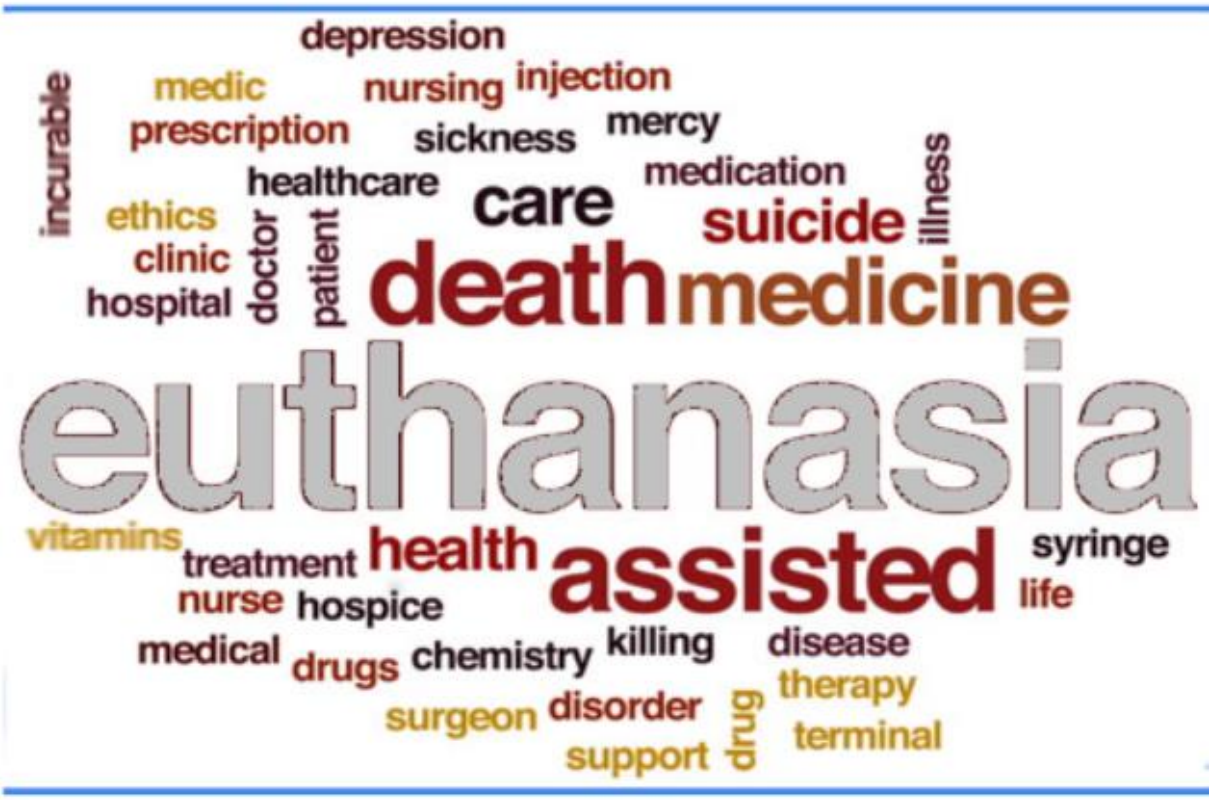
The Ethics of Euthanasia:



Bioethics versus Family Ethics

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Summary

Despite euthanasia continuing to be a controversial topic in worldwide medical ethics discourse, knowledge gaps exist: firstly, qualitative investigation of individual ethical perspectives has not been conducted. Secondly, euthanasia has not been discussed within the frame of a bioethics versus family ethics conflict, or any such frame of multiple established medical-ethical perspectives. This thesis seeks to fill these knowledge gaps, creating an analytical framework based on bioethics / family ethics conflicts, and using this framework to assess through in-depth interviews the ethical perspectives of individuals with euthanasia experience in the Netherlands. Transcript analysis showed participants to substantially favor bioethics values like patient autonomy and individuality, while still attributing value to family ethics thinking when it did not conflict with these values. Follow-up research should be conducted to assess euthanasia discourse and individual medical-ethical perspectives on euthanasia in a more thorough and elaborate manner.

Key words: euthanasia, medical ethics, family ethics, bioethics, the Netherlands

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Introduction

Beverly and Athol's final decision

On June the 20th 2017, Australian married couple Athol Winston (80) and Beverly Ann (79) took their own lives in Peru using narcotics they bought in a local animal shop. On the Dutch publisher NRC, an article appeared called 'Beverly and Athol's final Decision' (Steenbergen, 2018). It describes their story, motivations, and the experience of their friends and family leading up to their self-administered euthanasia. A 17-minute documentary by the name of 'Our lives completed' was also published on the NRC website.

The main motivation cited by Athol and Beverly for their euthanasia was wanting to pass in dignity, and avoid the inevitable medical 'deterioration' that would occur in the future. More specifically, Athol's physician predicted he would become wheelchair-bound within a few years. Beverly and Athol expressed not wanting to live such a life of handicap, and decided to take their own lives. Aside from this motivation, Beverly and Athol also cited having had fulfilled and beautiful lives as a reason for their decision.

