient's *suffering is hopeless and unbearable.* Occasionally the physicians doubt and struggle to understand the patients' suffering. This is especially the situation with psychiatric illnesses when the condition is not physically visible.[70] Van Tol et al. have researched the understanding of unbearable suffering: The role of empathy and the application and the willingness to grant the request.[71] This study of empathy and the application of the criteria of unbearable suffering focuses on 15 doctors by asking how they make their judgment. The study concluded that doctors use different cognitive routes to make the decision: The physician may imagine how he would experience the condition or aim to understand how a particular patient experiences it. In both cases, the doctor's decision is always influenced by his personal feelings, views, and norms about euthanasia and performing it. As suffering is a very subjective experience, the doctors find this the most demanding criteria in their decision making.[72]

[68] Snijdewind et al. 2014, 1129, 1131-1133.
[69] Snijdewind et al. 2014, 1129-1133; Van der Weide et al. 2005, 1701.
[70] Snijdewind et al. 2014, 1130.
[71] Van Tol et al. 2012 (and 2010).
[72] Van Tol et al. 2012, 296-297.

When discussing the role of empathy, the physicians were balancing the impact of *imagine self* and the *imagine other*-approaches. Van Tol's study points out that when doctors use *the imagine other*-approach, they stress the patients' biography and personal traits in their decision-making process.[73] The process of evaluating whether one's suffering is enough, binds together the emotional world and empathy, with the technical assessment process to estimate the law's requirements. In practice, the doctors with more experience with euthanasia were more likely to agree with the patient's experience of the suffering as unbearable. Most doctors tend to require the patient's suffering to have a somatic origin but might occasionally make exceptions. Thus, evaluating unbearable suffering is open to interpretation and relies heavily on the doctor's ability to empathize.[74]

The reports by the Regional Review Committee (RRC) offer another source to interpret the criteria of unbearable suffering.[75] The reports paint an interesting picture of suffering as a question wrestling between two worlds: Personal and mental experience are bound together with a commonly understood and measurable factor. On the one hand, the reports state how persons suffer instead of bodies. Eventually, the committee state that even though suffering is subjective, it should be understood inter-subjective in a sense that makes it assessable for others. The physician must judge the patient's experience of suffering, so the assessments always rely to some extent on the doctor's compassion. The RRC has advised the physicians to consider whether the patient's situation is unbearable for the patient *himself* – not to the doctor making the assessment or people in general.[76]

2.4 Discourse Analysis – the Theory in the Background

Discourse analysis approaches speech as a way to forward meaning.[77] When statements, expressed for example, in a conversation or written text, are connected, we have a discourse.[78] Discourse forms an organized entity, which is a goal-oriented process that can be provided with a heading.[79] In this study, I observe the interviews of the people working in the Dutch pro-euthanasia field, as this goal-oriented action from the perspective of qualitative research practice. Before my fieldwork in the Netherlands, I had not realized how broad the field of discourses surrounding the advocacy is. As Eskola and Suoninen

[73] Van Tol et al. 2012, 299-301.
[74] Van Tol et al. 2010, 170-171.
[75] Regional Euthanasia Review Committees' Reports are available online: www.english.euthanasiecommissie.nl.
[76] Van Tol et al. 2012, 297-299.
[77] Ilmonen 2010, 127.
[78] Hirsijärvi & Hurme 2001, 51.
[79] Caron 1992, 53.

point out to be often the case with qualitative study, the theoretical framework was constructed in a dialogue with the research material.[80]

From the perspective of discourse analysis, speaking causes us to take a stand on the broader social reality, in which we do not exist alone. If the social reality involved only one person, we would not need to influence it by expressing views via discourses. According to Wooffitt, *"language can be used to produce factual or authoritative accounts.[81]"* Considering the background of my research topic, the Dutch lawmakers did not introduce the Euthanasia Act overnight, but euthanasia existed first in coffee table conversations, television's talk shows, and newspaper articles – the discursive reality. The idea about language being most of all a builder of this reality is called constructionism. This idea doesn't understand the use of the language of simply being a channel for reality but an inseparable part of it in itself. The constructionist perspective of language as the generator of reality proved to be a helpful idea when writing this study: As a background notion, it contributed in understanding how the interviewees didn't merely comment but *constructed* the society's relation with self-chosen death and themselves as an organization.[82]

My objective is to find common suppositions, comparisons, repetition, and trains of thought, which create and point out the existing discourses. This demonstrates and makes visible how supporting the practice with speech and the use of language create a set of discourses favorable for it: For example, how religion can be viewed as the articulation of social connections.[83] When discourse analysis examines the meanings passed on by language, it makes it possible to observe how social reality is influenced and produced through it.[84] According to this view, we never merely describe the reality but inevitably create it, allowing us to approach a written text with the background notion of language's role as something that forms reality.[85] Discourse analysis has been used in various ways, and it cannot be understood as a uniform and coherent method of data analysis. This approach allows the researcher to pay attention to how language produces representations of reality, and the focus is not in finding a representation of truth.[86] In light of this, choosing to use discourse analysis as a theory felt natural as I'm interested in finding out how the respondents use the language to express their support for the practice and observing what they actually do when they discuss the topic – in this case, where they place authority and religion.

[80] Eskola and Suoranta 1998, 19-20.
[81] Wooffitt 2005, 3.
[82] Jokinen et al. 1993, 9.
[83] Erickson Nepstad & Williams 2007, 420.
[84] Ilmonen 2010, 133; Jokinen 1993, 10.
[85] Jokinen et al. 1993, 27.
[86] Suoninen 1999, 19; Pesonen 1997.

2.5 Choosing the method for data-analysis – The Revival of Death and authority over dying

As mentioned, the very first day I entered NVVE's office in Amsterdam, several respondents pointed out the existence of the *two camps* within euthanasia's supporters: I was told how an advocate tends to support the practice either by emphasizing medicine and suffering or underlining the value of individualism and autonomy. I could not forget this once it was mentioned to me, and began to see the interviews through this idea. That is to say, my analyses were subjected to biases before any other part of this work was written. Right after finishing the fieldwork, I came across Tony Walter's theory of the Revival of Death. Reading about his ideas of different cultural responses to death influenced how I began to understand and examine the research data. I perceived Walter's analyses to speak about the same phenomena the respondents brought up, only with different concepts. Before I wrote the first sentence of this work, I had already begun to consider the collected data in light of Walter's conclusions. In a way, I began to utilize this tool for data-analysis very early in the process.[87]

With the help of discourse analysis as the theoretical background, I aim to have a dialogue with the material and not to make a complete list or index of the discourses emerging from it. In the method of data-analysis, I use mainly Walter's theory of the revival of death. I also apply loosely Leila Jylhäkangas' idea of rolling speech in euthanasia comments,[88] and from time to time refer to Durkeim's, Waardenburg's, Demerath's and Erickson Nepstads & Williams' views and definitions of religion. I have organized the analysis chapters in themes by thematic wholes, which allow me to have a conversation with the research material and the theory. By doing this, I'm able to observe the respondents' speech as social action with relation to the revivalism, which is the topic of the next chapter.

3. DYING MY WAY – DEATH CULTURE IN TRANSFORMATION?

In this chapter, I present Tony Walter's theory of the Revival of Death and how I will use it as the method of analysis. Walter's theory is a sociological analysis of western death. One of the main

[87] In the fall of 2017, I attended a course about *Death, Ritual and Belief: Cross-Cultural Perspectives* and the key points of Walter's theory were introduced in the 11th of December, during a class about postmodern deathways.

[88] Jylhäkangas uses the name *rolling speech* for the comments that are unsure, balancing their opinion, or inconsistent in their statement. See Jylhäkangas 2005 and 2013.

arguments of Walter's theory is that the newly discovered authority of the *individual self*[89] is the engine for the current revival and changes in dying and death.[90] In other words, individualism has not only revolutionized living but dying as well.

Today death and dying are shaped more and more by the dying and mourning individuals themselves, moving away from the rules of religion or medicine. A culture that values individualism and the unique choices of each individual, also logically sees a good death as one the individual chooses. Living in my way implies – or even requires – also dying my way.[91] The aim to control death has many different approaches, such as the hospice and euthanasia movements. Even though the hospice movement generally does not view the euthanasia practice positively, nevertheless the two groups share a common goal to take back the authority from the medicine and church. Whereas the hospices are not in favor of euthanasia, they deliberately withdraw from life-prolonging care, encouraging to let the people *die as themselves*.[92] The groups on both sides, the advocates of euthanasia or those in favor of the hospice philosophy, both share the view that a good death is one where the person dies in his own way. Where the opinions differ, is how one should reach this way. [93]

3.1 Three types of death – Traditional, modern and neo-modern

In his theory, Walter introduces three cultural responses to death: traditional, modern, and neo-modern. He claims that none of these types of death exist outside the society, but are rooted in particular social and bodily contexts, which all permit a specific kind of authority. However, my work mainly utilizes the idea of *authority* instead of *social and bodily context.* Below the theory's building blocks and the main features:[94]

	TRADITIONAL	**MODERN**	**NEOMODERN**
BODILY CONTEXT	Death quick and frequent	Death hidden	Death prolonged
SOCIAL CONTEXT	Community	Public vs private	Private becomes public
AUTHORITY	Religion	Medicine	Self

[89] Italics added by the author.
[90] Walter 1994, 28.
[91] Walter 1994, 2, 37.
[92] The withdrawal can be interpreted of being passive euthanasia. See Breck 2008, 389-390.
[93] Walter 1994, 29-30. Read more about the hospice movement in Saunder's (1981) *Hospice: the living idea*. See also Kübler-Ross' *On Death and Dying* (1969) and Semino et al. (2014): 'Good' and 'bad' deaths in *Discourse Studies*.
[94] The table is from page 47 in Tony Walter's book The revival of death, 1994. The full table is presented in the attachments.

The features described in the table are in sociological terms *ideal types*. This means that in reality, they do not exist in neat categories but overlap, mix, and everything in between.[95] [96] The three types by Walter remind Demerath's idea of the appearance of secularization and sacralization in relation to the societal era: A state of sacralization without secularization resembles pre-modernity; secularization without sacralization reminds post-modernity; and the two coinciding can be called modernity.[97] Following Walter's thought about the typicality of an ideal type in real life – for example, the neo-modern idea of death being prolonged – does not mean that every death is prolonged, but an ideal type is most of all a theoretical idea, which is rare in reality. This idea doesn't represent the shared experience in our everyday society but captures some essential components and contributory factors of what the theory refers to as *neo-modern society*.[98] For example, the euthanasia of a demented person could be an ideal type of neo-modern death, even though it statistically covers only 2,3% of the deaths in the Netherlands.[99] Next, I will discuss the building blocks of the three types of death the table presented.

3.2 From parish to hospital and from medicine to individual – The shift of authority in death culture

Tony Walter constructs his argument by painting a picture of the historical movement in death culture, beginning the transition first from traditional to modern and later to neo-modern death. The ideal type of traditional death was community-based and religion centered. When the value of individualism became stronger in the west, so the traditional authority in dying weakened. The communal rituals stepped aside to give the dying more privacy, and modern death followed the traditional death. Gradually the doctor's authority replaced the church. When the death rate went down, people spend their last moments in hospitals and the mourners and bereaved kept their emotions to themselves. As death became an isolated event, it also became less real. As a result, the lonely, institutionalized and hidden death started to face criticism from the future revivalist talking about death as a natural part of life and criticizing its isolation: According to the revivalist thinking, death should not be dictated by the doctor or religion, but the dying person himself. Walter claims that it has become increasingly difficult to protect the modern pretense that death doesn't exist since a growing number of people live for years or

[95] Walter 1994, 47.
[96] Jylhäkangas 2013, 157-158. Applying Jylhäkangas' concept of *rolling speech* (in Finnish *keinuva puhe*), exemplifies this kind of speech where people tend to make comments where they hesitate or express even conflicting opinions.
[97] Demerath 2007, 67.
[98] Walter 1994, 49.
[99] www.knmg.nl.

even decades with life-threatening illnesses. Thus, the next logical step in the revival of death is the individual taking over the authority that was first possessed by religion and later medicine.[100]

As described above, the modern era depersonalized the dying by being simultaneously rational, bureaucratic, and secular. The medicalization of death began around the late eighteen-century when the doctor took control from the priest supporting the dying person. The change in the doctor's role was important since this used to be limited in predicting the precise time of death, giving the person the possibility to organize his last moments. With the shift in control, the physician was now present until the death occurred and dying transformed from a spiritual passage to a natural, medically monitored process.[101] The contradiction underlying the problem of giving room for the private feelings and experience made way for the attempt to revive death.[102] As the authority over death was medicalized, the deathbed moved from home into the hospital. The doctor's knowledge of the individual's body became superior to the experience and sensations of the dying person's himself, and Walter proposes that this removed the person by objectifying the body and making it a subject to medical procedures.

The modern era didn't only medicalize death, but it also changed the language used to address it: Now death and dying were labelled either good or bad. When the religious authority used to call death either moral or immoral, the modern professionals of medicine and science categorized the death to be either normal or abnormal.[103] Together medicalization and secularization form the modern, hidden, and institutionalized dying. If in the Middle Ages people were afraid of what would happen to their souls, in the Renaissance, they worried about their reputation after death.[104] After the fear of hell was reduced, and the spiritual risk was out of sight, death became a matter of medical and psychological concern.[105] [106] Next, I discuss the turn that attempted to take power from medicine: The neo-modern death.

3.2.1 Postmodern and late-modern – Two sides of neo-modern

The rise and development of modern medicine fired the starting pistol for the revival of death by rejecting and repressing the personal feelings and experiences of dying and grieving. In the core of the revival is the attempt to challenge the absence of personal feeling from the public discourse. Two strands can be differentiated from the revival: In *the postmodern* part, the personal experience invades the public

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[100] Walter 1994, 184.
[101] Ibid., 12.
[102] Ibid., 5.
[103] Walter 1994, 10.
[104] Walter 1994, 5; Aries 1981, 472.
[105] The fear of hell was reduced after the First World War since no one dared to suggest that the men who lost their lives on the battlefield did not go to a better place. See Walter 1994, 15.
[106] Walter 1994, 15.

discourse, and in *the late-modern* strand the expert discourse directs and influences the private experience. These strands are reflexive and often exist together in the same organization as they intertwine in one's views and create either tension or strengthen each other, thus being collectively named *neo-modern*.[107]

The late-modern form connects the personal experience with the medical expertise: The person is encouraged to die his own way, together with the assistance of scientifically developed methods to relieve pain. Death is controlled by looking at it through medical and psychological perspectives. Death can be mastered if it is possible to understand and discuss dying in its physical decline, together with the psychological aspects and feelings associated with it.[108] Walter borrows a famous theory of the psychological processes when facing death. This well-known example of understanding the dying person's mental landscape and defining the patient's feelings as normal – since they follow a common path of pre-determined stages – is Elisabeth Kübler-Ross' bestseller *On Death and Dying*. Kübler-Ross describes the adjustment of the dying person by going through five stages: denial, anger, bargaining, depression, and acceptance. This process demonstrates the person's growth by coming to terms with his life, and its ending via psychological processes.[109] Walter interprets Kübler-Ross' theory as a process that places the dying person over medicine or church since he is the one going through these mental stages, making himself the master and authority of his death.[110]

The late-modern form has been criticized for presuming that everyone experiences their emotions according to a pre-determined model. What about all the people who do not grief in Kübler-Ross' neat five stages? *The postmodern* view rejects our tendency to control or predict how the other person griefs. When in the late-modern form the expert acknowledges the variety of the patient's feelings, the expert is still powerful in a more subtle way, as he can rule this emotional sphere either being normal or abnormal. The postmodern form introduces the public with the personal experience: *I* challenge the authority by telling the public how *I* feel according to *me* – not the experts. By doing this, the postmodernism fades the line separating the public and private. The doctors might make treatment choices more on the basis of their patients´ lifestyles instead of their own medical view.[111]

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[107] Walter 1994, 39, 46.
[108] Ibid., 40.
[109] Kübler-Ross 1970, 38-137. Tony Walter proposes on page 30 (1994) that Kübler-Ross emphasized the spiritual process that takes place in the dying person, but this side of her theory never became popular. For example, in *chapter II: Attitudes Toward Death and Dying,* she discusses the meaning and sense of suffering in relation to religion and the rewards in heaven.
[110] Walter 1994, 30-31.
[111] Walter 1994, 41-43.

By embracing the private feeling, postmodernism is in a clear lineage with the 19th-century romanticism. On the other hand, when romanticism was oppositional by setting reason against emotion, public against private and in the context of death the individual's needs and experience against the expectations and requirements of the church and societal norms, postmodernism aims to melt these two aspects by making the private needs concern for the public. Our current time is a fruitful ground for these two views to crash: When the romantic, the hidden, and the institutionalized dying are present during the same era, the revivalist need to take only a few steps to demand the institutionalization of the romantic death.[112]

3.3 The roots of cultural responses to death

The three cultural types of death – traditional, modern, and neo-modern – are based on three components. In this sub-chapter, I open the meaning of these components, which are also presented in the figure of three types of death: The bodily and social contexts, which empower a specific form of authority.[113] [114]

3.3.1 Bodily context

Neo-modern death includes a very "*prolonged and conscious dying trajectory.*[115]" The doctors are able to make early diagnoses of life-threatening diseases which they cannot cure. In other words, dying takes longer than ever – or perhaps it would be more apt to conclude that the period we are of aware of our bodies dying is longer than before. As point 4 of *Bodily context* and *see others dying* on the table presents, in the traditional religion-ruled society witnessing death happened frequently, but by the neo-modern society it had become common to witness dying but not death.[116] The neo-modern society has moved from the modern lack of contemplation over death to longer and longer time to process it. The characteristics of death – for example, whether death usually occurs slow or fast – influence how society arranges itself around it.[117]

[112] Walter 1994, 40-41; See also Aries 1981, part IV.
[113] See chapter *Three types of death – traditional, modern and neomodern*, for the building blocks and main features of the components.
[114] Walter 1994, 47.
[115] Ibid., 50.
[116] See the table in attachments.
[117] Walter 1994, 50.