The NRC article describing the case of Beverly and Athol sparked controversy. Care ethicist Brecht Molenaar responded with an opinion piece sharply titled '*Don't frame suicide as an art of living'* (2018). In this response, Molenaar states her discontent with both the actions of Beverly and Athol and the allegedly approving way it was reported by NRC. Molenaar starts by expressing her complete lack of understanding regarding how Beverly and Athol acted towards their friends and family. First, Molenaar spites the couple for the way they treated their son Carl; they had sent him to a boarding school while they had been living their 'beautiful lives', which had led to Carl becoming a 'loner', and estranged from his parents. Adding insult to injury, when Carl was just starting to become closer with his parents and had recently had his first child, Beverly and Athol decided to take their own lives. Secondly, Molenaar negatively regards the intention of Beverly and Athol to deconstruct relationships with friends and family because 'they would only be more people to say goodbye to'. After making these points, Molenaar closes by calling the ethos that Beverly and Athol applied 'disturbing' and again expressing her discontent with the supposedly positive way that the Australian couple's story is framed in the NRC article.

There is a clear conflict between Beverly's and Athol's actions and its portrayal in NRC one hand, and Molenaar's highly critical response on the other. Beverly and Athol's side celebrates their euthanasia decision under principles of autonomy, dignity, and self-empowerment. Molenaar, however, blames the couple for mistreating their friends and family by committing a suicide with self-centered motivations, and is appalled by the notion that such actions should be viewed positively.

A conflict of perspectives

The difference in ethical perspective demonstrated in this case can be linked to the conflicting nature of two contemporary medical-ethical perspectives: bioethics on one hand, and family ethics on the other. Bioethics is concerned primarily with the individual patient(s), and their right to autonomy (Verkerk, Lindermann, McLaughlin et al., 2015). This aligns with Beverly and Athol's perspective, who celebrated their actions under the guise of autonomy, self-empowerment, and dignity. Molenaar, however, counters this by arguing that the couple mistreated their family and friends through their decision-making and overall conduct, and that their actions were selfish. This aligns with the main notion of family ethics (Verkerk, Lindermann, McLaughlin et al., 2015): medical decisions should be made while keeping the patient's family in mind, as opposed to only concerning oneself with the autonomy and well-being of the patient as an individual.

This ethical conflict is relevant to not just euthanasia, but any medical decision where the patient's family is substantially affected by the outcome: reproductive decisions, handicaps, highly impactful care regimens, and so on. Those advocating for family ethics also argue that bioethics is not appropriate for approaching these situations due to their patient-centered view (Verkerk, Lindermann, McLaughlin et al., 2015). Since bioethics is still the paradigmatic ethical-medical perspective, and family ethics can still be considered a niche, the challenges that family ethics present to it invite investigation. Bioethics and family ethics are elaborated on in greater detail in the *Theory* segment. First, the aim and scope of this thesis are explained further.

Aim & Scope

Aim

This thesis aims to contribute to euthanasia literature and medical ethics literature by investigating the ethical perspectives of those who have had close experiences with euthanasia, and considering how they are connected or not connected to bioethics and family ethics. This aim fills two knowledge gaps in the field of medical ethics literature: firstly, euthanasia ethics have not been framed and/or analyzed in a context of a family ethics / bioethics conflict. Pieces like the one from McEvoy (2015) and Biggar, Dyck, Gorsuch & Keown (2007), will discuss the wider medical-ethical implications of euthanasia, respectively making points about the Hippocratic code and about the sanctity of life. These pieces do not, however, specify the implications of euthanasia for a specific set of medical-ethical perspectives like bioethics and family ethics. Secondly, perspectives on euthanasia ethics held by Dutch people with euthanasia experience have not been observed directly in any manner. Current medical-ethical literature about (Dutch) euthanasia is elaborated on in the *Background* section.

This thesis investigates ethical sentiments expressed by participants about euthanasia and links them to the bioethics perspective and the family ethics perspective. The nature of the experiences with euthanasia that participants have had may vary greatly; experiences could have been as a care worker, in regards to family members, or even in regards to themselves. Due to recruitment restrictions, the research population was retroactively changed to only include people with a pro-euthanasia view (see *Strengths & Limitations*).

Thus, in order to achieve this aims of this thesis, the following research question is formulated:

> *To which extent and in what way are bioethics and family ethics sentiments upheld by pro-euthanasia actors?*

Here, the term 'actor' is used to refer to anyone who has had an impactful experience with euthanasia in their past or present, or is likely to in the future due to current circumstances. It should also be noted that in this thesis, 'ethics' and 'morals' are used interchangeably.

Scope

The scope of this thesis is set through the ethical perspectives it discusses on one hand, and the medical topics it regards on the other. As explained earlier, this thesis investigates ethics of medical actors within a dichotomy of bioethics versus family ethics. Whenever possible, ethical sentiments expressed by interviewees will exclusively be framed within this dichotomy.

For the sake of conciseness, the scope is narrowed down further by selecting a single medical topic: euthanasia. This topic is chosen for multiple reasons. Firstly, because it is currently controversial, meaning that the ethics surrounding it have been discussed more, and are generally more relevant. Secondly, the topic is innately fit to be approached by both bioethics and family ethics; within euthanasia, there exists both a strong element of individual choice and preference, as well as a strong

relevance of family in the impact of (not) requesting euthanasia. In this thesis, euthanasia ethics is featured as both worthy of investigation on its own, and as an appropriate topic for investigating the prevalence of family ethics / bioethics sentiments among actors. The scope is also narrowed down to the Netherlands for two reasons: firstly, out of pragmatism: Wageningen University and the researcher's home lie within the Netherlands. Second, euthanasia has been debated relatively heavily in the Netherlands over the past decennia, as euthanasia is generally not considered a taboo. Although the actors involved in this thesis do not necessarily live in the Netherlands, only actors involved in medical decisions that are made within the Netherlands are selected. The Dutch euthanasia context is elaborated on in the *Background* section below.

Background: Dutch Euthanasia & Ethics

The Dutch government describes euthanasia as follows (Rijksoverheid, n.d., A):

> *A doctor administers lethal medicine to a patient to end endless and unbearable suffering.*

However, this thesis uses a more open definition of euthanasia to make discussing the matter with interviewees easier:

> *A doctor administers lethal medicine to a patient on the request of the patient.*

Although the government does differentiate between euthanasia and Physician-Assisted Suicide (PAS), it considers PAS under the same piece of legislation as euthanasia. The difference between euthanasia and PAS, as the Dutch government defines it, regards how the patient's life is ended; euthanasia and PAS respectively involve a doctor administering lethal medicine and the patient being assisted by a doctor in seeking a medical death. This thesis will mainly concern itself with euthanasia; euthanasia cases are much more common in the Netherlands than PAS cases (RTE, 2019). Of course, PAS could still become a prevalent topic in this thesis if interviewees talk about it extensively during interviews, regardless of not being prompted to do so by interview questions.

According to annual reports on euthanasia in the Netherlands provided by the Regional Testing commission Euthanasia (RTE), the yearly amount of euthanasia cases rose greatly since legalization. In 2002, 1882 euthanasia cases occurred (RTE, 2003); an amount that was almost four times greater in 2018, the year during which 6126 euthanasia cases were reported (RTE, 2019). Among those who received euthanasia in 2018, around 91% suffered from incurable cancer, nervous system failure, cardiovascular disease, lung disease, or some combination of these. Most euthanasia patients (32%) were 70-80 years old, while 24% was 80-90 years old, and 22% was 60-70 years old (RTE, 2019).

As one might expect, there are substantial restrictions on when euthanasia is allowed legally. In the Netherlands, only those above the age of 18 can receive euthanasia without the involvement or approval of legal guardians (Rijksoverheid, n.d., B). The patient must be mentally competent at the moment of request. Euthanasia can also be requested in advance though, meaning that euthanasia will be allowed if the patient meets legal requirements in the future; for example, a patient and a physician can agree to conduct euthanasia if the patient reaches a certain stage of a terminal disease in the future (Rijksoverheid, n.d., A).

After these two base conditions are met, the following 'due diligence requirements' (Rijksoverheid, n.d., C) must be fulfilled:

- The physician is convinced that the patient's request is voluntary and well-considered.
- The patient is suffering unbearably and endlessly.
- The physician has informed the patient about his situation and prospects.

- The physician and the patient have reached the conclusion that no reasonable alternative is possible.
- The physician has consulted at least one other physician who has seen the patient. This physician has judged the situation in writing, in accordance to due diligence norms.
- The physician has conducted the euthanasia or PAS in a medically appropriate way.

Euthanasia cases are also evaluated in The Netherlands to see if they are conducted in accordance to the due diligence requirements. After an evaluation in 2017, 99.8% of euthanasia procedures were found to have been done in proper conduct (RTE, 2018). On average in 2018, patients received an approval or rejection of their euthanasia request after 37 days (RTE, 2019). The length of this procedure can range anywhere from a few weeks to over a year, though (Levenseindekliniek, 2019). This duration depends greatly on the complexity of a case, which is mainly determined by the patient's disease status; for example, cases where psychological afflictions motivate euthanasia are generally more complicated than cases with physical afflictions.

Euthanasia in the Netherlands has been discussed extensively in the wider medical ethics literature, likely due to the Dutch euthanasia systems being historically progressive in comparison to that of other countries. The presence of the Netherlands in this literature rarely seems to be more than as a case or reference point, however; the situation in the Netherlands is used to discuss and argue the medical ethics of euthanasia in a general sense. This literature discusses the ethics of the Dutch euthanasia system, but not the euthanasia ethics held by people in the Netherlands. For example, Lerner & Caplan (2015) argue that slippery slope argumentation in regards to euthanasia legalization has some validity to it, using Dutch euthanasia statistics to support their claims. Even when pieces like the one by van der Veer (1999) do discuss the underlying reasons for the progressive Dutch stance on euthanasia, they do so on a societal level rather than an individual level.

As exemplified by these pieces, a knowledge gap exists about euthanasia ethics in the way that they are held specifically by individual Dutch people. This thesis aims to fill this gap, next to the earlier mentioned gap regarding euthanasia in the conflicting frame of family ethics and bioethics perspectives. Some of the euthanasia ethics discourse in the Netherlands is presented below.

Dutch Euthanasia Ethics

Even though Dutch euthanasia law can be considered quite progressive when compared to other countries, there is still a large debate surrounding the current euthanasia legislation. In 2016, a proposal to 'loosen up' euthanasia legislation was presented to Dutch political parties (Klomp & van der Aa, 2016). This proposal would allow individuals with a self-identified 'fulfilled life' to receive euthanasia, although under 'heavy restrictions'. The proposal was debated heavily among political parties; while proponents expressed sentiments related to autonomy and freedom, opponents feared normalization of euthanasia, and claimed that the current system is adequate. As shown by Brecht Molenaar's response to Beverly and Athol's story, however, the debate around euthanasia is not confined within politics. Current Dutch discourse about euthanasia ethics centers around two main themes:

1. <u>The value of a patient's life</u>

The matter of a patient's - and in general, a human's - value of life is fundamentally significant for euthanasia ethics, since euthanasia is ultimately a matter of life and death. Within euthanasia discourse, value of life concerns can be divided into three points. Firstly, value of life concerns regard sentiments - religious or otherwise - about the sanctity of life, and the innate value that a human life has. The Dutch political opponents of the 2016 proposal to loosen euthanasia law expressed such sentiments (Klomp & van der Aa, 2016), also implying that more normalized euthanasia in turn

compromises the value of human life; if it is normalized that people choose to abandon life, what does that say about the value of their lives and the lives of others?