3.3.2 Social context

Traditionally the death of a person affected the whole community, which as a whole lost its member. When death became a private and isolated event, the loss was understood to touch only the deceased's partner or immediate family, as they were left to process the grief alone. For the neo-modern society, it is typical that the loss and grief work combines the private and public: The grieving widow no longer needs to handle the emotions alone but can choose to receive help from counselors or bereavement- and self-help groups. When the mourner's *mourning* was understood to happen by itself in the traditional, religion-led society, the modern society replaced mourning with *grief*, but the neo-modern context replaced these automatic processes by introducing grief as something that requires work: *grief work*.[118]

3.3.3 Authority

The three forms of society in Walter's theory differ in their view of authority. More specifically, who is seen as the authority and whose voice is heard and obeyed when one looks for guidance or finds oneself faced with a question as big as the his mortality. One of the three has the control over death: God, doctor or I. It is not unheard of for a person in the neo-modern society to trust authorities or experts selectively: We might understand the individual to be the only authority, but yet we need to rely on experts in certain situations. For example, we might question the doctor's expertise, but when technology fails us, we rush to an expert to fix things. Thus, the characteristic feature of a neo-modern society, the option to doubt authorities and experts, is not unbroken or without gaps, nor is it limited only on questioning the doctor and deciding over one's death. This doubt reaches our outlook towards institutions, which are bearers for a specific form of authority. Walter concludes that: *"the self is rooted in the family and counseling. Hence the revivalist vision that if the dying person is to regain control over their own dying, they had better die at home.*[119]*"* Nevertheless, dying is regarded increasingly in the light of personal choice and medicine or psychology, instead of religion, with the limitations set by the public.[120]

3.4 Critic on Walter

Walter's theory of the Revival of Death has faced criticism concerning its background assumptions. For example, Árnason and Hafsteinsson question Walter's conclusion that the revival of death in the west is the result of social transformations, and the dichotomous aspect of viewing the driving forces of neo-modern death either as individuals seeking for freedom of expression or experts wishing to control them.

[118] Walter 1994, 53.
[119] Ibid., 54
[120] Ibid., 54-55.

Relying on the work of a bereavement counseling organization in the UK, the patient and the counselor are both introduced as experts side by side, and the recent shift in managing grieving and dying are connected to "permutations in 'governmental rationality.'"[121] Árnason's and Hafsteinsson's critic concentrates mainly in questioning the assumed development behind the neo-modern death, precisely the process leading to its direction. Where Walter points the finger in sociological factors, the critics question this and dividing the neo-modern death into the concepts of postmodern and late-modern.

The book *Death, Gender and Ethnicity*, is constructed of several independent articles written by various scholars. This comprehensive book about different perspectives of death culture repeatedly refers and quotes Walter with nearly any of criticism. For example, Walter's ideas are used as references in the article about *"Women in Grief – Cultural Representations and Social Practice,"* which considers gender and emotional response to death in public and private and its representations in media.[122] The article relies extensively on Walter's ideas but lacks observations of possible shortcomings or points of criticism. Walter's ideas are mainly referred with expressions such as *"as Walter (--) points out[123]"* or *"as Walter (--) argues correctly.[124]"* The only part where the authors show some reservations about his ideas and conclusions appears early in the book. After introducing the key points of the theory about the Revival of Death – how the change began with the turn-up of the public discourse of medicine taking the authority from religion and evolving from there on – the author refers to Walter's theory by stating, *"as well as suggesting that there has been a revival, and acting as something of an advocate of this revival (…)[125]"* Here Walter's theory is referred to as a *"suggestion,"* and he is stated to act as a *"somewhat advocate"* for this theory. Potentially the fact that Walter is one of the authors in one of the articles of this volume explains the apparent absence of criticism towards his ideas.[126]

Walter has also utilized his theory of the revival into more practical suggestions of how to develop the end-of-life-care, by addressing an article for the people working with terminal patients and witnessing everyday end-of-life care.[127] The article is published in a journal of social work, and its main suggestion is to advise the hospice and palliative care professionals to redirect their focus in the network mobilization by community engagement. By efforts as this, Walter's agenda has been interpreted aiming to break the taboo – even though the critiques question the taboo's existence.[128] Considering the critic towards the theory and his response to it, it appears that the critic focuses mainly in pointing out the shortcomings about the interpretation of the social factors that form the base the theory was built on,

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[121] Árnason & Hafsteinsson 2003, 43-44.
[122] Hockey 1997, 90, 93.
[123] Ibid., 94.
[124] Ibid., 99.
[125] Lovell 1997, 34. The end of the quote mentions the presence of death in media.
[126] Walter is one of the authors of the book's article "Beauty and the Beast, sex and death in the tabloid press."
[127] Brown & Walter 2013, 2375-2377 & 2386-2388.
[128] Lee 2008, 746-747.

and his unquestionable advocacy for the presence of death's revival. Even though Walter addresses those that work with the bereaved and the dying, this appears to be the very group criticizing him. As mentioned, the critic considers the theory's background notion of the society's social state, not so much its results.

Personally, I agree with Walter's conclusions of the commonalities and typical characteristics between the modern and neo-modern death culture, and the role of authority in it. Still, I find some of the conclusions about euthanasia's advocates to be somewhat limited and one-sided. Walter writes: *"'Euthanasia' literally means good death, and advocates of euthanasia see the good death as one under the dying person's control.[129]"* I agree with his notion about how control often has a vital role in the advocates' views, but disagree with the idea that euthanasia's proponents see control as *a requirement* for a good death. Occasionally the respondents stressed the importance of the *possibility for control,* but at the same time emphasized how it is not necessary for a good death: Dying unexpectedly could also be good, or even the best, way to go.

4. EUTHANASIA IN THE NETHERLANDS – PAST DEVELOPMENT AND FACTS AND FIGURES OF THE PRESENT

"But it is legal in Holland!" I was having dinner with a small group of people in Helsinki, a Dutch acquaintance among them. I had just been explaining my thesis topic and, she was in disbelief when I stated that euthanasia is not legal in the Netherlands. She is certainly not the only one, and her assumption gives a good example of the paradoxical Dutch legal culture, where tolerating euthanasia grew out of practice. The Dutch criminal law defines euthanasia as a crime. So how can nearly 5% of the deaths in the Netherlands be due to euthanasia?[130] The answer lies in the article 293[131], formed in 2002, which decriminalizes euthanasia when carried out by a doctor, but as long as the physician follows the due care criteria (s)he is immune from criminal prosecution. Thus, the euthanasia is not technically legal in the Netherlands, but one example of the famous Dutch tolerance, which *allows* certain forbidden actions but holds on to the possibility to interfere with this activity by keeping it punishable.[132]

[129] Walter 1994, 29.
[130] www.euthanasiecommissie.nl; www.knmg.nl.
[131] Article 293 of the Dutch criminal code: Paragraph 1: Anyone who deliberately ends the life of another at his specific and serious request is liable to a punishment of at most twelve years. Paragraph 2: The act referred to in the first paragraph is not punishable if it was performed by a doctor who complied with the demands for due diligence as intended in Article 2 of the Termination of Life on Request and Assisted Suicide Act.
[132] Van Rossum 2014, 287-292.

This history chapter allows the reader to see how the past events are still very much present in today's discursive reality around self-chosen death and have commonalities with the option of revival. By introducing these aspects, the review of history underlines the common goal and social condition these examples drove to change – even though this occurred unintentionally.[133] The widely reported watershed cases have each left their mark in the common discussion of how, when, and with whose help, people are allowed to end their existence. The legal culture of the Netherlands is paradoxical on many levels, euthanasia not being an exception of this. Understanding the word *beleid* can help to grasp it: "*Beleid*" translates to policy or discretion, describing a legal culture that tends to be pragmatic and cover all those touched by the issue. Thus, rules are not made only for their own sake but to seek consensus.[134] Euthanasias were reported in the Netherlands before the legislation and allowing it without clear legalization has its bases in seeing the practice as a victimless crime among other offenses, such as drug use.[135] Thus, to understand the current situation, one must know the key events of the Dutch debate.

4.1 The sick body and force majeure

In 1971, a woman's wish to die made the Netherlands a target of worldwide attention. A doctor called Gertrude Postma notified an elderly home's director that she had intentionally administered a lethal dose of morphine to her mother. Her mother, a seventy-eight-year-old, partially paralyzed, and deaf woman had pleaded her daughter to end her life. When Postma reported her action, she was charged with a mercy killing. She received notable support from the Dutch public and fellow doctors when many physicians confessed to having done the same than their colleague on trial. Postma's case didn't only sell newspapers at the time but had far-reaching consequences: When the Dutch court took a stance on the moral question of the doctor's actions and conscience, the movement supporting Postma took an organized form, manifesting itself by becoming an association, the NVVE.[136] After the trial, also other organizations were founded to strive for legal possibilities of euthanasia.[137] The Court of Leeuwarden found Postma guilty but ruled on a light sentence of one-week imprisonment and probation of one year. This sentence took the first steps on the journey towards the contemporary Dutch euthanasia protocol.

[133] Read more about the ideology and movement culture associated with collective action in the sociology of religion. See Erickson Nepstad and Williams 2007, 423.
[134] Van Rossum 2014, 287.
[135] Schur & Bedau 1974, 17-34.
[136] See chapter *NVVE: establishment and objective.*
[137] In comparison, the NVVE has more members than the nation's biggest political party. See www.nvve.nl.

The court found Postma's motives to be good and the action to be justified and began to formulate the criteria for comparable cases.[138] [139]

The years following the Postma-verdict tested the precedent set by the Leeuwarden's Court when other doctors were brought to trial. Eleven years after Postma had been found guilty for doing something the court found to be justified, doctor Schoonheim was acquitted on the grounds of what the Dutch law called *force majeure*, the conflict of duties. Schoonheim successfully argued that his duty as a doctor to relieve suffering was in conflict with the legal duty of not killing. His 95-years old, seriously ill patient had clearly expressed her wish to die, and the court agreed that as a physician Schoonheim's duty to help his patient overruled the principle of protecting life. Soon after the acquittal, the case proceeded to the Supreme Court. During this process, the Royal Dutch Medical Association (KNMG)[140] found it essential to formulate criteria, to reassure the current situation where the profession accepted – and practiced – euthanasia, but where any clear criteria for this practice were missing.[141]

In the case of Schoonheim, the Supreme Court agreed with the original ruling by stating the following:

> "(I) As a general rule euthanasia and assisted suicide are punishable. The Penal Code defines both activities as a crime.
> (II) However, when a physician is confronted with a conflict of duties, he or she may invoke the so-called "defence of necessity". A conflict of duties arises when honouring a patient's request to die with dignity is the only way available to end unbearable and hopeless suffering.
> (III) The criteria for accepting the defense of necessity are to be derived from professional and medical-ethical opinions formulated by the medical profession."[142]

Since the criteria formulated in 1984 carry the same core notions than the current law, the most significant change lies in the criteria's status, as the Medical Association's guidelines from 1984 evolved into an official law in 2002.[143] The Supreme Court's statement gave the question of euthanasia a legal opening. It also respected the national tradition of leaving the decision making in the hands of those

[138] Thomasma et al., 1998, 7.
[139] 19 years before the case Postma another doctor was on trial for euthanizing his brother, a cancer patient. Thus Postma was not the first euthanasia trial in the Netherlands, but her case fired the starting pistol in the public debate, the literature on the topic and founding societies promoting legal options for euthanasia. See Thomasma et al., 1988, 7.
[140] From here on, I refer to the Royal Dutch Medical Association in its Dutch abbreviation, KNMG.
[141] The criteria formulated in 1984 is similar to the euthanasia law of 2002. The criteria by KNMG in 1984 are: "1) there is a voluntary, competed and durable requests on the part of the patient; 2) the request is based on full information; 3) the patient is in a situation of intolerable and hopeless suffering (either physical or mental); 4) there are no acceptable alternatives to euthanasia; 5) the physician has consulted another physician before performing euthanasia." Thomasma et al., 1998, 21.
[142] Legemaate 2004, 312-323.
[143] Thomasma et al., 1998, 7-9.

touched by the issue – in this case the doctors and patients – instead of limiting this relationship. This reasoning of the Supreme Court served as the foundation for euthanasia before the Act of 2002. After Schoonheim's case, the next step of the development took place in 1990, when the government appointed the so-called Remmelink Commission. This panel was to report the extent and nature of euthanasias carried out by Dutch physicians. In order to do this, the commission needed the doctors to cooperate. The KNMG and the Ministry of Justice made several agreements, such as giving immunity from prosecution for doctors participating in the study. In exchange, the doctors refrained from issuing a natural death declaration in euthanasia cases but instead informed the local medical examiner by preparing extensive report. After the Remmelink-report, the government made the temporary arrangement permanent by establishing a legal mechanism for the doctors to report euthanasias.[144] This gave the previous agreement between the physicians and the Ministry of Justice a permanent status by taking the euthanasia practice again one step closer to its de-criminalization. Under the law of 1993, the public prosecutor viewed each case individually, with the instructions to prosecute if the report left unclear whether the patient had explicitly expressed the request for euthanasia.[145]

4.2 The suffering itself – Chabot and Sutorius

The Remmelink-report concluded that most requests for euthanasia cite *the experience of suffering from the loss of dignity,* as the reason for wanting to die when the *pain* was mentioned in less than half of the cases. Pain can be felt anywhere in the body, but the suffering caused by pain is always experienced in the mind. Sometimes the suffering emerges without physical pain and the Dutch have debated whether this is enough for euthanasia.[146] Seale and Addington-Hall argue that the Dutch can accept the position of existential suffering, whether it was caused by the process of dying or other factors, as the main reason for a death wish.[147] Eventually, the mind's suffering was the question handled in the courtroom during the trials of Chabot and Sutorius.

4.2.1 Chabot – Mental Suffering

In 1991 Boudewijn Chabot helped his patient with her suicide. The psychiatrist was found guilty but left without punishment. The court ruled that in the case of euthanasia the *cause of the suffering* is not relevant, but the *suffering itself.* In a three years' time, the woman, referred to here as Mrs. B, had gone through a divorce and lost her two sons for suicide and cancer. Soon after, she tried to commit suicide,

[144] The Dutch Senate passed the Bill 22572 on 30.11.1993. See Thomasma et al, 1998, 11.
[145] Thomasma et al., 1998, 10-11.
[146] See table 1: the reasons for requesting euthanasia, in chapter *Euthanasia in the Netherlands – facts and figures.*
[147] Seale & Addington-Hall, 1994, 649.

but to her disappointment survived. Mrs. B was afraid of being admitted to a psychiatric hospital against her will and ending up handicapped, in case she would survive a second suicide attempt. Finally, she contacted the NVVE and came to contact with Chabot. The psychiatrist interviewed Mrs. B and spoke with her for approximately 28 hours and consulted other healthcare professionals about her case. Finally, he agreed to assist her to die by providing lethal medication.[148]

The experts consulted for the Supreme Court's case included the Medical Association, the Inspectorate for Mental Health, and the Dutch Association for Psychiatry. They stated the following: *"From the point of view of medical ethics, there may be circumstances in which assistance with suicide is legitimate in the case of persons whose suffering does not have a somatic origin and who are not in the terminal phase of their disease.*[149]*"* Thus, the requirements clarified by KNMG in 1984 were confirmed and elaborated ten years later as part of the Chabot-case, when the justice system legitimized the role of suffering in euthanasia, despite its origin and cause.[150]

4.2.2 Sutorius – Existential Suffering and Completed Life

In 2000, the same year the Dutch parliament discussed the euthanasia law, a general practitioner Philip Sutorius helped his patient, an 86-year old man, to die. The patient, a former senator Edward Brongersma, had no serious physical or mental illness but wanted to die because he experienced his existence hopeless and was obsessed with his physical decline. Sutorius helped his patient to die since he believed him to suffer unbearably, and was originally acquitted in 2000. One year later, the Amsterdam appeal court made a different ruling and found Sutorius guilty of a criminal act of assisted suicide. Even though the second ruling was different from the first one, the court didn't impose any punishment but believed the doctor had acted out of good means. The appeal court based its decision on an argument about the nature of Mr. Brongersma's suffering: Without medical bases, the general practitioner does not have the experience to make judgments about existential suffering. The Supreme Court dismissed Sutorius' appeal, thus ruling that doctors are not allowed to assist with suicide or perform euthanasia if the patient is not suffering from a classifiable physical or psychiatric sickness or disorder.[151]

[148] Griffiths 1995, 233-235.
[149] Ibid., 235-236.
[150] Ibid., 232-248.
[151] Sheldon 2003, 71.