Secondly, the value of a patient's life, as some argue, is compromised in how it is affected by the patient's quality of life and will to live; in the same political conversation, proponents of loosening euthanasia law argued that although human life should be preserved, this does not apply to those with a long-term death wish.

Third, some argue that the value of a person's life goes beyond the patient himself; a person's being alive also has value for others, mainly friends and family. This argument can be seen in Molenaar's response to the Beverly and Athol case; she spites the couple for abandoning their son and granddaughter in their selfish decision, because Beverly and Athol do not seem to consider the value they hold for their peers in their process of self-killing.

2. Autonomy

In euthanasia ethics, autonomy is featured in two different ways. On one hand, it is present as a basic and moral right to freedom of choice that should or should not be fulfilled in the context of euthanasia. The right to choose ('the right to die') is an innate theme within the ethics of euthanasia, since increased legality of euthanasia is ultimately about allowing a choice. It is no surprise, too, that the rise of euthanasia in public discourse has been linked to increasingly patient-centered health services (McCormack, 1998) wherein patients expect greater independency in making their medical decisions. It follows that the right to autonomy is exclusively used to formulate pro-euthanasia statements. In the case of Beverly and Athol, the right to choose ('the right to die') is a central point of argumentation in favor of Beverly's and Athol's actions being ethical, and even worthy of celebration.

Autonomy is also present in the matter of euthanasia as a legal prerequisite. See, for example, the Dutch legal prerequisite of ''The physician is convinced that the patient's request is voluntary and well-considered'' (Rijksoverheid, n.d., C). In this sense, perceived lack of patient autonomy during the euthanasia decision is used as an anti-euthanasia argument; one political party feared that some would commit euthanasia out of feeling like a burden if legislation was loosened (Klomp & van der Aa, 2016), which is a reason that may suggest a lack of autonomous choice. One could argue that the autonomy of patients is compromised in situations like those, because the patient feels an externally driven urge to choose a specific option.

Theory & Framework

Bioethics

In comparison to family ethics, bioethics is the far more established, and even paradigmatic medical-ethical perspective. Bioethics has its roots in the ancient Hippocrates oath, which established four key principles for ethical care: autonomy, non-maleficence, benevolence, and justice. Bioethics has gone unchallenged until the later part of the 20th century, when a variety of societal trends caused it to become a center of critical attention (Steinberg, 1995).

Three main characteristics of bioethics are as follows (Hardwig, 1990 & Steinberg, 1995):

1) Bioethics is utilitarian in nature. Focus is put on the outcomes of certain medical decisions rather than the methods through which an outcome is achieved. Morality is decided by the nature of the outcome rather than the nature of the actions that were taken leading up to it.

2) Bioethics' scope centers around the individual patient. A physician's responsibility is entirely to a single patient, and only the interests of the patient himself are taken into account when it comes to medical decision-making. Little to no attention is directed at the patient's social environment.

3) In an attempt to achieve optimal outcomes for the patient, bioethics greatly favors the value of patient autonomy. Autonomy is considered key to optimizing patient outcomes when making medical decisions.

In recent decades, these characteristics of bioethics have been criticized increasingly, and multiple medical-ethical perspectives have been born as a response to bioethics (Steinberg, 1995). The main point of criticism expressed by family ethics authors regards the individualistic, patient-centered focus that bioethics employs, which ignores and dismisses the interests of the patient's family.

Within the topic of euthanasia, bioethics could generally be expected to support relatively loose euthanasia legislation, since patient autonomy increases when euthanasia law becomes less strict; if more patients are allowed to undergo euthanasia as a result of legislation becoming more flexible, these patients gain autonomy because more medical options become available to them. In regards to the earlier described case '*Beverly and Athol's final Decision'*, bioethics would align neatly with Beverly and Athol's sentiments; the couple made a strong appeal to the moral importance of their personal autonomy.

Family ethics

Family ethics contrasts bioethics not only in perspective, but also in its establishment. Family ethics can be considered a fairly niche perspective within medical ethics, that is also dwarfed by other critical responses to bioethics like Ethics of Care. It should be noted, though, that *medical* family ethics is a part of a wider family ethics philosophy; one that does not specifically regard the family ethics of medical scenarios, but of any morally interesting scenario (Bøyum & Gamlund, 2017). In contrast to medical family ethics specifically, this general family ethics philosophy is well-established in its respective field of literature; interest in family ethics is continuing to rise amidst hotly debated reproduction issues and a growing concern with so-called 'associative duties' (Bøyum & Gamlund, 2017).

Medical family ethics literature started appearing in the second half of the 20th century. Family ethics' defining feature is, in relation to bioethics, a scope of medical decision-making that is expanded beyond the interests of the patient alone, also including the interests of the patient's social environment, the *family* (Hardwig, 1990). Within family ethics, the concept of family is typically viewed in a constructionist way, meaning that those who are considered by the patient to be family, or consider themselves family of the patient, are family. As such, a person who is not related by blood can be family, and those who are related by blood are not automatically considered family (Hardwig, 1990). The moral concerns that family ethics regard - both in general and specific to medical ethics - vary in terms of unique scenarios (e.g. euthanasia, reproduction) but also in terms of unique type of family relationships (e.g. parent-child, family friend) that each feature unique challenges and considerations for the family ethics perspective (Bøyum & Gamlund, 2017).

The moral relevance of families in medical decision-making has been justified by family ethics authors using the following arguments:

1) Family has both an instrumental and an inherent value to a patient (Verkerk et al., 1995). This inherent value is unique to families. It is also in the patient's interest to keep family in mind when making medical decisions, as certain decisions may compromise familial relations that the patient holds.

2) When a patient is part of a family, his life is in some ways owed to the family through responsibilities to other family members (Hardwig, 1990); the lives of family members may be deeply intertwined. Consequently, attempting to isolate a patient from their family in medical decision-making is fundamentally misguided.

3) When it comes to major non-medical decisions, they are normally not made without consulting family members (Hardwig, 1990). For example, parents are expected not to make major career decisions by themselves when they are providing for other family members as well. It is only fair that major medical decisions should not be made by just the patient as well.

Family ethics' main thesis that is supported by these arguments, is that the interests of both the patient and the patient's family should be taken into account when making medical decisions. Note that this does not specify how the interests of the patient should be weighed in comparison to those of his family (Hardwig, 1990). Family interests could be weighed as less important, just as important, or more important than those of the patient.

When advocating for family ethics, Verkerk et al. argue that family ethics can be used to approach medical-ethical scenarios that bioethics and care ethics cannot. Herein, they provide a case of a sister choosing whether or not to donate a kidney to a stranger, so that her brother in need can receive one in turn. Since the case transcends any individual (bioethics) and does not necessarily involve asymmetric caring relations (care ethics) only family ethics is useful in for analyzing the case (Verkerk et al., 1995). Inversely, family ethics admits that its perspective is obsolete when the patient has no family, in the constructionist sense of the word. In this situation, bioethics' patient-centered focus is considered adequate.

Within the topic of euthanasia, family ethics input would likely contain similar sentiments to those expressed by Molenaar in her response to Beverly and Athol's story; Molenaar brought up the pair's value and responsibilities to their family: their son, their granddaughter, and their friends. Cases like that of Beverly and Athol are relevant to family ethics, because euthanasia decision-making impacts family just as much - if not more - than other impactful medical decisions. It should be noted, though, that requesting euthanasia does not go against family ethics per se. Euthanasia can certainly be in the best interest of the family; for example, a terminally ill patient could want to avoid being a financial detriment to his low-income family. Family ethics' likely opposition to looser euthanasia legislation is because of the autonomous, patient-centered arguments that are presented in favor of it.

Framework: opposition of perspectives

Based on the insights that literature offers into the respective characteristics of family ethics and bioethics, they are positioned below as conflicting ethical perspectives (see Table 1); it is reasoned that in any medical-ethical consideration, bioethics and family ethics cannot both be satisfied fully, since these perspectives directly oppose each other to a substantial extent. This opposition between bioethics and family ethics primarily occurs in regards to the individual versus the collective; a bio-ethical viewpoint necessitates an autonomous individual, while a family ethics viewpoint necessitates the inclusion and consideration of a patient's family in medical decisions. Still, it should be noted that family ethics and bioethics do not conflict completely; for example, a patient's family can still be considered in some ways without compromising a patient's autonomy.

Bioethics	*Topic*	Family ethics
Pro-euthanasia; euthanasia enables more options for autonomous decision-making.	*General stance euthanasia*	Neutral; morality of (no) euthanasia determined by whether family is considered.
Determined by patient's view- point.	*Value of life*	Determined by patient's view- point and the meaning of the patient's life to family.
Complete autonomy as highest moral priority.	*Autonomy*	Patient autonomy relativised compared to autonomy of family affected by decisions.

Table 1: analytical framework

Table 1 serves as an analytical framework that is based on the established Dutch euthanasia ethics context, and in turn guides interview questions and data analysis.

Methods

Data collection: interviews

Data collection was exclusively done through interviews, meaning that only qualitative data was collected. Interviews were planned to take around 35 minutes. Most interviews were held in locations of the interviewee's choice: in café's or the homes of interviewees. Two interviews were done over the telephone. In-person interviews were audio-recorded and transcribed afterwards, and telephone interviews were transcribed during the interview itself. Interviews were semi-structured in nature; although specific questions were formulated in an interview guide (see Appendix 1), these questions only acted as general topical guidance. The larger part of interviews were spent discussing questions other than the ones in the interview guide.

The three topics in the analytical frame (see Table 1) determined the questions asked during interviews, together with the central topic of bioethics versus family ethics. Each topic in the analytical frame was represented by one question (see Appendix 1A), as was the bioethics / family ethics conflict. Sub-questions were added for some topics in order to provide additional guidance with topics that were expected to be relatively broad and/or vague; for example, sub-questions served to distinguish between two types of stances on euthanasia (moral and legislative) and two 'forms' of the value of a patient's life (on its own and for peers). The interview was structured as follows: first, introductory questions were asked about the general and euthanasia-related background of the interviewee. Secondly, the first of two hypothetical euthanasia cases, 'Michael', were explained to the interviewee. Then the questions regarding euthanasia stance, value of life, autonomy, and familial involvement were then asked on the basis of this case. These questions were then repeated for the second hypothetical case, 'Robin', whilst avoiding needless repetition of points that were made by the interviewee whilst discussing the 'Michael' case.