4.3 Euthanasia in the Netherlands today – Facts and figures

After considering the historical development of the euthanasia, this section considers what we are strictly speaking talking about when we refer to euthanasia in the Netherlands: What do the Dutch mean with euthanasia, what are its criteria are and how common is the practice? The Dutch define euthanasia as: *"intentionally taking the life of another person upon his or her explicit request.*[152]*"* The euthanasia debate in the Netherlands has always been about balancing autonomy and suffering. In 2001, the already existing euthanasia practice received legal ratification from the Dutch parliament. The *Law on Termination of Life on Request* does not mention the word *euthanasia*, but it determines that killing on request and assisting with a suicide is not punishable if committed by a doctor who follows the *due care criteria*[153] and reports the euthanasia to the coroner, whose duty is to forward the form to a local *assessment committee*.[154] The Dutch law allows euthanasia on children if the parents of a 12 to 16 years old child agree with the decision. When the child is over 16 years of age, it is enough that the parents are merely informed.[155]

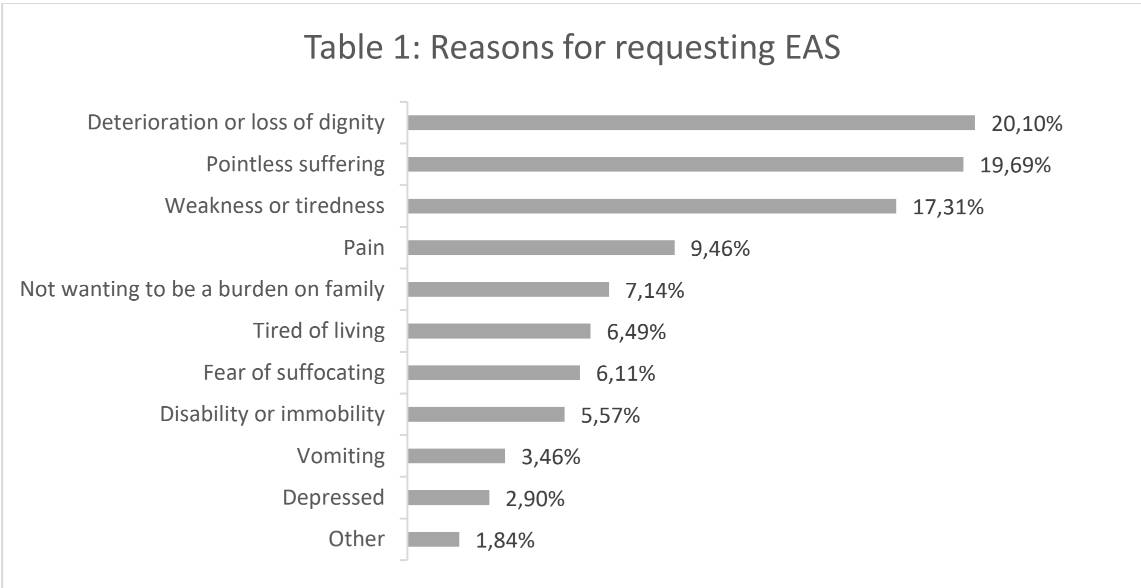
The requirements specified by *the Law on Termination of Life on Request,* are:

> "Doctors must:
>
> a) be convinced that the patient's request is voluntary and well-considered;
>
> b) be convinced[156] that the patient's suffering is hopeless and unbearable, and that there is;
>
> c) no prospect of improvement;
>
> d) inform the patient about his situation and further prognosis;
>
> e) discuss the situation with the patient and come to the conclusion that there is no reasonable alternative;
>
> f) consult at least one other physician with no connection to the case;
>
> g) and exercise due medical care and attention in terminating the patient's life or assisting in his suicide.[157]"

The patient's lifetime-expectancy is not mentioned in the law and its criteria.[158] Strict steps must be followed after euthanasia has been carried out: The coroner must be notified immediately in order to report the case to one of the five Regional Review Committees (RRC), to assess the case and how it met the criteria. In case the committee concludes that a case does not succeed in meeting the necessary

[152] Thomasma et al., 1998, 3.
[153] The points a – g stated in this chapter.
[154] Weyers 2006, 802.
[155] Vrakking et al. 2005, 802-803.
[156] The points a and b point out how important the doctor's interpretation of the patient's condition is. E.g., the criteria state that the "doctor must be convinced that the patient's suffering is hopeless and unbearable."
[157] The requirements are available in many sources. See for example van Tol et al. 2012, 297.
[158] Weyers 2006, 802.

criteria, the public prosecutor is notified.[159] After the law came into force, only one doctor has been prosecuted for performing euthanasia. In August 2019, a nursing home doctor faced prosecution for the euthanasia of a demented 74-old patient, but the judges had not yet reached a verdict by the time this thesis was submitted.[160] Three other cases of patients with psychiatric problems or dementia are under investigation.[161] In order to understand the meaning and reality of euthanasia in the Dutch culture's context, I chose to include tables presenting the leading reasons for euthanasia requests (Table 1) and the diagnoses behind these requests (Table 2), without forgetting that doctors are involved with death also in other ways, pointing out the often grey line in what we call euthanasia (Figure 1).



[162]

Table 1 shows the results of a study carried out by Van der Weide et al. The research focused on undecided, withdrawn and refused requests by asking general practitioners to answer questions about the last euthanasia request made to them in the last 18 months. The research concludes that the most common reasons for asking euthanasia were a weakness, loss of dignity, and pointless suffering. All these reasons are highly open to interpretation and individual experience.[163] It is worth mentioning that the experience of being a burden or depressed were most often among the refused requests, as was the

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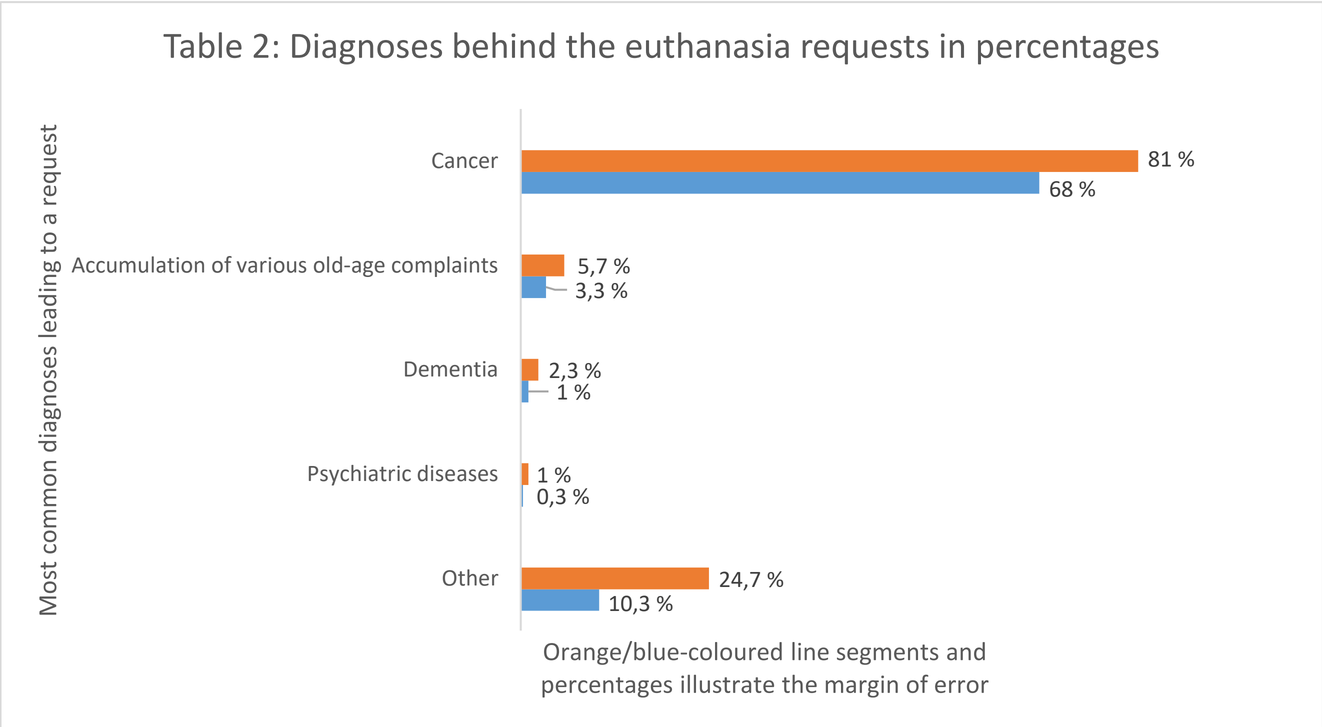
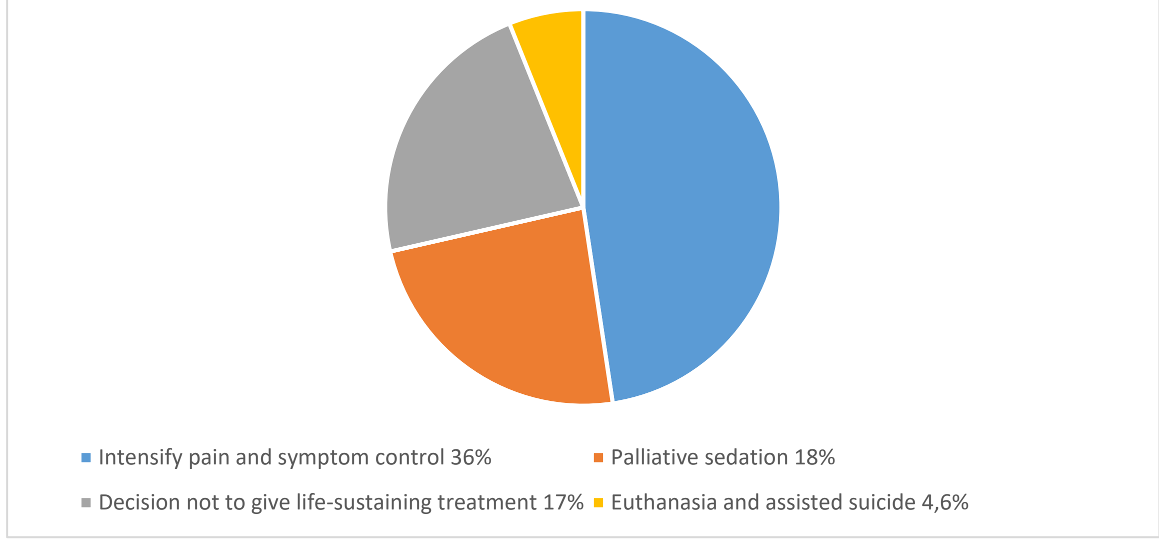
[159] Van Tol et al. 2012, 296.
[160] In this watershed case of the Dutch legal history, the doctor relied on the living will of a demented patient, in which she expressed her wish to have euthanasia. According to the media, the doctor sedated the patient by putting a sedative in her coffee and later held the patient down, so the rest of the drug could be administered. The court will assess whether the doctor was entitled to rely on the patient's living will. The judges are expected to reach a verdict on September 2019. See www.theguardian.com or www.nltimes.nl.
[161] One of the cases failed to follow the criteria by not consulting an independent doctor. In the two other cases, the consulted physician did not agree with the decision, or the patient refused treatment. www.theguardian.com.
[162] The table was constructed by the author based on the study of the granted, undecided and refused requests, by van der Weide et al., 2005, 1698-704.
[163] Van der Weide et al., 2005, 1698.

case if the patient was over the age of 80.[164] Altogether, the physicians answered questions concerning 1681 requests. Out of this number, 940 euthanasias were performed. In the remaining cases, the patient died before the euthanasia was carried out (217 cases) or before the doctor had made the decision (164), or the doctor refused the request (150). In rest of the cases (144) the patient changed their mind.[165]

According to KNMG's estimation, in 2015, there were 67 700 requests for euthanasia 'in due time' and 17 9000 explicit requests 'in the foreseeable future'. In light of these numbers, only a small number of the requests were fulfilled, and the doctor performed euthanasia or assisted the patient to die upon his or her requests. Nevertheless, the numbers have risen. In 2010 the doctors reported 3316 euthanasia cases, when six years later, the number was 6091. The diagnoses behind the requests vary. As visualized in the table below, between the years of 2011 and 2016 cancer was the leading reason, covering 68% - 81% of all the euthanasias performed. Accumulation of various old-age complaints was the reason in 3,3% - 5,7% of the deaths, psychiatric diseases 0,3% -1 %, dementia 1% - 2,3 %, leaving the remaining cases with 10,3% - 24,7%. In the major of the cases (84%) the patient's general practitioner performs the euthanasia, a medical specialist in 3%, geriatrician in 3% and another medical doctor in 10%.[166] Approximately 150 000 people die in the Netherlands every year. Most deaths, 58 % involve a doctor. Physicians' involvement covers a wide range of procedures, and only a small percentage is considered euthanasia.[167] The table below illustrates the commonality of different diagnoses:[168]



[164] Ibid. 1698-1699.
[165] Van der Weide et al., 2005, 1701.
[166] The statistics are provided by KNMG: www.knmg.nl.
[167] Twycross 2017, 13-15.
[168] The table was constructed by the author based on the information provided by KNMG (www.knmg.nl.)



[169]

The table above shows how euthanasia is not the only manner physicians are involved with death. Doctors are involved in cases of palliative sedation (18% of the deaths), intensify pain and symptom control (36%), the decision not to give any life-sustaining treatment (17%) or euthanasia and physician-assisted suicide (4, 6%). Palliative sedation is often defined as the use of sedative drugs in dying patients to induce unconsciousness in order to relieve intolerable suffering.[170]

5. RIGHT TO DIE-MOVEMENTS AND THE THREE ROUTES

The three routes refer to the different ways a person can end his life, the key question being who, if anybody, helps the person to die. The routes are often referred to as *the autonomous, the medical,* and *the assisted route*. This chapter shows how the elements of the routes overlap with the core questions asked in the course of the Dutch debate on euthanasia.[171] [172]

[169] The table was constructed by the author based on the information provided by KNMG: www.knmg.nl.
[170] Twycross 2017, 13-15; The statistics are provided by KNMG: www.knmg.nl.
[171] The source for the three routes is the interview material collected by the author.
[172] The three routes cover the same questions and note similar cultural ideas than Tony Walter's notions of modern and neo-modern death ways. See chapter 3.

5.1 Nederlandse Vereniging voor een Vrijwillig Levenseinde – Establishment and Objective

The NVVE was founded in 1973. Firstly, the association was established to support Postma, secondly to strive for legal possibilities for euthanasia. The Dutch euthanasia law took almost 30 years of court cases and public debate, NVVE being a relevant part of the activist-movement. The NVVE is based in Amsterdam, where it employs approximately 30 persons and maintains a phone advice center. Across the Netherlands, the association has more than 150 volunteers participating in different activities, such as home visits, lectures, and other events. The NVVE has approximately 165.000 members – which is more than the biggest political party in Holland – and is growing annually. The association does not employ doctors to help members die or prescribe any medication. The sole source of income is the membership fee of 17.50 euros per year (per person).[173]

The associations' general goal is to allow people to have a self-chosen death of their preference. In order to make this happen, they strive to realize the three routes:[174]

Quote 1

> R: "We at the NVVE try to realize three different ways to die. Like the medical way, that is just the euthanasia, and this is the dying that's already happening and is legal now. And then we have like the assisted way, that somebody else can help you, and then the autonomous way that you can just do it yourself. So like euthanasia, the medical way is legal but the other two, we are still trying to fight."
>
> L: "Yes the assisted way is not legal in the sense that anyone else than a doctor could help you?"
>
> R: "Yes. It would be nice that, what we at the NVVE say, that like the end-of-life is medicalized. So it shouldn't be a doctor. That can also be like a philosopher, somebody with a more spiritual thing."
>
> **Sophie, employee**

More specifically, the NVVE has declared its goals as follows*: "Advancement of use and social acceptance of existing legal possibilities towards a free choice for the ending of life. Advancement of social acceptance and legal regulation of free choice for the ending of life in situations which are not*

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[173] www.nvve.nl.

[174] In the absence of academic publications concerning the three routes, the main source for the concept are the interviews. They are also found in a document available in Dutch for download on NVVE's website: www.nvve.nl.

within the scope of existing legal possibilities. Recognition of free choice for the ending of life (and assistance thereby) as a human right.[175] *"*

As the NVVE has members with varying opinions, goals and, wishes, but as an organization supports all the routes equally, it has contributed to establishing other organizations that can concentrate on more specific routes. Like many other organizations, the NVVE does not only concentrate on fighting its ideological battle but provides its members with different practical services. For example, the members can be assisted with writing their living wills or provided with 'no CPR'-medals. The association also organizes and arranges questions hours, lectures, presentations, workshops, regional meetings, publishes a quarterly magazine *Relevant* and maintains an advice center, which can send a consultant over to meet the member.[176]

5.2 Medical route and the End of Life Clinic

Medical route refers to physician-assisted suicide and euthanasia.[177] When the *termination of life and suicide act* was ratified in 2001, NVVE's original goal was accomplished. Nevertheless, the association is still very active and wishes to extend the law's boundaries. Currently, the medical route is mainly realized by the patients' own physicians, the general practitioners.[178] Around the turn of the century, NVVE began to work on a solution for the people whose doctors were not open for the idea of euthanasia. The answer to this was the End of Life Clinic, founded in 2012. The NVVE was actively involved in the establishment of the clinic.[179]

The clinic offers to reconsider euthanasia requests made by people whose original request was denied by their physician. The main focus is on those patients whose cases are complicated, for example, psychiatric patients, people with dementia, or persons with chronic but non-fatal diseases. The clinic is not a hospital or a hospice, but a foundation with teams of doctors and nurses who work separately and visit the patients at home. If the patient's general practitioner refuses to carry out euthanasia, the person can apply to be helped by the End of Life Clinic.[180]

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[175] www.nvve.nl.
[176] Ibid.
[177] For the readability of this work, I refer to both – *physician-assisted suicide* (in which case the doctor provides the patient with the lethal drink, but the patient drinks it himself) and *euthanasia* (when the doctor injects the lethal poison into the patient) – as *euthanasia* unless otherwise specified.
[178] 84% of the physicians providing euthanasia were GPs, 3% medical specialists, 3% geriatrician, 10% other medical doctor. The statistics are published yearly by KNMG in www.knmg.nl.
[179] See Johan's interview quote in the attachments.
[180] Explained in a personal interview with the clinic's medical manager. See the quote in the attachments. See also www.levenseindekliniek.nl.

The statistics show how the most difficult cases are brought to the End of Life Clinic and how the clinic is receiving a growing number of requests. In 2013 the clinic provided 3% of all the euthanasias in the Netherlands. In 2016 this number was already 8,1%. Psychiatric diseases and dementia cover 1-2% of the euthanasias in the Netherlands, but almost 10% of the clinic's cases. In 2013 nine persons with psychiatric diseases approached the clinic and received help from them. Three years later nine had grown into 46.[181]

5.3 Autonomous route – Completed Life and the Cooperative Last Will

Autonomous route refers to a self-chosen death with no involvement from others. For example, the doctor's permission is not needed nor even asked. In the course of years, the autonomous route has aimed to take many forms, and different kind of efforts have taken place to make it a reality – such as training NVVE's consultants, pushing for the law proposal of completed life and establishing the Cooperative Last Will-organization.[182] Next, I will shed light on the meaning and practice of these options.