These hypothetical euthanasia cases were adopted into the interview guide for a number of reasons. Firstly, to reduce ambiguity by presenting a concrete, specific euthanasia case. Second, to try to approach an ethical grey area; the case scenarios described hypothetical patients with suffering that was less than the legally required 'endless and unbearable', but added that the euthanasia legislation in the hypothetical scenario would allow for the cases to legally receive euthanasia anyway. Thus, it was set up to be more lenient than the current real-life euthanasia legislation in the Netherlands. The motivation for this set-up for the cases was to present a more ethically provocative scenario for interviewees, thus making it easier to expose their ethical values regarding euthanasia. Also, discussing

euthanasia ethics based on the current legal scenario of endless and unbearable suffering instead would have been problematic: it was expected that the pro-euthanasia interviewees would be very likely to largely dismiss any kind of discussion about the ethics of this scenario, under the premise that the need to alleviate such a degree of suffering would by far transcend all other considerations. This would make it very difficult to study the central theme of this thesis; the ethical perspective of interviewees when it comes to familial involvement in euthanasia decision-making.

The 'interview disclaimer' (see Appendix 1C) was mailed to interviewees in advance, and explained again before the start of interviews. Verbal consent based on this disclaimer was then requested. Next to the disclaimer, it was emphasized to interviewees that although questions could seem confrontational in nature and content, the intention was always to learn of their ethical perspective, not to challenge or judge it.

Data analysis

Data analysis was based on the analytical frame in the *Opposition of perspectives* section that also guided the questions that were asked during interviews. Transcripts of the conducted interviews were read multiple times. Important passages of transcripts were manually highlighted. Based on these highlights, individual in-depth analyses were first conducted for each interviewee (see *Individual Analysis*). Individual analyses sought so cohesively go through the themes presented in the analytical framework and the opposition theme, linking statements that participants made across responses to different questions. After individual analyses were completed, a more general and broad overview of the most common and relevant sentiments among all interviews taken together was written (see *General Analysis*). This method served to provide both a convenient overview of all findings taken together and an in-depth analysis. The general analysis closely followed the structure of the interview guide, separating topics more strictly than the individual analysis.

Recruitment

The study population was defined as 'individuals who have had substantial personal and/or professional experience with euthanasia, and had a Dutch nationality'. Other inclusion criteria were sufficient mental and general health, out of both practical and ethical considerations. Recruitment was attempted through personal channels, contacting medical institutions (hospitals, GP's), and posting in the Facebook page of the NVVE (see Appendix 2); a Dutch pro-euthanasia union with the goal of propagating and spreading awareness about euthanasia. At the start of recruitment, an introductory-type interview was sought out to test the interview guide and inform possible iteration of it.

Results

In total, ten interviews were held. One interviewee was recruited through personal connections, which served as an introductory interview. The NVVE Facebook post yielded nine interviews; although twelve people responded to the post, three were excluded due to only having insignificant experiences with euthanasia, or none at all. Contacting medical institutions yielded no interviews, mainly due to a lack of time available on the part of medical professionals.

Out of the ten interviews, eight were held in café's or the homes of interviewees, and two were held telephonically. Interviews took between 33 and 54 minutes, with transcripts between 4 and 12 pages of length. The age of people interviewed ranged between 54 and 81, aside from one 24 year-old interviewee. Excluding this outlier, the average age was ~66.7 years. Six interviewees were male, four were female.

Interviewees had a variety of professional and / or personal backgrounds with euthanasia. Three had had experience with euthanasia as care workers. Eight interviewees had had personal experiences with euthanasia (one interviewee had had both). These experiences regarded either a family member or friend receiving euthanasia, or interviewees seriously considering euthanasia for themselves in the past, present, or future. The connection to the NVVE also varied in nature and intensity; some had little to no commitment to the group besides the Facebook group membership, whereas others had done extensive volunteer work for the NVVE and thus were far more connected to the group.

Individual analysis

Below, in-depth analyses are provided separately for each of the ten interview transcripts, based on direct quotation of statements made by participants. Participants are referred to with aliases for the sake of convenience on the author's end, and anonymity on the participants' end.

Interviewee #1, alias: Justin

Justin has had experience with euthanasia as a terminal care provider. It should be noted that Justin's interview had an uniquely exploratory function and was structured atypically, and that Justin was the only interviewee not recruited via the NVVE Facebook group. This is line with Justin's relatively strict moral and legislative perspective on (Michael's) euthanasia; Justin explicitly stated that euthanasia is meant for those who suffer unbearably and endlessly, also saying *''...people can also be done with their life and step out of it, suicide, and that's not what euthanasia is meant for.''* Justin did present a concern that could be considered a challenge to his restrictive view on euthanasia availability, namely the subjectivity of a person's suffering: *''It's of course a subjective piece of information, not something you can measure with a ruler, [...] something that is unbearable for one person, another person goes through effortlessly so to speak.''* Justin added that this subjectivity meant he inevitably had to apply his personal norms as a doctor.

When asked about the value of Michael's life in regards to his euthanasia wish, Justin objected to the notion of judging the value of someone else's life, saying *''That's entirely up to him [Michael], to assess that.''* Justin had a more fundamental objection when asked about the value of Michael's life to others, saying that *''it's difficult to make statements about that'',* referring to the concept 'value of life'. As such, Justin did not feel comfortable commenting either on Michael's value of life on its own, or to others. However, when Justin was later asked this question about Robin's case, Justin did directly respond, saying that Robin's euthanasia wish could compromise her relationships: *''I think that the death wish sometimes negatively affects family. Like 'we love you, we want to care for you'.''*

Regarding the importance of Michael's autonomy, one more important factor Justin named was the autonomy of medical staff: *''If the other, especially the physician, doesn't agree with that then he can't be forced to do it [euthanasia].''* The interview moved directly into the topic of family involvement afterwards. Justin stated that Michael should make his euthanasia decisions individually: *''I think that he should primarily consider himself. I think that family can be a complicating factor.''* Justin also used the latter sentiment as a main reason that productive communication between patient and peers is important: *''For the [euthanasia] process it's important to find agreement. If there isn't agreement, you can expect some misery. Family can have a very negative influence in that situation.''* Justin also made a statement about what he considers proper conduct of physicians in balancing the euthanasia patient's autonomy and their family: *''It should be made clear [by the physician] what's going on. That it's the patient's choice, and that the family should respect the patient's autonomy.''* Justin furthermore said that physicians should encourage productive communication between patient and family.

Overall, Justin's perspective was uniquely pragmatic, often directly drawing from his experience as a physician. This is clear by considering the statements Justin made about practical alternatives to

euthanasia, and the overall 'concrete-ness' with which Justin formulated his responses. It seems that this pragmatism, as it manifested itself throughout Justin's long career as a physician, made Justin particularly certain about his moral perspective on euthanasia and familial involvement.

Interviewee #2, alias: Judith

Judith has come into contact with euthanasia as a care worker, ethics teacher, and in her personal life. Judith praises euthanasia on a spiritual level, because she views it as a socialization of dying that is in line with the natural socialized state of human existence: *''Euthanasia, that's asking for the end. And you should really do that together [...] you're a social being, so why wouldn't you be able to do it [a single person's euthanasia] together?''* Despite this positive sentiment about euthanasia, Judith did not say that Michael's euthanasia is ethical, instead emphasizing the possibilities Michael could still have to improve this life: *''That's not unbearable and not endless because he still has another life, he can do many more things. And that's teaching people to look at what you can do, not what you can't do.''* When told that Michael's case assumed he had tried everything, Judith remained skeptical, suggesting that there may always be something left to try. This optimistic attitude towards the changeability of Michael's condition bleak condition was a strong presence throughout the entire interview.

When discussing the value of Michael's life in regard to his euthanasia wish, Judith implied that the value of Michael's life is determined by his own satisfaction with life, and his ability to create meaning in his life; After naming some possible activities or methods for Michael with these goals in mind, Judith said *''I just think he needs more. Then he also has a valuable life''* As such, Judith seems to employ a perspective wherein the value of one's life is not equal per se between people, and is instead dynamically determined by the meaning and satisfaction that one's life brings them. Regarding the value of Michael's life to others, Judith elaborated on a factor in Michael's case other than the euthanasia wish: *''...you become very lonely when you're handicapped, you can't join in anymore. That's terrible, if you're not used to that.''* Thus, Judith suggests that Michael's medical issues themselves rather than his wish for euthanasia are a factor that compromise his interactions with others.

In response to the question about the importance of Michael's autonomy in his euthanasia decision-making, Judith opened with a sentiment against autonomy and in favor of restricted euthanasia availability: *''...your free choice - your freedom is bound to things that are possible. Euthanasia may not lead into murder. And that's what you're doing when you let a human being with a competent mind and power in his body be killed.''* Judith raised one other concern about the wellbeing of those involved in Michael's euthanasia procedure: *''What he does to others by requesting.''* With these sentiments, Judith expressed a perspective that holds multiple strict conditions for euthanasia to be ethical.

When asked about familial involvement in Michael's euthanasia decision, Judith confidently stated *''you can't claim someone's life''*, morally objecting to the idea of Michael changing his decision based on considerations for his peers. In line with her earlier ideal of a sort of 'socialized dying', Judith placed great emphasis on the importance of Michael properly communicating with his peers. Judith romanticized this communication ideal by saying the following: *''She [Michael's granddaughter] is allowed to say no, and then they get together - that isn't a difference of opinion, that's a different opinion: 'I love you dearly, but I'm requesting it [euthanasia] anyway'.''* Judith expressed the same sentiments after switching to Robin's case, not considering either Robin's more extensive social life or her responsibility towards her daughter reasons that should compromise Robin's autonomy morally.

Interviewee #3, alias: Jeffrey

Jeffrey is actively affiliated with pro-euthanasia organizations, and considers it his personal mission to advance euthanasia as a means to increase autonomy in the process of dying. He mentioned two major aims in this context. Firstly, he would like to see euthanasia legislation loosened greatly. When asked if he would find Michael's euthanasia should be legal, he said *''Yes. In my mind, voluntary life ending should always be possible for adults.''* Jeffrey did add three conditions. He wants to ensure that self-killing would not be possible impulsively, would be done responsibly in regards to close peers, and not force medical staff to kill another person. The latter ties into his second major aim: removing medical staff from the euthanasia procedure, both for the sake of personal autonomy in looking to exit life and out of consideration for the mental health of the medical staff.

When asked about the value of Michael's life, Jeffrey decisively dismissed the question, saying that *''It is not up to me to determine the value of his life, that is up to him. He can make up the balance in his social life and think 'what is it worth, and what is the price I pay if I continue living'.''* The 'up to him' sentiment was repeated when asked about Michael's life for others. Jeffrey also denied the idea of the value of Michael's life being relevant to how Jeffrey perceived Michael's wish for euthanasia, saying *''I want to go very far in respecting someone's considerations, regardless of context.''* This outlook that seems to focus on a liberal non-invasiveness also showed in his general view on the ethics of euthanasia, saying that it's interesting but should not 'force itself' onto people.

Regarding the priority of autonomy in a case like Michael's, Jeffrey restated the problem of dependency on other actors in euthanasia procedures. Jeffrey only mentioned this pragmatic concern as something that could transcend the importance of personal autonomy in ending one's life, re-affirming his perceived major importance of this autonomy.