If the patient's doctor refuses to help with euthanasia, the person might turn to NVVE and its consultants. A consultant is a volunteer who can answer questions about euthanasia. The consultant is familiar with the Dutch legislation of euthanasia and has been taught the different ways of ending one's life without a doctor's help. The organization sends a consultant to visit the person, and depending on the case, the consultant might help the member by providing the information.[183]

Currently, Dutch law requires the existence of a medical issue – physical or psychological – as a condition for euthanasia. The question of completed life focuses solely on the person's experience.[184] As discussed earlier in this work, the same idea was originally expressed in 1991 by a judge, van Drion. In 2017 the Dutch public, politicians, and media discussed again the option of assisting healthy but old people to die if they wished so. The law on completed life proposed by Pia Dextra, the representative of the Democrats 66-party, did not proceed to parliament. The law would have allowed people above the age of 75 to be helped to die if they are healthy but feel their life is completed.[185]

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[181] The statistics by KNMG: www.knmg.nl.
[182] Pia Dextra is a member of the Democrats 66-party and an advocate of the completed life law. The law draft and its explanation: www.d66.nl.
[183] See Lisa's interview quote in the attachments and the website www.nvve.nl.
[184] The question of a person's right to ask for doctor's assistance to die, even when medically healthy but considering the time to be right, was already present is the case of dr. Sutorius. See chapter *Sutorius - existential suffering and completed life.*
[185] www.d66.nl.

The organization called Cooperative Last Will was founded in 2013 to come up with a solution for those wanting to die without undergoing the bureaucratic requirements. The NVVE assisted the organization's establishment, and the founders used to work with the NVVE. In September of 2017, Cooperative Last Will announced it can now legally provide its members with the lethal substance.[186]

5.5 Assisted route

Assisted route refers to having someone else than a doctor helping with the suicide. The NVVE has campaigned for legalizing this route, but assisting with suicide remains illegal and punishable in the Netherlands. The state has been clear on not allowing others than doctors to assist with suicide. In 2008, a man called Albert Heringa helped his 99-year old mother with her suicide by mixing 130 pills into a custard that the mother ate. Soon after, the mother died. Heringa filmed his action, and a documentary was published a year and a half later. In January of 2018, the fourth ruling of the Heringa case was made. The court in Den Bosch gave him a six-month suspended sentence, this being the heaviest sentence of all four trials covering the incident.[187]

6. ANALYSIS

The analysis process of this research began the first day I met NVVE's employees and was introduced to the idea of the two groups within the pro-euthanasia community. This had a strong impact on choosing the research themes and questions for the interviews. As discourse analysis sees speech as a goal-oriented social action, the importance of this notion made itself clear right from the beginning: Had I began the interviewing process before the informal talks with the organization's employees, my preliminary assumptions and hypothesis would have probably been different. As I began to interview people, my ideas of the research were not yet fully formulated. I was curious about why they supported the practice, but I was not yet confident with the approach.

After I had completed the last interview, I focused on coding the data. Even though I had chosen the themes before starting with the interviews, every discussion took its own direction and the order of how specific themes were present varied with every respondent. When I had read through all the interviews, I looked at the extent and frequency of each code's appearance and decided which codes – or discourses – would be included in the analysis. In order to answer the research question and prevent the area of

[186] See the website www.laatstewil.nu and the press release in the attachments under Cooperative last will.
[187] www.nltimes.nl.

focus from jumping through the roof, I narrowed down the relevant sections of the data. This meant leaving out great parts of the material. Thus, the coding was a careful and slow process, but finally, I was ready to cluster the material and form the study's structure. When doing this, I paid attention on how certain values and ideals appeared to be collectively shared as they were repeated from one interview to another, thus forming a moral world aspect to view the world.[188] In this process, the theoretical concepts and conclusion began to replace the expressions used in the primary data.[189] By reviewing the primary data as applying the theoretical conclusions, Waardenberg's idea of religion's role as a collective orientation system towards the society transformed from an abstract idea into an apt description of the data.[190]

Finally, I formed three main categories, each constructed by one or several sub-categories within them: 1) Discourses of compassion; 2) Discourses of me-ness; 3) Counter-reactions. This study is theory-related in the sense of how the theoretical background affected the analysis by pointing a ready-made viewpoint for examining the discourses. However, these are not directly derivative from a theory.[191] My goal was to find out and present how the different discourses created include ways of understanding euthanasia's role in society. This was done either by placing the authority over death in the hands of the medical profession or the individual self and by paying attention whether religion was brought up in this process. My intention was to point out how the respondents did not merely have differences of opinion but to suggest how these differences may reflect the presence of a different societal era, the modern or neo-modern society. To make the analysis even more multi-leveled, the separation of the discourses of compassion and me-ness doesn't mean a certain discourse has no commonalities with the other category but simply looks into the points of resemblance this idea has in the given group.

6.4 Beginning to formulate the discourses

In the analyses, I study how the aspect of possessing *authority* is present in the data and how its role is formatted. In order to do this, I apply discourse analysis and the categories presented in Walter's theory of the Revival of Death, which places the authority either with the medicine in modern society or the self in a neo-modern society.[192] In this sub-chapter, I present two examples of this division and later on look into the different aspects and components of Walter's theory when suspected to analyses as they

[188] See Laitila 2007, 17; Erickson Nepstad & William 2007, 420.
[189] Tuomi & Sarajärvi 2009, 110-111.
[190] Waardenberg 1986, 31.
[191] Eskola 2001, 137.
[192] See the table in the chapter: *Three types of death: traditional, modern and neo-modern.*

appear in the primary data. Walter's idea of the shift in society with discovering the authority of individual self, has common ground with Demerath's views: The active roles or secularization and sacralization are always attached to the current societal era and the role of the self in it.[193]

In Walter's terms, the modern era changed the language used to address death and dying, labeling it either good or bad. When the religious authority used to call death either moral or immoral, the modern professionals of medicine and science placed it in the categories of good and bad.[194] Interviewing people made me understand how many respondents saw a connection with the sense of having control over one's death, or the lack of this, as a way to measure whether the death was, in fact, good or bad.[195] The research material offered the grounds for a large number of different discourses, but the themes of *suffering and autonomy* were present in each interview, often forming the thread in the respondents' speech. Before proceeding with the analyses, it is worth noting how these two notions have a tense – and even competing – connection in the interviews. Some respondents expressed that everything limiting euthanasia or setting rules for suicide is automatically, and unjustly, also limiting the person's right for autonomy and self-determination, and therefore wrong. The next comment is an example of this:

Quote 2

> "I think *it is in principle wrong* to make *a law that gives the doctors* the opportunity to have this very mighty role.[196] I'm puzzled every time again to see that in every country doctors have this role in euthanasia. And the *only explanation is because the means you have to use to get killed, are kind of medicine*. (--) That, where the doctor comes in, but *the doctor isn't educated for existential opinion making*. He is educated to help people with medicine with illnesses but not as an existential issue. And I think in principle the doctor shouldn't have the last voice, the last saying about my or other ones' lives. So, *don't make a law that gives the doctor that kind of position. That's principally wrong*. Give people *the right to decide* about their own lives and death. And the possibility to obtain the means to do so."
>
> **Jos van Wijk, Cooperative Last Will**

Van Wijk sees the wish to die as an existential, not medical, issue, as he questions the doctor's role and supports the core notion of autonomy above suffering. By stating "*it is in principle wrong to make a law that gives the doctors the opportunity to have this very mighty role",* his comment reminds Demerath's notion of the attitudes towards secularization: More precisely, how persons with opposing opinions

[193] Demerath 2007, 66-67.
[194] Walter 1994, 10.
[195] See the subchapter of control under the *Discourses of Me-ness.*
[196] Van Wijk was talking about the doctors' have in judging who can ask for euthanasia and who not.

begrudged the power or religious institutions and welcomed their perceived decline.[197] Considering van Wijk's comment, it appears this grudge has shifted its focus towards the medical community. Contradictory to this view, some respondents saw euthanasia as the last result when the doctor can no longer help his patient in other ways. Rob Jonquiére is an example of this, as he sees euthanasia as a medical question and a possible solution to rely on when medicine has nothing else to offer:

Quote 3

> "*The basic idea is that the patient is suffering unbearably* and you have done whatever you can to make it bearable, and you have felt in all your trying's. Then you can say as a doctor this is hopeless."
>
> **Rob Jonquiére, the former director of the NVVE and a medical doctor**

In the first quote, van Wijk's speech produces the view of the self as the authority, having an echo with the *neo-modern* cultural response to death. On the contrary, the notion of suffering has a similar role in Jonquiére's speech, thus corresponding to the *modern* response. Most of the interviews did not create such a clear impression. Sometimes the discourses were clashing, as a person could express discourses that overruled each other. No matter how unsure the respondents might be with their stance on other questions of euthanasia, the understanding of authority's role tended to stay the same throughout the interview. The discourses locate in Walter's idea of modern and neo-modern society, or balance between the two worlds, thus indicating *rolling speech.*[198]

7. DISCOURSES OF COMPASSION

The discourses in this chapter often have their base in a feeling: the experience of putting oneself in the shoes of another, and sympathy towards this person.

7.1 Suffering

Many respondents emphasize suffering as the base for the whole discussion around euthanasia. Often these statements focus on euthanasia as a solution for suffering as a medical problem, even though the discussion varies.

[197] Demerath 2007, 57.
[198] Jylhäkangas 2005, 6-8.

Quote 4

> "(--) if you are younger then you have seen older people dying and, you know what it is if *people are suffering and nobody wants to suffer*. (--) It is also hard to see people suffer and in that case, I think it is very good we are fighting for *the rights to have a peaceful end of life* and that you are not suffering at the end. *Or at least suffering at life at all in one way. (--)* There is always new ways to, at least to the small part that still suffers. (--) So we can also help them, we fight for this part of people as well. *The law we have now is not fully used.* And I think we have a role in this, that we can still make clear to other people that okay, listen, *you suffer and… That you don't have to*, you know it, eh?"
>
> **Jelle, employee**

In the above quote, Jelle combines the issue of suffering with the right for a peaceful end of life. He begins to talk about suffering in relation to dying of physical illness and the unnecessary pain that may come with it. He continues by stating how the current law is not used to its full extent since not everyone is yet aware of the option of not suffering – and they should be told this, as "*nobody wants to suffer".* The view of suffering as an unwanted and pointless side effect appears as a commonly shared experience and the NVVE as the group that *"fight(s) for the this part that still suffers".* Besides emphasizing the role of suffering, Jelle refers to the option to avoid suffering as a right: "*it is very good we are fighting for the rights to have a peaceful end of life and that you are not suffering at the end."* Thus, by painting a picture of the right-to-die equaling the right-not-to-suffer, Jelle's comment is an interesting example of rolling speech in its way to combine the modern and neo-modern responses to death. Rob Jonquiére discusses suffering from a doctor's perspective:

Quote 5

> "Let them[199] realize that *terminating a life is not actually terminating life but terminating suffering*. (--) all those *diagnoses[200],* in my opinion, must fit in the concept of unbearable and hopeless suffering. And the reason, like what Els[201] said, it doesn't matter why you are suffering, but you are suffering, and that is why you want to have that stopped. *And if no one can stop it, then the only way out is to terminate suffering by terminating the life*."
>
> **Rob Jonquiére**

Rob Jonquiére sees euthanasia as something that requires a medical diagnose that leaves the doctor powerless. By presenting the limits of medicine as the border for euthanasia, his comment exemplifies the cultural response of modern society. He also found terminating suffering to equal with terminating life – which made me suggest a conclusion that if terminating suffering also terminates life, life is as big

[199] Them = doctors.
[200] *All those diagnoses* refer to all the diagnoses resulting in euthanasia.
[201] Els Borst was a politician pushing for the euthanasia law. See www.d66.nl.

as its suffering. Resembling Rob Jonquiére's comment, Marion presents the reasons behind euthanasia being the wish to exit suffering, not life:

Quote 6

> "*Most people don't want to die, they want to end the suffering*. That's a different thing. (--) So you always have to analyse if, I think, if there, for that person is, if the final exit is indeed the final exit. Because it is not, that's what I started to realize by working here (--) It's hardly, how do you say it, *hardly ever so that people long for being dead. People long for ending the suffering*."
> **Marion, employee**

In Marion's speech, the death wish appears to be a stepping stool for another wish: saying goodbye to suffering. Interestingly, she also states that most people do not actually want to die, but to succeed in eliminating suffering, they also need to eliminate the life within them. A more personal point of view is introduced by Claudia, who first addresses the topic by referring to her friends who had euthanasia due to aids:

Quote 7

> "Y*ou don't have to, they didn't have to, suffer till the end*. It's like people now with cancer, *what's the point of suffering* so badly and have so much pain?"

Quote 8

> "I really strongly believe that *it's not necessary to suffer*. Especially is you know you are going to die anyway, then why suffer so much? In a lot of diseases, they can't do anything anymore, just give you painkillers. What kind of life do you have then?"
> **Claudia, employee**

By stating how suffering is unnecessary Claudia's comment resembles Jelle's view. After telling her friends' story, she moves to question the meaning of suffering on a more general level. She does this by expressing not to believe in the *necessity of suffering*: *"I really strongly believe that it's not necessary to suffer."* She also refers to the limited possibilities of medicine: *"In a lot of diseases, they can't do anything anymore, just give you painkillers. What kind of life do you have then?"* Not being able to change the course of suffering appears to question the meaning of staying alive. Even though control wasn't mentioned, alleviating the inability to cure the illness causing the suffering, reveals its presence.

The respondents emphasizing suffering tended to connect euthanasia with medically diagnosable illnesses or refrained commenting on the roots of the suffering. They did not only tend to rule suffering

being pointless, but the pointlessness of it appeared in itself to be a reason to exit life. As the focus is on eliminating suffering, the weight of this discourse tilts the balance on the modern side of Walter's theory.

7.2 Compassion, mercy, and empathy

When pain causes suffering, witnessing this brings out the experience of empathy towards a fellow human being in agony. According to Walter, the human encounter with death has been split in the modern era. I see the euthanasia debate in the Netherlands to battle these two sides: The culture encounters the bureaucratic processes of medical expertise together with an increasing need to accommodate an individual experience and loss. A neo-modern person wants to have the benefits and help of the medical specialists, but he also wants to make the decision autonomously – the doctor shall forbid nothing, only give advice if asked.[202] Interestingly Jos van Wijk, a dedicated representative of the *autonomous route,* speaks of compassion in relation to individual autonomy and physician's role. In the following comment, he gives first an example of a conversation with a doctor:

Quote 9

> ""I'm going to do this but I'm diabetic, so I use this medicine, and I have another disease, so I use also another medicine. So, do you think pentobarbital could harm me or could interfere in a wrong way than what I'm using it for? So, give me advice." We want to have this kind of role of a doctor, *as somebody who has compassion and will help you*. But *not the kind that gets to decide for you*. Not the government, not the doctor."
> **Jos van Wijk**

Van Wijk spoke of the need for the doctors to be *compassionate* so that a person could have support and advice from a physician while preparing for his death. For example, the physician could provide information about possible side effects. As the doctor's role is moved from being a judge, into being a compassionate adviser, the authority is also shifted from *medicine* to *self,* and the doctor should be a part, not a barrier, in one's death. The above quote resembles rolling speech when giving the authority to the *self* but does so with help from the *medical* expert, whose compassion should ensure cooperation. During another interview, a volunteer shares a case of a rabbi explaining to him how euthanasia is not wrong if done with the right intentions – this intention being compassion:

Quote 10

> "I talked to a rabbi and, (--) he is pretty conservative. And he has told me, well, *when it is done, giving euthanasia, with compassion, it is no problem*. It was surprising."

[202] Walter 1994, 9.

Hans, volunteer

In Hans' comment, the feeling of compassion justifies the action. He brought up religion to underline the transformative power compassion may have. The reasons for giving the euthanasia are not discussed further in this example, but the physician's inner motivation has the central role in making otherwise forbidden act acceptable. Also, Hanna addresses religion by sharing a case where a religious authority surprised her with his words. She had a presentation about euthanasia in a protestant church, and a catholic priest was in the audience:

Quote 11

> "I thought, what is this man going to say, what is this man going to do? Because I know what the official point of view of the Roman Catholic Church is. Then, after break he stood up and he said: "For me, god is a god of love and not a god of suffering. And *this god of love allows you for an end of the suffering*." He was pro-euthanasia."
> **Hanna**

When the rabbi had emphasized the compassion of the doctor, the Catholic priest focused on suffering, or more precisely, on the god of love that allows to end the suffering. Another volunteer, Lisa, is NVVE's consultant. She sees empathy as something that helps her to do her work: She explains how a person has the right to decide whether he wants to die, but how empathy helps her to give the person the advice, even if she fails to understand the death wish:

Quote 12

> "You have to speak with the client. Not that he has to convince me, but I want to see how it is. And *I hope to have empathy*, but is he dependent on my empathy? That's what I struggle with. (--) Sometimes I say, I don't understand. But *does he have to convince me to approve? It's not my role*, I think. *I give it to the people themselves.* That is sometimes difficult."
> **Lisa, volunteer (consultant)**

With her comment, Lisa sees empathy as a useful idea in helping to recognize one's authority over deciding to die: While she has the information the client seeks, empathy acts as the tool that helps her to move beyond her approval. Jenne Wielenga, the medical manager and doctor at the End of Life Clinic, presents another interpretation of suffering as the road to euthanasia. He gives an example of a case where mercifulness was not enough to fulfill the euthanasia request, but overruled by other factors:

Quote 13

> "Male, (--) deep depression since a month, two suicide attempts in two weeks. Antidepressant drugs started ten days ago, no affect, he did request for euthanasia by his general practitioner and he said no euthanasia, because there are other reasonable solutions. His psychiatrist came to the same conclusion and he came to us and our psychiatrist came to the same conclusion. *So, here the moral evaluation was that protection of life is more important that mercy for the patient*. And if we look at the legal criteria, (--) It was well considered, *it was absolutely unbearable*, (--) but there was a real prospect of improvement."

Even though Jenne Wielenga believed the patient's suffering to be "*absolutely unbearable",* he saw the criteria of possible improvement to overrule the mercy towards the suffering. So, in this case, the empathy for ending suffering did not equal ending life. Later he addressed mercifulness, and performing euthanasia in general, in relation with Christianity:

Quote 14

> "Actually, my moral balancing could also be regarded from a Christian view, because *mercifulness is a real Christian principle*! And the statement that god is the only one who has to decide about death and life, in that case resuscitation should be forbidden. And in that case actually all medical treatments should be forbidden. *On the other hand you can say "god works by men's hands". And in that case we help god when we perform euthanasia.* That's my Christian view about it."
>
> **Jenne Wielenga**

Jenne used Christianity to underline the role of mercy and mercifulness in euthanasia decisions, but also to give an ultimatum: *"And the statement that god is the only one who has to decide about death and life, in that case resuscitation should be forbidden. And in that case actually all medical treatments should be forbidden."* With this example, Jenne Wielenga presented euthanasia in the line of all the other medical treatments, and if only god is allowed to decide over life and death, all the medical interventions, including euthanasia, should be forbidden.

7.3 Conclusions of the compassion discourse

The discourse of compassion turned out to be an interesting and challenging one to analyze since its tendency to waver in between the modern and neo-modern responses of possessing authority. Finally, I began to see this discourse as having an intermediary role with authority. In the material, compassion appears as the factor that makes the person standing in the away of dying, to give away this authority to

the one who wishes to die: The experience of compassion makes the doctor, and the consultant to give advice on how to die, and the same factor might even make a rabbi approve of it.

At the same time, even if the *self* is seen to have the final right for authority, compassion towards suffering has a role in it. Occasionally this role has an intermediary nature, by permitting the pass of information, means to die, or to carry out of euthanasia. Religion was brought up with examples that challenge the assumed negative response to euthanasia, with those of compassion and love. Those who suffer are presented as a group that deserves mercy or should be informed about the possibility to exit this unnecessary experience. Thus, the group that suffers becomes a part of the community that does not have to and may choose not to, surrender to suffering in their lives. This way, suffering took the role of a philosophical idea and absolute value, and it became the authority over dying. The status of suffering as the requirement, reason, and a necessary part in euthanasia gave it nearly a sacralized position: Suffering is based on individual experience, yet outsider's assessment of this experience is a requirement of euthanasia. To be sacralized, suffering had to be secular, a part of the ordinary life in the beginning, before it became a pathway to euthanasia.[203] Occasionally the reaction towards suffering reminded an ultimatum: if suffering does not leave, I will.

8. DISCOURSES OF *ME-NESS*

If discourses of compassion arise from a feeling, then discourses of me-ness focus on the principle of autonomy and the idea that a person rules oneself. Thus, the more individualistic the culture, the stronger the ideas of *I* and the unique *me-ness* of it.[204] Several respondents emphasize the ability to live according to one's individual preferences and personal values – often with the continuum of also dying according to them. When *me-ness* controls life, it may also control death, and the higher the requirements towards death are, the less likely it is to follow a common formula. This can make the standard medical practices handling the end of life, such as the rules dictating eligibility for euthanasia, problematic. In the following discourses, the starting point is *me* and the attitude towards doctors and the medical profession, in general, or concerning euthanasia, vary between being moderately doubtful to being close to truculent.

[203] See Demerath (2007, 65-70) to read more about the process of sacralization.
[204] Levine 1988, 14: According to Levine's research of conscious living and dying, the collective and individualistic cultures differ in their view on death: The demise of the *group* is feared when person's identity depends on others when an individual-oriented culture fears the demise of *I*.

8.1 Autonomy and freedom

The questions of autonomy and self-determination were present in many of the interviews. As our death is a personal event regulated by law, the widely used phrase *"personal is political"* also applies to dying.[205] The fact that society has a saying in how we can die made many respondents angry. Thus, the discourse of autonomy appeared occasionally as a way to rebel, making the self the unquestionable authority over death:

Quote 15

> "So, we *want to have a legal way to get your stuff to end your life* when you are 18 years or older. No questions asked."
>
> "If I want to die, I want to die! *I don't have the obligation to live. That's fundamental, that's like a dictatorship in the 21st century* – you tell me I have to live, and I don't want to live, I want to die."
>
> **Jos van Wijk**

In Jos van Wijk's comments, the discourse of autonomy appears as an uncompromised value. Limiting access to the means to kill oneself is seen as setting an obligation to live and comparable to dictatorship. In the next comment, the respondent opposes the legalization of the completed life law – not because he is against allowing euthanasia for old but healthy people, but because of the restrictions and regulations that would come with the practice:

Quote 16

> L "Do you think it is gonna pass, the law? The voltooid leven question?"
>
> R "I don't hope so."
>
> L "You don't hope so?"
>
> R "No."
>
> L "Okay."
>
> R "No, I'm opposed."
>
> L "Okay. Can you tell me about that?"
>
> R "The political party who has this proposal, *they say they have to build in guarantees*, that people who are helping[206] are able to judge if this is a real and not imposed by other people,

[205] The phrase "personal is political" has been widely used in activist and theoretical meaning in the past sixty years. The original source for the famous phrase is not known, but it is often linked with the second-wave feminism, which in a nutshell claims that many of the choices assumed to be personal are actually socially constructed and limited. See, for example, Heberle (2016), in The Oxford Handbook of Feminist Theory. This famous phrase is worth mentioning, as many of the people interviewed for this study mentioned the connection they saw between feminism (especially abortion rights) and the right for a self-chosen death. In the end, these different questions both address the right to privacy and one's body.

[206] The hypothetical counsellors that would be trained to evaluate a completed life-requests.

spouse or children who are interested in someone's death. And *there must be an education for those people helping, certificates and so on*. (--) I don't see anybody with a certificate helping me to die (holding back his laughter). (--) Paternalistic, I think. *It is paternalistic*."
Patrick, volunteer

Patrick does not oppose allowing old but healthy people to die if they feel their lives are completed, but he is against making a specific law for this, due to the safeguards that would control the practice. It appears the respondent sees it better to either have a practice which would not limit one's authority to decide freely or not to have a practice at all. On the other hand, knowing the authority through a counsellor, such as the suggested personnel that would be a part of the completed life procedures, instead of a doctor, is one ingredient in the change from modern to neo-modern societal era in the theory of death's revival.[207] Another volunteer, John, is an advocate of the completed life law, and he emphasized the idea of freedom as the core value behind this and euthanasia when the practice was still stabilizing:

Quote 17

"There is one key word in this legislation at that time[208] and there still is. *And that is freedom! The patient is free to request euthanasia. The doctor is free to help this patient with that. Freedom is a key word.* At least in the euthanasia law and it most probably will still be in this other law that is coming, the voltooid leven. (--) *And again, I say it again, the principle is freedom. No one is obliged to undergo euthanasia. No other professional is obliged to help.* There is a lot of resistance, there is still resistance but what is (--) often forgotten in the discussion is the freedom. People who are against it are never obliged to follow that. Yet they are against because they think they make the decision for another person. *Individual freedom is sort of cultural development from the, in the last 50 or 60 years in this country.*"
John, volunteer

John addresses freedom as a cultural development starting from the '60s: Individuals have the freedom to ask, and doctors have the freedom to help. During the interviews, it was apparent that the most determinant proponents for the autonomous route did not have the need to convince me to agree with them – and occasionally this was brought up with the idea of freedom:

Quote 18

"*Nobody asked me if I wanna be in here, on this earth. Nobody asked me to be born. So, I think I have the right to die if I want to, whatever reason that is…* So as for me, if I could say, then I would say give us the medication to end our lives ourselves."

[207] See the attachments and the table of three types of death (point 11).
[208] The time before euthanasia's de-criminalization.

Quote 19

> I'm not here to convince people. It's a free country I mean. If you wanna suffer till the end, then suffer till the end. *It's your choice."*
>
> **Claudia, employee**

Claudia starts by introducing euthanasia as something that one is free to choose. The notion that the respondent did not ask to be on this earth entails the right to end the existence. This assumption of freedom includes the possibility to possess lethal medication. In Claudia's comment, the self has full authority since it is understood to be a right. Also, Hans's comment follows the idea of freedom:

Quote 20

> "I feel now that I'm fighting *for the right of freedom for a person to make his or her own choice.* And that it must not be prevented by*, it is such a personal event*, that is must not be interfered by religious – well maybe for the, if a person doesn't want euthanasia because his or her religion, it is okay, but it doesn't have to be prevented by someone with another religion."
>
> **Hans, volunteer**

Where Claudia sees the freedom to die to come with the notion of not having asked to be born, Hans reasons the right for freedom with the death's nature as such a *personal event* so that religion must not interfere with it. In the interview material freedom did not appear only as of the freedom to decide, or freedom from suffering, but also as *freedom from dependency*:

Quote 21

> "When I want to have the possibility to choose the end of my life, *that's my choice*.
> (--) About well-thought *suicide*, I can understand *people want to do it themselves and not be (--) dependent*. They don't want to depend on a doctor to get euthanasia, so they want to do it themselves, or people who are not ill but just want to end their lives."
>
> **Rene, employee**

Rene begins to talk of the technicalities and after this the reasons for wanting to die. He discusses ending one's life as a choice the person can make, and how he understands that by withholding any help from the doctor, a person can avoid dependency. He continues to address the lack of motivation to live, as part of the end of life decisions:

Quote 22

"*I can accept that there are people who just want to die not because of some illness or something, they just are not motivated to continue their lives*. (--) Suicide is a big taboo (--) because mostly you think suicide of jumping from a building or in front of a train, but there are good ways to end your life, it's very good that it is possible. *It's a way for people to end their lives because they want to stop it. For what reason, it's not my business*."
Rene, employee

Rene moves further from euthanasia by excluding the necessity of the medical basis, since there are people whom *"are not motivated to continue their lives"* and the needlessness to justify the reasons behind suicide since *"for what reason, it's not my business."* On the other hand, even though another respondent stated that the value of personal autonomy was her reason to support the law on completed life, she continued to tell how she understood the view of autonomy being an illusion:

Quote 23

"I think, having explained this about *having your own autonomy, having your own idea that you can influence the end of your life*, I'm in favour of this law."

Quote 24

"I can understand that people say this *autonomy is an illusion*, which is in a way true. *It is the feeling of having autonomy* at the very end. Always things happen that are not planned. And you have to accept that."
Maarit, volunteer (consultant)

The comments valuing personal autonomy and freedom emphasized the right to choose to die, but also the right to move one step further from euthanasia by not including a doctor with the dying, thus expressing a clear neo-modern response. The option of ending one's life without a doctor still included the use of medication in the respondents' speech. This way, the question turned out to be the right to have access to the lethal medication to kill oneself – and the principle of autonomy sees attempts to prevent this unjust.

8.2 The feminist discourse

Some respondents brought up feminism and abortion laws when discussing euthanasia. The fight for abortion rights, or the more general nature of moral dilemmas, were brought up together with the euthanasia question. The option for abortion was compared with the fight for decriminalizing euthanasia: Both topics focus on the right for bodily self-determination. I call this discourse, which brings up the abortion right or emphasizes similar laws, the feminist discourse. The next three quotes are examples of how abortion is linked to euthanasia:

Quote 25

"It is such a fundamental thing[209] for the whole feminist society. And I think *this will be a little bit of the same, like death emancipation, like we will get further as a society and embrace death like a part of life*."

Quote 26

"We are trying to be propagandic, like pro-choice. *That's a nice frame, pro-choice*. Pro-choice really worked for the abortion thing you know, because the pro-life, they branded it like they were against life and they branded it pro-choice and it really worked."

Sophie, employee

Quote 27

"There are so many other, *vaccination*, you have the very strict people who say we shouldn't do that. So*, there are more questions,* abortion, of course, there are more questions. So, this *euthanasia is only one of them!* (--) There are so many issues where you have to, to make up your mind. And we have the Christian parties, (--) we have the very strict parties."

Maarit, volunteer

Quote 28

"*I think euthanasia is the normal medical practice*. But the KNMG does not acknowledge euthanasia as a normal practice. I can understand that a little bit because *if you say it is a normal practice, like abortion is,* then doctors who do not perform that, you can accuse them of being non-professional."

Johan, volunteer

Sophie compares the feminist development and legalizing abortion to euthanasia laws, suggesting the latter to predict a society's development towards embracing death in a new way. On the other hand, Maarit addresses euthanasia as one of the ethical questions of bodily self-determination, among the topics of vaccination and abortion, which a person comes across and must make up his mind – without forgetting the assumed opposition from the Christian parties. Johan took a different approach by comparing abortion to euthanasia as *a normal medical practice* even though he understands the doctor's union's disagreement. The comment approaches euthanasia in connection to other questions of bodily self-determination that need the co-operation of the medical profession. Thus, in this example, authority is a combination of the modern and neo-modern views: I did it my way but with the co-operation of the doctor.[210]

[209] Here the "fundamental thing" refers to the option of abortion.
[210] See the attachments for the number 11 of authority in Tony Walter's table of the three types of death.

It appears that the roots to compare euthanasia with abortion run deep. Interestingly, when a respondent mentions abortion in connection to euthanasia, he or she also tended to refer to politics.[211] The respondents discussed, for example, of euthanasia as the next logical successor for the feminist movement and together with abortion as something that should be protected. I find this, presenting euthanasia in logical continuum with feminism, particularly interesting, since one of the assumptions of this research is that a person makes sense of the surrounding world and constructs it through language – and as Sophie pointed out in her comment, it is not irrelevant whether something is called *pro-death* or *pro-choice.* A person orients towards the world when creating a reality based on language by categorizing and naming the different things, items and phenomena surrounding him – If euthanasia is referred as the next logical step in patients' rights or individual freedom in general, it becomes less extreme and more neutral subject.[212] It is not irrelevant whether killing by request is called *homicide, euthanasia* or *murder,* or whether taking one's own life is referred to as *suicide* or *self-euthanasia* – or *dignicide:*

Quote 29

> "We have been trying for the World Federation, with a group of people, *we have been trying to find another word for suicide, for assisted suicide actually*. Especially (--) suicide, (--) is connected to horrible things. Suicide is something you do, jumping or, and we have been trying to come up with an alternative for suicide and we couldn't find a proper word in a long term. *Finally, they suggested to try to get installed the name dignicide.* In principle that's a strange word because dignicide actually means that you kill dignity. Like suicide, dignicide, homicide."
>
> **Rob Jonquiére**

Rob Jonquiére brought up the word *dignicide* as an amusing misstep when trying to change the negative association of a specific act by introducing an alternative word. Nevertheless, he underlines the weight the use of words and their sub-meanings carry, just as Sophie did by borrowing the pro-choice frame from the feminist community. Our common language is an arena for the social game of constructing and maintaining meanings. People, with the questions of one's right to his or her body, exist and function within limits set by the language. Together with people's actions and the surrounding social context, a language cannot function without an inseparable connection with these factors.[213] With its name, the World Federation for Right to Die, the organization emphasizes the *right* in dying. If the name was the

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[211] I present more comments of this nature in the subchapter of the discourse of others and threat to the practice.
[212] See, for example, Suoninen 1999, 19; Wooffitt 2005, 3; Jokinen et al. 1993, 9, for languages role in producing reality by describing it.
[213] Berger & Luckmann 1971, 65-70; Pesonen 1997, 133-149.

World Federation for Euthanasia Societies, the focus would, by euthanasia's definition, be directed to the doctor's role, thus not covering the autonomous and assisted routes. When a person's right to control his or her body is under discussion, this does not happen in reality separated from the language and culture.[214] Following this logic, the person's experience of having the right for a full autonomy has been formulated under the culture's influence.[215] Potentially the permissive Dutch attitude towards euthanasia could be viewed as an extension – or an inseparable part of – the idea of a person's bodily self-determination, as the feminists argued to be the case with abortion.

8.3 Control and individualism

As this work has already indicated, *control* has an essential meaning in euthanasia. Many of the interviewees brought up its role in euthanasia requests and the general discussion. In the following quote, Sophie explains how she saw a relative regaining her control after the doctor agreed to perform euthanasia:

Quote 30

> "And when she heard the doctor was going through with it, she was really calm. I think that's also nice for people that *they know that they have the control back. I think the disease makes people feel that they don't have control anymore, and if you, if this is a way to control it, then you can maybe bear it longer*. It's also what they say, if I know I can have euthanasia when it gets too heavy, then they tend to live longer. Because then you know, at least you know you have an exit and it is easier to bear."
> **Sophie, employee**

In Sophie's comment, the sense of control has a similar effect than medicine since it can extend the patient's life by making the illness more bearable. The discourse of control gives authority to the individual, and this can happen with or without the help of medicine. Even though control was highly valued in the conversations, one interviewee expressed another kind of view. When we spoke about making a living will[216] she gave me an answer opposing the neo-modern view of control:

Quote 31

> "I don't want to be in a coma, but I don't know, it's kind of what happens. Well then, and for some people, it might be a solution to die then, but yeah, well, maybe it's just life. Maybe I

[214] Weedon 1989, 23.
[215] The "soft whenever possible" approach describes the Dutch approach of managing personal freedom in society. See van Rossum 2014, 287-296.
[216] A living will is a document dictating the limits a person has set for his treatment: for example, denying resuscitation. See www.knmg.nl.

think otherwise when I experience it but now, I think well, some things just happen. *The things you can't control are the things worth living for* mostly, so."

Anna, employee

Anna directly questioned the meaningfulness of having control over life (and death) by calling the things outside its sphere, *"the things that are worth living mostly."* Despite questioning the individual's control, she does not reflect modern society by giving the control on to the medical profession, or the traditional society by trusting it with religion, but leaves the cultural response to death open.

In his theory, Walter discusses the power that comes from possessing the dying or the dead body. When a person dies in an institution, the relatives must ask the staff for permission to see the diseased.[217] Walter proposes that a person can regain control by dying at home. Interesting enough, before this research, I was not aware of how common dying, or giving birth, at home is in the Netherlands. Neither did I know that the body was kept at home for some days after the person had died. I was introduced to this habit of home-death without the presence of medical professionals when Claudia told me how her father was sedated for his last days:

Quote 32

L: "Was it just the family members taking care of him, or was there like a doctor coming in or a nurse?"

R: "Yeah after three days we decided to have an evening and night nurse so we could sleep, because before we were just taking turns by his bed." (--)

L: "(--) good that you corrected me that no, it was home."

R: "Yeah why should he be in a hospital? He was dying. (--) It is same thing with a baby being born here in Holland, also a lot of babies are born at home. (--) Because here in Holland we believe that having a baby is a natural thing, it's not a disease so why should you be in a hospital? (--) It's the same with dying, *I wouldn't wanna die in a hospital. It's better with your family around you.* (--) *It's the same when he was dead, we decided to have him in a house for five days.* In a coffin. You know, *just to get used to the fact that he was dying – he was dead.* That people could say goodbye to him. And after five days we closed the coffin for the, for the funeral."

Claudia, employee

In contradiction to Walter's assumption, the Dutch did not regain control by decriminalizing euthanasia, but simply raised the bar, since dying at home was already common before the law. Nevertheless, it shouldn't be forgotten that in the Netherlands, the doctor carries out the euthanasia usually *at the*

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[217] Walter 1994, 17.

patient's home. This appears to be a unique combination of possessing the control: The doctor possesses the power of the medical community by practicing the only profession allowed to help someone to die. At the same time, the patient can and usually prefers, to die at home. In this way, the control and power over the last moments of life are shared between the medical profession and the dying person himself. Drawing conclusions from Walter's theory, this comes across as a liminal space where the modern and neo-modern death ways meet: I die my way, but can't choose anyone else than the doctor to assist me.

Jos van Wijk's speech reflects the conflict over the rightful possession of the control. He wishes to complete the shift from modern to neo-modern response to death by giving the individual the tools of medical professionals – the tools to end a life with medication:

Quote 33

> "There isn't any, any comment of a doctor or a psychiatrist or family, *you are the only one that can make that decision*. (--) You have a very personal lock, like your iris or your fingerprint. No one else can use your safe with the medicine in it to kill somebody, because you are the only one who can open it. So, there is a very good and safe system to keep the stuff at home."
>
> **Jos van Wijk**

Being able to have the lethal medicine at home is given much thought, as Van Wijk speaks a lot about safety measures and the technology needed to make it possible. These safety measures combine highly developed technology and medicine, without the bureaucracy of getting permission. Naturally, this doesn't merely increase the feeling of having autonomy and control, but it would concretely maximize the control by giving the person the means for ending life. A Dutch person seeking to strengthen his self-control can contact other professionals besides doctors. For example, Ton Vink, a philosopher, offers consultation for people that are making preparations for their deaths. He begins by giving an example of why people come to meet him, and continues to open his own opinion of the euthanasia practice:

Quote 34

> "There also may be people who just say "well, I am looking towards the end of my life and I want to live as happily as I possibly can, but it would contribute to my happiness *if I had the means to full self*-control over my end of life.""

Quote 35

> "I am not here to help and assist people with their suicide… *I'm helping and I am here to assist people with gaining their self-control*, which I think is a different thing of course because often they live for a long period before dying of something else. (--) There is a lot of

discussion about the review committees[218] and how they are functioning. (--) *My problem, well problem, my question, (--) is that they never asked, "Did my patient die a good death*?" This is a bit strange because we are talking about euthanasia and euthanasia literally means a good death. For some reason, this question is never asked and that's a bit weird."
Ton Vink

The search for control appears to be one of the main reasons for many people to meet him. He continues to discuss combining the possession of control and autonomy over one's life with the notion of a good death. I interpret from Vink's words that for many of his clients it is enough to have the feeling of control, in other words, the knowledge of how to end one's life, and carrying out this act doesn't necessary take place: *"I'm helping and I am here to assist people with gaining their self-control*, which I think is a different thing of course, *because often they live for a long period before dying of something else*." By speaking about a good death as a currently missing but desirable criteria in the euthanasia's evaluation process, Ton Vink moves the shift from euthanasia as the answer for relieving suffering, to a neo-modern choice that a person can make in his seek for the good death.

With the medical discourse and its bureaucratic practices, modern death failed to succeed in describing private grief. When I consider the changes that have occurred around the deathbed in the light of my study, it appears that by gaining control over the different aspects of dying, the individual plants private experience into public discourse. One step in this path is to replace old authorities and specialist, whether they were religious or medical experts, with the power of the self that views limitations negatively and sees a choice to be good because the self makes it – and not because an authority agrees with it.[219]

8.4 The standards of living

Modern medicine has certainly made death in the twentieth century less painful than in previous times. These possibilities, offered by the scientific progress, have also made the dying bureaucratic, creating conflict and laying the ground for the wish to revive death.[220] When the difference between easing pain and ending life is a matter of how much the doctor administers the same drug, the rules guarding health care are more detailed than ever before: The individual can choose from several treatment options and receive more help, but the rules for the very final moments are set by the society and politicians and guarded by the doctors. For the persons valuing their personal autonomy greatly, this may feel unjust.

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[218] The Royal Dutch Medical Association and the Royal Dutch Pharmacist Association have published a detailed instruction booklet for euthanasia and physician-assisted suicide. The 56 pages explain in detail the administration of the drugs and even advice to switch off the cell phone when performing the euthanasia.
[219] Walter 1994, 27.
[220] Ibid., 22.

The discourse of *the standards of living* is interesting in its nature of being two-sided: Firstly, euthanasia is described as a sort of an inevitable *result of the technologically developed society,* where medicine doesn't exist only to cure but to serve individual goals. Secondly, it introduces *a spiritual side* of existence.

Jenne Wielenga, the medical manager and doctor at the End of Life Clinic, walked me through an example, where the personality of the patient requesting euthanasia, helped him to reach a decision. The patient was an older man with cancer and Crohn's disease:

Quote 36

> "(-) *my first impression was, he is fine for his age*. (--) The patient told us he was a self-made man. (--) he ended his career as a CEO (--) and his wife told us that his work people are afraid of him, because of his very high demands, but that he had also high demands of himself and *he couldn't fulfill his own demands anymore. It was a part of his suffering*. (--) *So, suffering that would not be unbearable for me, if it was my suffering, was, in fact, unbearable for this patient with his character and his biography*."
> **Jenne Wielenga**

Jenne Wielenga's comment is an illustrative example of the combination of the elements in modern and neo-modern societies: The bases for the euthanasia request were medical, but they were evaluated according to the patient's character. Also, Walter proposes that striving for the simultaneity of *social and physical death,* is becoming more and more popular, suggesting that euthanasia fastens the physical death to meet with the person's experience of his social passing.[221] This seems descriptive of the old man's euthanasia-request. On the other hand, receiving assistance with dying based entirely on social factors, the completed life issue, was viewed skeptically *"as a luxury problem:"*

Quote 37

> "I think that two years ago, (--) I was really believing in a law for voltooid leven, completed life. I was really, I believed in the necessity of it and it should be possible (--) And now I'm a bit more sceptical about it. And I think *I understand that all these people don't want to get old and want to leave their life before they don't like it anymore*. And, but… I think *it's a bit of a luxury problem now*."
> **Kirsten, employee**

Kirsten expressed to understand how *people "don't want to get old and want to leave their life before they don't like it anymore."* The comment brings forward the anticipation of social death: if euthanasia

[221] Walter 1994, 50-51.

fastens the physical death with the social one, leaving the life before not liking it anymore predicts and prevents this experience. Despite of understanding the wish, Kirsten referred to this scenario missing the medical basis as *"a luxury problem."* In the next example, the opportunities offered by a developed society are linked with a person's possibility to control his or her physical appearance, or the option to arrange euthanasia:

<u>Quote 38</u>

> "*We choose for euthanasia. It's a way that belongs to our very technologically arranged society. It's an evolutionary, cultural development*, I think. 'Cos *all the other things that are arranged, we have to arrange this as well*. (--) We get organized to have a baby if we can't have the baby. We can organize that we get another body if we are not happy in our bodies. *We can organize everything. But it also means that we have to organize our death.*"
> **Marion, employee**

Marion approaches euthanasia as an option co-existing with other possibilities, such as assisted reproductive technology or plastic surgery, to change a person's physiology to resemble the wanted outcome. She addresses euthanasia as cultural development, just as John did in the chapter of Autonomy and Freedom. During the interview with Sophie, she asked about the limits of the Finnish euthanasia initiative:

<u>Quote 39</u>

> L: "In the legislation that might happen in Finland, (--) only physical suffering is enough."
> R: "I think that's also a little bit, like, *old-fashioned because now being a human being has so much more* than eating, drinking… *Like with the whole yoga thing and mindfulness thing,* and we are just more in the mental health, not really mental health, but more *spiritual level,* like, it's not like, because *we have such a high standard in living now*."
> **Sophie, employee**

Sophie proposes that society has moved past from the physical suffering as a condition to euthanasia since being a human in current society has evolved from this physical state. The comment paints a picture of a neo-modern society, where individual's ability to reach the *"high standards of living"* and *"spiritual level of being",* can be requirements for experiencing life as worth to live. Bringing up *inner spirituality*, instead of a specific religion, resembles strongly the neo-modern experience.[222] The high standards are present also in the next two examples, as the respondents describe euthanasias, they either had heard of, or themselves witnessed. In the first example, the NVVE's consultant described the euthanasia of a person she had offered consultation to:

[222] See the attachments for the section 14 in Walter's table of *Three types of death.*

Quote 40

"But *it was so wonderful,* with a class of wine, music, candles. (--) So, it can be like this. And *you would give it to all people* who wanted to be like that."

Lisa, volunteer (consultant)

Quote 41

"He had *music of Bach on the background* and it was a beautiful memory. And *I would want to die myself that way because it was very beautiful.*"

Inge, employee

In both comments, the circumstances of the dying were individually planned, such as playing the music the patient wished to hear as he died. In this way, the individuals' personalities while living were made a part of their dying. Therefore, the standards of living were extended into the standards of dying.

8.5 *Self-euthanasia* – Discovering needs and creating a reverse discourse

Creating and maintaining a reverse discourse is often linked with a goal of political nature. For example, Foucault reintroduced the discussion of homosexuality when a new, positive discourse, was created for the term, by letting it speak for its own behalf. [223] Considering this research, the counter-discourse appears to focus on the concept of suicide, which carries a strong negative connotation. The word is reintroduced as a good option for an autonomous person, instead of a tragedy, by renaming suicide *self-euthanasia*. This way, the groups that are dealing with the question of self-chosen death, create a non-traumatic discourse for ending one's life:

Quote 42

"*Suicide in Holland is associated with horrible things*. Jumping off from great heights, jumping in front of the train, using all kinds of medicines to kill yourself, drowning yourself. That kind of things. The horrible ones. (--) That is suicide. *Self-euthanasia would be, we say, is carefully planned, prepared with people around you and good means to do so*."

Jos van Wijk

Quote 43

[223] See Foucault 1981, 101: When the nineteenth-century psychiatry disqualified any other sexual behavior than heterosexuality, labeling other orientations perverse, homosexuality began creating a positive discourse for the term; It did so by using the same categories that had been used to disqualify it, demanding the recognition of its naturality.

"Self-euthanasia, it is actually a composition of three, the words tell it itself: it's 'e' and 'u' and 'thanasia'. So, *it not just a death but it is a good death, and it is a good death that you control yourself* and you are yourself responsible for. So, you could say (--) every case of self-euthanasia is also a suicide because you end your own life, but not every case of suicide is a case of self-euthanasia, because you may use traumatizing means."

Ton Vink

Self-euthanasia can be considered an anomaly[224], because it locates simultaneously in the categories of euthanasia and suicide, without belonging to either one entirely. If euthanasia is understood as a self-chosen death that the others (or at least the doctor) agree with, self-euthanasia is a self-chosen way of dying – but unlike suicide, it takes the positive association from the word euthanasia, without asking the permission from others. The words carry their meaning in connection to the discourse and gain this meaning, perceived as self-evident, because of this context. Thus, the weight words carry are open to questioning and change.[225] It appears that in the interviewees' speech, suicide is perceives as an act of taking one's life *without* control and self-euthanasia as an option for suicide *with* control.

Self-euthanasia places the authority of dying fully on the shoulders of the individual. If the individual is free to make the choices without anyone else's permission, he also needs to discover the needs that require choices in the first place. Nevertheless, discovering one's needs is a project. Jos van Wijk brought up *living room-groups*, a form of activity arranged by the Cooperative Last Will, where people gather to discuss their death-wishes:

Quote 44

"We call it living, kind of living group, in a house they have a living room, *you have living room groups.* And we mentioned it and NVVE started to organize it as well. (--) When you are in a small group, let's say, four people, eight people max... *It is good to have a very close environment that makes it possible for you to talk about your death, how you want it, what you don't want."*

Jos van Wijk

[224] Mary Douglas (1966, 38-41) observes the culture specified taboo-thinking by directing the attention to anomalous i.e., diverging meaning in a person's thinking. She defines an anomaly as an element, which doesn't fit or belong to a given group or series. Even though the Netherlands is not the strictest country on its stance on suicide, does the word still carry a tragic meaning, thus giving a foundation for introducing *self-euthanasia*. According to Douglas' theory this new term, *self-euthanasia*, appears as "anomaly" among suicide and euthanasia: it is a suicide, but not a tragedy. It is also euthanasia, but unlike euthanasia by definition, it doesn't involve others.

[225] Charpentier 2001, 39; Weedon 1989, 23-25.

The living room-groups Jos Van Wijk describes, remind me of the various support groups offered today for people struggling with different problems: Alcoholics or Narcotics Anonymous for people suffering from addiction, or support groups for others fighting cancer, or for those who are reproductively challenged. Walter links *"the seek to discover needs"* with finding the real me with the help of therapists, relationships and self-help psychology books. The former helps me with the discovery when family-relations and tradition hide the real me.[226]

8.6 Conclusions of the *me-ness* discourse

Compared to the discourse of compassion, the discourse of me-ness is more strongly present in the material, but it also has more variety within itself. The aspects of autonomy and freedom, feminism, control and individualism, standards of living, or self-euthanasia, all shed light into the different perspectives to be analyzed within the me-ness discourse. By constructing all the listed sub-discourses, I wished to point out how vivid the notion on authority may be, and how the people rooting for the same goal can base their thinking in different values and assumptions of society's role. One interesting detail that caught my attention during the interview and analyzing processes is the tendency of the older respondents of being ardent supporters of autonomy, instead the more subtle way emphasizing suffering was present in the material. Some of the older respondents approached euthanasia as cultural development. For example, John referred to the euthanasia practice as the result of a development that started approximately 50 years ago – the development of individual freedom. Interestingly, this coincides with the time period where Demerath locates the academic curiosity towards the idea of western faithlessness.[227] The question emerges, will the role that was given to autonomy loosen its grip on the pro-euthanasia field on the coming decades? If this were to happen, the time frame of modern and neo-modern societies would turn upside down or form a circle: Modern society led to neo-modern society, only to eventually turn around and return to the modern era.

Especially the respondents underlining the importance of autonomy often appeared somewhat defensive about the topic, and questioning the practice was occasionally perceived as a senseless and oppressive attack towards the Dutch culture and its values. The advocates of the autonomous route appeared to seek to erase two sides of the triangle illustrated in Figure 1, by removing the physician and relatives from the process of reaching euthanasia decision, thus leaving only the patient in the picture (page 16). Thus, the values of autonomy, freedom, and self-determination are not only self-evident but untouchable. I

[226] Walter 1994, 27. See also Campbell (1987): *The Romantic Ethic and the Spirit of Modern Consumerism*, on the phenomena of creating greater needs and services to facilitate self-expression.
[227] Demerath 2007, 57.

interpret this to resemble Durkheim's idea of the connection between community and holy:[228] In this case, the value of autonomy is untouchable, and thus something comparable of being sacralized, as the community of proponents protecting it occurs as something comparable to holy.[229]

9. COUNTER-REACTIONS

The chapter of counter-reactions is two-sided in its discourses. By naming this chapter counter-reactions, I aim to point out the discourses that were not in alliance with the general tone of the interviews: This can mean the critical view of individualism or the specific naming of threats to the euthanasia practice. The discourses of counter-reactions illustrate that even though religion doesn't appear in various examples discussed above, it manifests itself in those views that question or see the contemporary situation from a critical point of view - or in the comments that presents religion as a threat.

9.1 Taking a step back from individualism

Now and then, the discourses of suffering and me-ness bring out a counter-reaction. In the chapter of *counter-reactions,* I aim is to focus on two aspects. First, occasionally, a person rooting for individualism did also address the downsides or doubts of this value. Also, it is essential to point out how advocating for euthanasia did not mean a person would not respect other choices as well. Secondly, in the sub-chapter of *the discourse of others*, I shed light into the perceived threats for the Dutch euthanasia practice.

I start with an example of a counter-reaction to *individualism*. Martijn begins by stating that as a member of the NVVE he has the autonomy, but continues to question the happiness of individualistic people and reveals his counter-reaction to it: Sending his child to a Christian school so that he could experience collectivity and caring of other people:

<u>Quote 45</u>

> "T*he people like NVVE and us*, we make our own decisions (--) *We have the autonomy ourselves*. I've grown to think okay, that other[230] is not necessarily better. I think *the individualistic people are very lonely,* it's not that it's perfect or anything to be so in charge

[228] Laitila 2004, 66-81; Durkheim 1980.
[229] Ibid.; Demerath 2007, 57.
[230] The other = collective and vs. individualistic culture.

of yourself (--) they sometimes long for somebody who is telling them what do to. (--) *I've got kids* (--) and what I never held possible is *that he is going to a Christian school because I like him to get the feeling of collectivity and caring about each other. That's not there in individualistic school or humanist schools*. (--) And he is gonna learn all about, because we might think that we are not living in a religious society, but we definitely are. (--) I think it's very important to my children to learn what it is and how it forms people, and he gets to know all kinds of religions."

Martijn, employee

He concludes the thought by referring to a colleague, who questioned the continuation of the individualistic view, as it would be time for something new:

Quote 46

"I just talked about with X[231] he said *maybe the world is going away from this individualistic*, because to reach everything there is to reach, individuality, *it's a time for something new*. Shouldn't we be more like (--) I cannot be happy if you are not happy, that we are together. The togetherness of the world."

Martijn, employee

By stating *"it's a time for something new"* Martijn's thought resembles the notion made in the *me-ness discourse's conclusion* chapter: If the value given to freedom and autonomy lose their position, the continuum of modern and neo-modern societies would form a circle, as neo-modernity takes a step back from its position in valuing individuality above all. In that chapter, I also introduced my observation of the ardent fighting spirit many older advocates have. In accordance with this notion, Martijn had himself noticed a change moving away from the determinant fighting spirit of autonomy:

Quote 47

"(--) the NVVE youth, for the younger people, when they are in a debate it's much more respectful. *They are much, much more understanding of the people who are against it, or any opinion at all.* And that also feats me in this thought that the next, *the new generation is coming now*. And this, on *the barricades, was useful in the '60s or '70s or whatever but might not be the best solution to future problems.*"

Martijn, employee

Hanna describes a situation in which a person has lost his autonomy. A friend of hers is paralyzed, and thus entirely dependent on others. In many interviews, the respondents did not see a sense of staying

[231] Person's title erased by the author.

alive, if one was lost the ability to function independently. Opposite to this view, Hanna admires her friend for living:

<u>Quote 48</u>

> "(--) he can only move his head, he is paralyzed by an accident. This happened in 2003. It's already 14 years. (--) It's up to them, they know what I do if they want more information or not. (--) *I still think that it is very brave* (--) *that he wants to continue living*. (--) He can go by with a wheelchair because he can still move it… He needs to be fed, during night time by a professional, during day time he is in their house."
>
> **Hanna, volunteer**

Hanna begins by telling how the person has been paralyzed by 14 years. After saying, *"I still think that it is very brave that he wants to continue living,"* she describes how the person is dependent on others to assist the daily activities, such as eating. The admiration of independence and fear of dependency are strongly present in the material, but Hanna's comment caught my attention as a counter-reaction to the common view. Moving away from questioning autonomy and independency, Maarit questions the view of a religion being a barrier for euthanasia. She expresses that appreciating tradition or having a religion should not be a black and white issue, but something to be combined in the euthanasia discussion:

<u>Quote 49</u>

> "And *you can be religious and not be against it (euthanasia) that much.* (--) And if you were, if I were religious, I would make up my mind and I would ask, well if you know what is the best decision here? And *I would just meditate and think*, okay, I think in this situation you could finish this life now. You know? *You can combine that*."
>
> **Maarit, volunteer (consultant)**

She continues by talking about the manner rituals are feared among many advocates of individual autonomy and euthanasia:

<u>Quote 50</u>

> "It is a ritual what you really appreciate. Yeah, I think it is a bit lacking in the Netherlands, that we all, we all in one side if you... You can hold on and appreciate the rituals and not be that strict religious about the god anymore, eh*? It's maybe a bit our problem that we, it is either this or that*."
>
> **Maarit, volunteer**

Maarit brings up a view questioning the lack of collectivity and mentions the fear of rituals among the advocates of euthanasia and autonomy. Just like Sophie's words earlier, (quote 39) Maarit's thoughts

remind me of Walter's notion of the rise of spirituality: The revival of death links the habit of replacing religion with spirituality. Without going into details in the differences between the two concepts, I find Walter's notion to capture something of an essence: *"If religion puts you in touch with God out there and with meaning and mores external to the self, spirituality puts you in touch with your inner self and with the God within."*[232] Maarit speaks about the pity of black-and-white thinking, referring to the assumption that being religious equals being against euthanasia. She also gives an interesting example of reaching a decision with the help of meditation – *if she was* religious. As mentioned earlier, I refrained directly asking the respondents about religion. Despite this, the topic was usually brought up when I mentioned euthanasia's opponents and asked whether the respondents could understand them. A typical answer to this question was to assume the opponent had a religious conviction.

9.1 The discourse of the others – The threat to the practice

By this far, the research has pointed out how religion, medical professionals, and politics, may be understood to pose a false authority or threat to the self-chosen death. Even if religion was not presented precisely as a threat to euthanasia, it was the most commonly mentioned reason for somebody to be against the practice. Claudia's comment is a typical example of this kind of response:

Quote 51

> L "Do you understand the opponents of euthanasia?"
> R "I think the majority of the people in Holland are, uhm, pro. (--) I don't know the exact numbers, maybe you know."
> L "No, I don't know."
> R "Cos I think it's about 80 percent, who are pro. Yeah, I think so. (--) Sure there are some religion who don't believe in euthanasia, but it's not that many."
> **Claudia, employee**

Whereas Claudia mentions religion as a very distant factor, Kirsten has a closer look. I asked Kirsten how people react when they hear about her job, and she mentioned Christianity as a reason not to discuss it with people:

Quote 52

> "I'm a bit prudent telling about my job because I don't know what people think of it. And especially where I live, the place I live in Amsterdam, there lives a lot of Christian people,

[232] Walter 1994, 28.

and for myself, *I'm not a believing Christian, so I don't know how people feel about euthanasia,* how offensive it is if I speak about it."

Kirsten, employee

Kirsten presents Christians, or *"believing Christians",* as others that might be offended by euthanasia, although she didn't label them a threat and left her own conviction open by referring to herself as *"not believing Christian."* Rene views religion in a very different way, as a direct barrier for euthanasia. He tells about a case in Italy, and how he started to volunteer for the NVVE because of it – and because religion is not part of his life:

Quote 53

"(--) a situation in Italy, someone (--) had an accident and was for years suffering and nobody in Italy wanted to help. *So, I got furious and I thought I want to do something with that, so I came here as a voluntary. Because for me the religion is not a part of my life,* so I don't think there is some kind of entity wanting to tell us how to live. (--) it's okay when some people have a religion and when they want to live according to that religion, but it is their choice and I don't have any problems with that. *But I don't want them to tell me that I have to live according to their believes because I don't believe. And I don't want to believe.* And I don't want them to tell me that they are superior to (--) my view of life. So, that makes me angry that you think that when you have a belief that you can tell others they have to think same."

Rene, employee

Even though Rene doesn't directly say that the person in Italy was not assisted to die due to the church's role in the country, I interpret his comment to count religion responsible for this and a more general attitude of opposing euthanasia. In the following two examples, Hans, a volunteer-consultant, first shares his thoughts about religion as part of the completed life discussion, and then continues to share the case of NVVE's Catholic member:

Quote 54

"When I consider my life voltooid, another one can't say it is not yet voltooid. And even more bad than, is saying this like it is not allowed because god gave you your life, you can't take it yourself. That is for me, more in the direction of the *Islamic state and philosophy, who also know what their Allah wishes and wants everything to behave in that way. And so here the Christian party knows what their Allah wants to*, although they have him a different name."

Quote 55

"And once I've been with a Catholic lady and her husband had died in a very awful way and she didn't want that. And he was always organizing everything, and she lived in a village (--) and he decided (--) all things. And *she, he was very Catholic, very against, he was very*

against euthanasia, and she may be too, but when she saw what happened to him… No, that's not what I want. Then she asked the, for one of us to come. (--) She said: "You don't even see a foreigner here! No, *I don't want to be watched anymore.*""

Hans, volunteer (consultant)

Hans begins by telling how religion should not limit his choices about the end of life, as religion isn't a part of his life. Later he continues to describe a client who didn't any longer want religion to limit her plans for the end of life decisions: The Catholic lady took the authority from the religion-led community and gave it to herself by refusing to be watched anymore. When Hans discusses religion on a more general level as a threat for the individual freedom to decide to end one's life, Marion sees specifically Islam to be the threat for the practice, and not only the practice but to the Dutch culture that achieved it:

Quote 56

"I can't imagine that I would go for a job where they would not stand positive towards euthanasia. For example, I would never want to have a doctor that is a Muslim, a physician for many reasons. But also, *I hear sometimes that people say that "my doctor is not for euthanasia because it's a Muslim."* And then I think well, I would never want to have a doctor who is a Muslim because I'm a woman, but also *if a doctor isn't grown up with the Dutch values, I wouldn't feel comfortable.* I also won't feel comfortable when I'm in a hospital and I would be treated by a Muslim nurse or so, it's a difficult issue right now in Holland, that *euthanasia is verworvenheid, something that we gained in our democratic society and now it's changing because there is ever greater and greater population that is very much against for example euthanasia*. (--) Different values, it's difficult (--) *It's not only the part of euthanasia* but we are talking now about euthanasia, so."

Marion, employee

In Marion's comment, religion is not merely seen as a threat to the euthanasia practice but to society's values on a larger scale. Marion uses the word *verworvenheid,* which translates to *achievement,* to explain how euthanasia is one of these achievements of Dutch society. But, by stating, "*euthanasia is (--) something that we gained in our democratic society and now it's changing because there is ever greater and greater population that is very much against for example euthanasia. (--) Different values. (-) It's not only the part of euthanasia",* she introduces the new population, presumably Muslims, as a threat to this and other achievements of the society behind the development.

The following three quotes bring up religion, together with politics, as threats to euthanasia and abortion practices:

Quote 57

“There are parties who want to get rid of abortion and euthanasia. So, let’s keep what we have.”

Johan, volunteer

Quote 58

“Politicians are always watching us because we are (--) an association with a particular goal. We have also very strict Christian parties and (--) they don’t approve of abortion or euthanasia.”

Inge, employee

Quote 59

“When the Christian parties are in government, we are always the exchange. There are several parties that go with us, but the Christian parties no. Abortion, euthanasia… So, we are so happy with the law. We never give up.”

Lisa, volunteer

Each of the three quotes presents abortion and euthanasia as something to be protected from the disagreeing, religion-driven political parties. The earlier quote from Marion also underlined the threat of religion, even though she addressed Islam were the past three examples refer to Christianity. Overall, the repeating identification of euthanasia with abortion ties the practice determinately together with the general question of one’s right for bodily self-determination.

9.2 Conclusions of the counter-reactions

I started the chapter of counter-reactions with an example of the perceived downsides of individualism and continued to tell how a respondent reacted to this notion by sending his child to a Christian school. The respondents spoke about the inevitably for the original fighting force, the generation on barricades during the ‘60s and ‘70s, to step down. The counter-reactions illustrated a transformation beginning from the traditional society with religion as its authority, moving to the modern face of medicine, and finally reaching the neo-modern spirituality, where the togetherness of the world is proposed as an option for individualism and meditation is used as a tool to reach conclusions of end of life decisions. On the contrary, cultural changes in the form of interculturalism, or the impact of religiosity in general, are perceived as threats to Dutch culture and euthanasia as part of it. Earlier in this work, I discussed the pillarization of Dutch society, and how religions were seen as their own pillars. Excluding the counter-reactions, the religious pillars were seen represent a completely separate reality from the pro-euthanasia community. The respondents who did not place religion outside broke this code, and stress their place in the minority by not wishing to be open about this view with the pro-euthanasia community.

10. CONCLUSIONS AND POSSIBILITIES FOR FUTURE RESEARCH

This study has analyzed different aspects of the Dutch pro-euthanasia movement and the views among organization(s) associated with it. Due to historical reasons and development alongside the case law, the use of the current euthanasia practice leaves plenty of room for interpretation, thus making the inclusion of a wide range of diagnoses possible. Despite the law's tolerant approach on the patients' condition, it still requires doctors' cooperation, either by assisting with suicide or executing the euthanasia. Thus, when the uncertain times of naming the suitable diagnoses were over, the discussion around self-chosen death shifted the focus in questioning the doctors' authority and role in making the final decisions of life and death. This created tension between the views supporting the current state of affairs, with the medical profession as the decision-maker, and those advocating for a possibility to replace the doctor with someone else, such as a family member or a person offering spiritual guidance. The respondents created several discourses to pass on these views, either by giving the authority for the medical profession, individual self, or by creating counter-reactions.

Studying the topic was interesting but quite challenging from time to time. During the fieldwork, some respondents became very emotional in the course of the interviews, and at that moment, I was often able to relate to their way of thinking. This added one challenge to the neutral analysis: I had to decide determinedly to categorize the statements with a technical grip, and not to concern myself with the possibility that some respondents might not like my analysis. This was especially challenging when I needed to draw critical conclusions from conversations that could still vividly remember having with respondents I had come to like as persons. Also, the more I studied the topic, the more I became aware of the variability of opinions and attitudes among those I had labelled as *euthanasia's advocates* or *pro-euthanasia organizations.* In this last chapter, I take a final look into these differences. First, I repeat the question asked in the beginning:

I. What is the nature of the discourses created to reflect views on authority over dying and do these discourses address religion or indicate the differences in society according to the theory of death's revival?

To summarize the analysis chapter, the material formed two main discourses, with several sub-parts and a counter-reaction: 1) *Discourse of Compassion* and its sub-discourses of *Suffering*; and *Compassion, Mercy and Empathy*. 2) *Discourse of Me-ness* and the sub-discourses of *Autonomy and Freedom; Feminism; Control and Individualism; Standards of Living;* and *Self-Euthanasia and Discovering*

Needs. 3) *Counter-reactions,* including, *Taking a step back from individualism;* and *the discourse of others and threat to the practice*. The discourses of compassion occasionally addressed religion in a favorable light with connection to empathy, mercifulness, or love. Also, some of the counter-reactions brought up religion in a positive connection as an option to individualism, or a phenomenon that could be combined with it. On the contrary, the discourses of me-ness tended to bring out religion as a threat to the practice, the values of the Dutch society, or something completely separate from the pro-euthanasia groups. This closing chapter digs deeper into these findings by focusing on three key notions: 1) The presence of different societal era in discourses based on a feeling and principle; 2) The sacralized individual and religions place; 3) The contemporary consumerism of dying and future research. Next, I have a look at these findings.

10.1 The different social era in the discourses based on a feeling or principle

In a modern welfare society, such as the Netherlands, a person's death is no longer an economic disaster for the family, but those touched by the loss experience grief on a personal level, instead of burdening the society. The economic problem is solved, but the emotional vacuum left behind might be greater than before.[233] I propose that the wish to give the individual control over his death is in a logical continuum, perhaps even the assumed next step, following the impact the changing death ways have on a given society. The values of self-determination, together with the feeling of autonomy and control over one's death, strip dying from the element of surprise. When death is no longer a public spectacle, but an experience shared only by the immediate family, the decisions about it are preferably made in private as well, and not under the values and bureaucracy of the public community. The dying person does not want to lose the relief provided by modern medicine but wishes to set his own rules, which might not be shared with others. This leaves the individual trying to make the public discourse meet with his private experience.[234] I conclude from the interviews, that if the private experience sees religion as a positive resource, this is often kept to oneself and preferably not expressed to others. When people are left alone with questions related to death in modern society, the neo-modern society tries to do the contrary by selectively returning some of the power to the traditional society, by partially adapting its idea of community: Now people don't have to suffer alone, but they have a community of their choosing, such as the groups of the pro-euthanasia organizations, to share it with.

The respondents expressed several notions that have an echo with certain aspects of Walter's theory: As concluded, people associated with the pro-euthanasia organizations tend to express their views either through the bodily and medical discourses – reflecting the modern side of the Revival of Death – or the

[233] Walter 1994, 23.
[234] Ibid., 27.

mental and psychological (or spiritual) discourses, reminding the aspect of the self. In the analysis, the discourses of *me-ness,* and especially its sub-discourse *the feminist discourse,* appear to be mainly based on a matter of principle, whereas the discourses of *suffering, compassion, and mercy* tend to merge from a feeling and the ability to sympathize. This was an interesting finding since the discourses underlining an emotion or feeling often saw euthanasia to concern medical problems rather than existential unhappiness. Thus, when the feeling determinates the stance, the medicine was more likely given the authority to decide over euthanasia.

Another interesting finding is how the discourses based mainly on compassion, a feeling, favoring doctors' role, aroused from a long pondering and were commonly presented with careful consideration, whereas the discourses focusing on the idea of the self, were usually presented as self-evident statements, likely to question the physician's role. The respondents underlining compassion expressed more hesitation with their opinions, and hesitation was much less present for the determinant advocates of the autonomous route. I see the organization, NVVE, walking a tightrope between these two standpoints. As a whole, the Dutch pro-euthanasia field reflects both models of society by Walter, modern and neo-modern, with the weight on neo-modern's side. It will be interesting to see how the Dutch practice develops in the coming decades since the older generations were more radical in their opinions. Despite this dichotomy between the modern and neo-modern sides, the pro-euthanasia community shares a strong emphasis on the individual that lays the basis for orientation towards the outside society – which was occasionally presented to have its own framework for reality, thus making a dialogue between the two parties irrelevant. One of my goals in the analysis was to point out how the respondents did not merely have differences of opinion but to suggest how these differences can symbolize the presence of a different societal era, the modern or neo-modern society, in one's personal reality. In a way, the results turned Walter's theory upside down, since the older generation was more likely to represent the neo-modern society and the younger the modern. This made me think that the interviewees had differences in how they understood the individual's relation with the society: Whether the person has obligations towards it, which could also limit one's self-determination, or not, and thus take into consideration the possible repercussions one's personal choices might have on a larger scale. The respondents stressing personal autonomy above all did not find the discussion of euthanasia's borders meaningful, as this was seen to possess a threat to the society by unjustly limiting the person's right to choose, which the state should enable, instead of attacking itself. The idea of reality as different worlds helped me to grasp the varying ways the respondents experienced this, and thus had different reasons for supporting (or questioning) the euthanasia practice.[235]

[235] Paden 1996, 3-18.

10.2 The sacralized individual and religion's place

Increasing individualism combined with diminishing taboos around death, together with questioning the meaningfulness of prolonging life, offer some explanation for countries to legalize euthanasia. But only a few western countries have made euthanasia an option.[236] I find parts of the views within the *Discourses of me-ness* to address authority in a manner that reflects something I would call *ultra-individualism* – in lack of a better term – where death represents one aspect of life that the individual should (or at least could!) have control over. The individual is the final and almighty authority of himself. Individualism was always present in the respondents' speech, whether they stressed suffering or autonomy, but especially strong with the statements underlining maximized self-determination. While conducting the research, I began to see points of resemblance in individualism's role as an authority resembling that of religion in some contexts. Many respondents appeared very passionate and defensive about the topic, addressing the question of euthanasia's acceptability as a self-evident truth and the act of questioning it an attack towards the profound values of the community or the society at large.

According to Durkheim, certain things are holy for a person, and this idea of holy is connected to community.[237] Developing this thought, when the community determines what is holy, it makes itself the subject and target of a religion. In relation with this study, I claim that the values enabling and protecting the euthanasia practice, such as autonomy and control, resemble the idea of holy. Individualism resembles religion in its uncompromising approach to the issues it sees as having a value. Liberal view on euthanasia and self-chosen death in general result from strong individualism. Therefore, self-determination and individualism as values appear to have the status that comes close to a religious value. The stronger the understanding of *me-ness* as something separate from everything else, the clearer is the feeling of separation from life when *me-ness* changes.[238] At the same time, most respondents named religion, without further specification, the main reason for anyone to oppose the idea of euthanasia. Thus, religion was placed in a category of reasons to reject euthanasia, since it was perceived to take a part of the individual's autonomy away by recognizing authorities, such as god, outside the *self*. Perhaps being able to choose the time and place for dying is a logical wish for a person living and dying in an individualistic society.

Religion's place was divided in the research material: Either it was placed in the category of *the other* and viewed a threat, or it was presented in a positive context in the counter-reactions. Most importantly, religion was usually placed outside the pro-euthanasia community as something that clearly did not belong in the picture – or the pillar[239] – and the worldview where the individual (and perhaps the doctor,

[236] Rietjens et al., 2009, 274.
[237] Laitila (2004, 67) interpreting Durkheim (1980).
[238] Lewine 1988, 14.
[239] To read more about the segregation of groups in the social order of pillar-society, see de Haan 2014, 22-44.

depending on the respondent), not god, had the authority. The heritage of the *pillarization,* referring to the social segregation of different groups by providing each of them with their own social surrounding, still has an effect on the contemporary Dutch society and the way others are perceived and often left alone by placing them outside one's milieu.[240] Interestingly, when religion is placed outside the community, the secular group repulsing it starts itself to resemble certain aspects of a religious community: Just as an organized religion, the pro-euthanasia community has all the relevant organizational resources, such as leaders, financial means, meeting spaces, an important message and the means to campaign it, and communicate regularly with its members.[241] Occasionally, in the discourse of compassion, religion was brought up in a positive context. At the same time, the discourse of me-ness brought up religion as a threat to the community – and with this, the community's characteristics reflect *"the articulation of social connection and collective identification[242]"* of a religion.[243] Thus denying religion and placing it outside the community's social reality, the group creates a secular religion – their community.[244]

10.2.1 Final manifestation of autonomy

A nominal definition of religion can narrow the concept down into faith or belief with the experience of holiness as a universal phenomenon that is connected to this belief.[245] I propose that through this simplification, it is possible to see the absolute value given to the idea of autonomy as something comparable to holy. In the material, autonomy is repeatedly presented as a value senseless to question, and denying it is even seen to resemble dictatorship or Islamic regime. If we understand religion as something that develops according to time and place, I propose we can view the concept of autonomy as something that has formed its status alongside the developments of the cultural and legal history of the Dutch: The debate began by underlining the compassion doctor Postma felt for her terminally ill mother, moving to the suffering of the mind and the existential experience, ending up with the attempts to replace doctor's opinion with the self by trusting individual with the full authority.

The final manifestation for the idea of autonomy is embodied in the establishment of the Cooperative Last Will, and its ritual of gathering the members into living room groups, with the purpose to share how one wishes to execute this autonomy in dying. In inverse function, the focus on individual requires

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[240] The pillar society or pillarization refers to a former Dutch way of organizing society, by segregating different groups, which are often based on religion or political views. This is discussed further in the chapter of *Previous research of euthanasia in the Netherlands.* See de Haan 2014, 33-43.
[241] Erickson Nepstad & Williams 2007, 434.
[242] Ibid., 420.
[243] Erickson Nepstad & Williams (2007, 420) interpreting Durkheim's ideas.
[244] Waardenburg 1986, 31.
[245] Laitila (2006, 12) relying on Durkheim (1980).

a group to back it up: As the pro-euthanasia movement drives to extend individual freedom, this causes simultaneously a group identity among the members fighting to change the social condition, the limits of self-determination, that are viewed to be unjust. From Postma-case to the group activities of the NVVE and the Cooperative Last Will, the motivation and mobilization of these groups is rooted in clearly articulated goals, strengthening the groups' roles as enablers of the individual. Just as a religious belief, moral worldview engages individuals in collective action.[246] It appears that as the irreligious or non-religious community pushes the traditional religion aside for the sake of autonomy, it simultaneously sacralizes the idea of individuality. Thus, secularization merges with sacralization by forming a continuum that keeps relocating its idea of sacred.[247] In the end, I see the Dutch pro-euthanasia group as a community that preserves certain core values, such as self-determination and the alleviation of suffering, in the center of its orientation system, thus creating a moral worldview that is simultaneously multivoiced yet coherent.

10.3 The contemporary consumerism of dying and future research

The subject of euthanasia and its proponents offer several possibilities for future research. While writing this work, I began to think whether the funeral directors will soon share an office with death directors, as euthanasia (or self-euthanasia) occasionally appeared as a choice requiring careful preparation and individual touch. This reminds the idea of *the consumer in dying as a part of the quality of life.*[248] Considering the high requirements of one's life and death, one topic of further research could be the socioeconomic status of the people behind the euthanasia requests. Earlier in this work, I referred to the living room groups organized by the Cooperative Last Will, and in the last page of this study, I find myself asking what other kinds of activities could underline the contemporary consumerism of death any clearer than this? The growing role of consumerism in death, and whether death's commercialization follows it, are topics worthy of closer look. Our society is already familiar with the existence of hospice care, but it would be relevant to study the commonality of incorporating the *quality of dying* with the aim to *institutionalize* dying, as the End of Life Clinic does. This work's findings speak on behalf of the need to manage death: Perhaps this is caused by having a longer time to process the idea of dying as people can live a long time with severe medical conditions. Not being able to erase death's existence, the modern human can make it a bit less real by styling it in his own way. What society counts to be a good death, will potentially affect how people die in the future.[249]

[246] Read more about the social condition and action behind religious and moral worldviews: see Erickson Nepstad & Williams 2007, 423.
[247] See Demerath (2007, 57) about the responses to secularization and the process of sacralization (65-66).
[248] According to Cambell (1987), emphasizing the individuals' experience and feelings leads inevitably for the need of businesses to discover, point out and fulfill the consumer's inner needs and enrich their quality of life.
[249] Dowbiggin 2005, 2.

11. ABBREVIATIONS

PAS.	Physician assisted suicide.
EAS.	Euthanasia and physician assisted suicide
GP.	General practitioner
RRC.	Regional Euthanasia Review Committees
KNMG.	De Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst/Royal Dutch Medical Association

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14. ATTATCHMENTS

Attachment 1: The press release by the Cooperative Last Will

Coöperatie Laatste Wil | Woerden |06 - 225 76 007
www.laatstewil.nu | post@laatstewil.nu

Woerden, 1 september 2017

Press release: legal last aid available

After a 4.5-year search, it has been the Cooperative Last Will (CLW) to find a safe and human means for its members that is legally available and leads to a worthy death in a small amount. With this, the Cooperative realizes a breakthrough in achieving her goal: the free availability of safe and humane means for adults. She is in favor of the autonomous route that wishes her own directives about her own death, without the need of medical decision.

The more than 3,300 members of the Cooperative find it undesirable, competent and patronizing that current laws and regulations allow the doctors and the government to assess whether an individual who wants to die for the opportunity to do so. They believe that the government must remove the obstacles to get the necessary means. For those who do not want to live, the obligation to live further leads to great personal and social damage. The Cooperative is supported by 63% of the Dutch population, as evidenced by recent research by the NRC (2016).
In the Netherlands we have been discussing the self-ended end of life for over 26 years, which has created a deeply rooted culture of conversation and search for possibilities.

The Cooperative Last Will thinks that great care must be taken when using these means and that high demands can be made on safety. Among other things, one can think of a safe with a personal biometric lock to keep the means safe.

A survey conducted by CLW members at the end of last year showed that 7% of the members have means at home. These means are usually illegally imported, or obtained by mislead the doctor. It also turned out that 90% would like to possess the means, in many cases because it gives peace of mind and even life energy if one possesses them. This possibility is now available.

Board of Cooperative Last Will,
Jos van Wijk, Petra de Jong and Patricia Koster

For further information, see www.laatstewil.nu , our YouTube channel, email to post@laatstewil.nu and phone 0031 6225 76 007.

Attachment 2: Table from Tony Walter's work *the Revival of Death* (1994, page 48)

Table 4.1 Three types of death

	Traditional	*Modem*	*Neo-modem*
Bodily context			
1 Archetypal death	Plaque	Cancer/coronary	Cancer/AIDS
2 Dying trajectory	Fast	Hidden	Prolonged
3 Life expectancy	40	70	80
4 See others dying	Frequently	Rarely	Witness dying not death
5 Human condition	Living with death	Death controlled	Living with dying
6 Typical death	Chitd	Elderly	Elderty
7 Social birth	Follows physical	At physical birth	Precedes physical
	birth		birth
Social death	Follows physical	Precedes physical	At physical death
	death	death	
8 Untypical death	Old (venerated)	Young (senseless)	Young (senseless)
Social context			
9 Social structure	Community	Public vs private	Private and public intertwined
10 Personhood	Belonging	Identity	Identities
Found in	Community	Family	Relationships
Death = loss of	Social position	Identity	Identities

Task post death	Reconstruct roles	Reconstruct	Reconstruct
		identity	identities
Done through	Mourning	Grief	Grief work
Authority			
11 Authority	God/Tradition	Medical expertise	Self
	The will of God	Doctor's orders	I did it my way
Known through	Clergy (male)	Doctor (male)	Counsellor {female)
12 Institution	Church	Hospital	Home/hospice
13 Meaning	Given	Abolished	Created
		{in public)	interpersonally
14 Religion	Given	Choice of church	Inner spirituality
Coping			
15 Courage shown in	Prayer	Silence	Talk
16 Coping strategy	Ritual	motto al privacy	Expressing
17 Lay support	Neighbours/Kin	Nuclear family	Self-help groups
1 Surveillance by	Priest/Neighbour	Doctor/Neighbour	Counsellor
of	Soul/Behaviour	Body/Behaviour	Feelings
The journey			
19 Traveller	Soul	Body	Psyche

20 Death	Result of sin	Caused naturally	inner journey
21 Mode of transport	Ritual action	Technology/Drugs	Talk
22 Funeral	Burial	Cremation	Life-centred
Organised by	Community	Commerce/	Memorial society/
		Municipality	DIY
Values			
23 Values	Respect	Health/Privacy/	EmoSon/Growth/
		Dignity/fighting	Choice
		Independence	Autonomy/Cotrol
24 Worst sins	Unbelief	Intrusion	Isolation/Denial
25 The good death	Conscious	Unconscious/	Aware/Precious/
		Sudden	My way
	Ready to meet	No bother to others	Finish business
	Maker		

Attachment 3: Informed consent

UNIVERSITY OF HELSINKI

This Informed Consent Form is for the employees and volunteers of the NVVE – Nederlandse Vereniging voor een Vrijwillig Levenseinde, who have agreed to participate in an interview about the views on euthanasia and volunteering/working for a pro-euthanasia organization.

Student: Laura Johanna Ruohonen
Organization: The University of Helsinki, Faculty of Arts
The interviews are carried out as a part of Master's Thesis

Supervisor: Terhi Utriainen
Organization: Acting professor in the Study of Religions, University of Helsinki
terhi.utriainen@helsinki.fi

This Informed Consent Form has two parts:

- Information Sheet
- Certificate of Consent

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction & Purpose of the research
The research's aim is to understand the views of people working in the field of pro-euthanasia organization. The research's goal is to understand the challenges and attitudes people working/volunteering for the NVVE come across, and how they discuss their work and the topic in general. The Finnish government will vote on euthanasia law this year, so interviewing people at the NVVE can offer a valuable insight of the potential changes and challenges occurring in Finland in the close future.

Voluntary Participation
You have voluntary agreed to participate in this research. You may still change your mind during the interview, in which case the tape will be deleted and your interview won't be used in the analysis. After the interview has been completed, withdrawal is no longer possible.

Procedures
The question will address your experiences in working/volunteering for a pro-euthanasia organization and your opinions about euthanasia and questions related to it. If you do not wish to answer any of the questions during the interview, you may say so, and the interviewer will move on to the next question. The information recorded is confidential, and no one else except Laura Ruohonen will have access to the information (recording or notes) documented during your interview. The entire interview will be recorded (audiotape), but no-one will be identified by name on the tape. The interview will be recorded with a laptop but removed to an USB-stick right after the interview. Recording (audiotape) the interviews is crucial for my research, as I will transcribe the recordings into text in order to analyse the material. If the interviewee prefers, I can provide him or her with the written transcription of the interview so that corrections can be made. I will analyse the interviews from these transcripts and pay attention to the emerging themes, potentially reoccurring answers and how the topic is addressed in the answers. This way I'm able to form a broad picture of the situation.
The recordings will be destroyed after the research has been approved and evaluated by the University of Helsinki, which will happen approximately in the spring of 2018.

Reimbursements
You will not be provided any incentive to take part in the research.

Confidentiality
No individual interviewee will be recognized from the material. I will not use the interviewee's real names but come up with code names or fictional pseudonyms for everyone I have an interview with. In my analysis, I will refer to the interviewees with these pseudonyms or case numbers (f.ex: interviewee 1, interviewee 2, etc.).

Who to Contact
If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact the interviewer: Laura Ruohonen, laura.ruohonen@helsinki.fi, +31657201873 /+358400114311

Part II: Certificate of Consent

I have been invited to participate in research about views on euthanasia and working/volunteering for a pro-euthanasia organization.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant______________________
Signature of Participant_______________________
Date__________________________________
Day/month/year

Statement by the researcher

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done

1. Interview about the volunteering or working for a pro-euthanasia organization and the interviewee's views about euthanasia.
2. Recording and analysing the interviews.
3. Publishing the results as a part of the researcher's Master's Thesis.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been given to the participant
Print Name of Researcher_____________________
Signature of Researcher______________________
Date______________________________

Attachment 4: Invitation for the interview

Onderwerp: Oproep interview

Hallo allemaal,

Vanaf volgende week zal de Finse student Laura 's woensdags op kantoor te vinden zijn. Ze doet voor haar Master onderzoek naar pro-euthanasie organisaties, en maakt daarbij een vergelijking tussen Finland en Nederland.
Graag zou ze jullie interviewen over jullie werkzaamheden bij de NVVE. Waarom werken jullie hier? Wat vinden jullie zo belangrijk aan het onderwerp?

De interviews zullen ongeveer 45 tot 60 minuten duren en worden gehouden in het Engels. Ze wil het interview opnemen en later transcriberen. Als jullie dat willen, kunnen jullie het transcript inzien voordat zij deze opneemt in haar onderzoeksresultaten. De interviews zullen geanonimiseerd worden.
Laura is flexibel: de interviews kunnen de hele week worden ingepland. Dus waar en wanneer het jullie uitkomt.

Ik hoor graag wie mee zou willen werken aan een interview. Dan kunnen we volgende week de interviews gaan inplannen.

Laura wil met haar onderzoek kunnen bijdragen aan de mogelijke invoering van Finse wetgeving omtrent euthanasie, waarover in de herfst zal worden gestemd. Het zou mooi zijn als we hieraan kunnen bijdragen!

Alvast heel erg bedankt!

Met vriendelijke groet,

Aanwezig: maandag, dinsdag en donderdag

020-6200690
Postbus 75331
1070 AH Amsterdam
www.nvve.nl

Attachment 5: Interview frame

Themes to be covered are typed with bold letters. The questions under each theme may be used to help if the respondents does not cover the topic otherwise.

Here & Work:

1) How did you end up working/volunteering for the NVVE?
   - How long have you worked here?
   - What motivated/directed you for this field?
2) Does the job or the topic sometimes get to feel too heavy?

Views:

3) Have your views about euthanasia changed during your time with the NVVE? How?
4) Do you have experiences with euthanasia that have shaped/effected your views about it?
5) Is euthanasia a question of (human) rights?
   - Should everyone asking to have EAS to receive it?
6) When is suffering enough? Why is euthanasia important?
7) What are the possible problems with the practice?

Outsiders & reactions:

8) Could you describe a typical reaction when a new person hears about your work?
   - Do you encounter negative reactions?
9) Do you need to justify your work to others?
10) Do you undertint why some people are against euthanasia?

Future & ideal situation

11) If you think about the future, what would be a scenario when the NVVE wasn't needed anymore – "so as the work would have been done"?
    - Do you think this is possible and what would have to change?
12) Do you have advanced directives yourself? In what situation would you request euthanasia yourself?

Attachment 6: Interview quotes

Below the full interview quotes referred to in the text. Presented in the order of appearance.

Footnote 180. Establishment of the End of Life Clinic.
Interview with Johan:
R In the beginning of the 21st century, the talk was started on, maybe we could institutionalize euthanasia. General practitioners won't do it because often they refuse to do it. Couldn't we find a situation where we can sort of start a clinic or hospital where that could be done by people who will not hesitate to do it if the indications are accurate, you know the law and we don't have to into that. That took quite a while but eventually after some meetings in 2012, you are probably aware of that, the Levenseindekliniek started on the first of March. (--)
L Oh okay.
R Yes, they were an extension of the NVVE but now they are separately, uhm, on their own.

Footnote 181. The agenda of the End of Life Clinic.
Interview with Jenne Wielenga:
"How do we work? We are not a hospice or hospital where patients can be admitted at the end of their life, no, we are an organization with teams of doctors and nurses all over the country and our goal is to help patients with request for euthanasia or physician assisted suicide that meets the criteria of due care, and that is not granted by the patient's own doctor. How does it work? There is an application form the patients can fill that, the doctors can fill that, everyone can fill out that application form."

Footnote 184. NVVE's consultants and the home visits.
Interview with Lisa:
L I have been explained that you can provide information but not like give instructions?
R Ja, what is instruction and what is advice? That's a grey area. Uhm, the plastic suck?
L The plastic bag?
R Yes, the plastic bag. You must not show it how to do it. I think… I think we do. The curtains down and you… Because that is instruction. We can say "okay you are doing well", but where is the, what is the limit? I don't know. But there are not many people who are capable to do this. It's, we get instructions how to do it, three times for me already, and every time I think ouch, this is not my favourite way of going, in a plastic bag like this… But we heard, if you do it well, it's a good way to go. But ja, it's difficult for most of the consultants. Yes we, okay it's way and if you want to do it, okay but…
L Do you mean that as a consultant you have been taught how to do it or –
R Yea, yea, yes, three times.
L Advised by NVVE?
R Yes, and to repeat it again we have all the things, baseball bat, plastic bag, how to do, yes, we do, we know how to.

Attachment 7:

Graphic 1: The graphic illustrates three types of death (Walter 1994) as part of the constant change in societal era and the rotating secularization and sacralization processes in the worldview (Demerath 2007; Erickson Nepstad & Williams 2007).