When discussing the involvement of family and friends in self-killing procedures, Jeffrey again emphasized the importance of taking responsibility in that process, strikingly saying *''If you have people around you that give you warmth and meaning in life, and you're wanting to end that life, you've got some explaining to do.''* Here, Jeffrey is in his eyes acknowledging a negative side of euthanasia and self-killing: the saddening implications it has for the peers of the actor. Jeffrey also mentions the importance of involving friend and family in the process, saying that 'misery loves company'. Although Jeffrey places great importance on considering peers' feelings, he does believe that someone should prioritize their own concerns when deciding to request euthanasia. His own pre-written euthanasia statement starts with *'This one time in my life I want to be selfish'*, to which he adds that he will die at some point, anyway. Not only does Jeffrey exclude the family's concerns from the decision-making itself, he also considers his family a potential threat to that decision-making: *''My family and friends could turn out to be my biggest enemies: 'it will be fine, I will help you, we'll still do fun things. Until I'm not mentally capable anymore.''* In the scenario that Jeffrey sketches here, family and friends are posed as a quite dramatic threat to the personal autonomy of the actor.

Switching the case from Michael to Robin mattered little to Jeffrey's ethical view on their respective euthanasia considerations. Jeffrey again expressed wanting to leave people to judge their own lives and trusting that judgment, and emphasized the inevitability of Robin's death. Most centrally, he reaffirmed his priority of personal autonomy in life-ending: *''Who is anyone to tell a woman of 75 'no, you're going to go on [living]'?''*

Interviewee #4, alias: Carl

Carl suffers from a multitude of severe medical problems. Finding that the medical aid he's received is inadequate, he is now looking into options like euthanasia. Carl has already set up a will informally, in which he describes the circumstances under which he'd like to receive euthanasia. After reading Michael's hypothetical case, Carl argued that it would be moral for Michael to receive euthanasia,

saying *''He feels like he's suffering greatly and that he wants to die, in that scenario I don't see a reason to reject that.''* Carl further emphasized that he considered the current 'endless & unbearable' legislation overly strict, and that he would like to judge these kind of situations highly contextually: *''I'd say it's very situation-bound. Michael only has one granddaughter and one friend, if he had still had family and kids…''* In the last sentence here, Carl also suggests that the presence of more family and friends would affect the morality of Michael's euthanasia decision.

When asked how the value of Michael's life compares to someone without a desire for euthanasia, Carl did not directly answer the question, but did imply that Michael's value of life is lessened in some way by the negativity of his situation: *''Well he clearly has much pain and discomfort, which is a negative influence of course, it makes sense that he goes in the direction of euthanasia more quickly, I feel that regularly myself.''* Carl repeated this pragmatic perspective and the emphasis on contextuality when asked about the relation of Michael's euthanasia wish and value to others: *''That depends. If the friend and granddaughter pay him a visit and he constantly yells 'I want to die' […] that is not a positive interaction. But if he doesn't communicate it further, his peers don't have to deal with it so much. Then it only has an impact when he talks about it.''* This quote also suggests a negative sentiment regarding deeply involving peers in the euthanasia procedure, based on the possibility that those peers may be affected by some sort of existential dread on behalf of the euthanasia patient.

Regarding the importance of Michael's autonomy in receiving euthanasia, Carl convincingly expressed that he did considered Michael's freedom of choice most important, and that no other matters play a role. This statement seems at odds with the earlier suggestion that the morality of Michael's euthanasia would be affected by him having more close peers, which was backed up by Carl suggesting that Michael's peers are not morally allowed to take part in Michael's decision-making because they are distant and few: *''That would be a reason to say 'well, no full-fledged joint decision making.''* However, when examining the ethics of Robin's euthanasia, Carl's stance became more clear: *''I think that it's Robin's decision in the end.''* Carl did put great emphasis on the difference between Robin's and Michael's case, saying that Robin's decision would be more difficult, and that Robin would need to communicate properly and be generally responsible throughout the process. When asked in greater detail about the ethics of how Robin makes her decision, Carl said *''If she chooses to continue living that is also her own responsibility, then she considers 'I'm also here for my family'.''* Here Carl implies that an euthanasia decision made with the needs of peers in mind is not inherently immoral, whilst still stating that the euthanasia decision is ultimately Robin's to make.

Interviewee #5, alias: Marie

Marie is a catholic Christian. Her husband requested and received euthanasia, which is a decision they were both behind fully; although, as Marie said, the teachings of Christianity forbid deeds like euthanasia. Still, she and her husband believed that people's lives belong both to God and themselves, meaning that one should have the autonomy to receive euthanasia if they please.

When asked about the ethics of Michael's euthanasia decision, specifically, Marie stated with confidence that Michael's receiving euthanasia would be ethical. She motivated this by saying *''no-one wants to end their life without good reason''*, and presenting what is effectively a prerequisite for morality; when asked if Michael's desire to end his life is sufficient as an argument, she responded with *''Yes, assuming he did not think of it [the euthanasia decision] lightly.''* In line with Marie's ethics of Michael's decision, she also believed that Michael should be allowed by law to receive euthanasia, saying: *''Yes. I think the current legislation is overly tight and overly medically concerned with physical pain and suffering. I think the psychological component isn't considered enough.''* So not only does Marie express believing that legislation is too restrictive in general, she also leverages a specific complaint about the ways physical pain and psychological pain are considered when deciding whether someone should be allowed euthanasia. She also claimed that said pain and suffering should be up to the patient to decide, either way.

Regarding the value of life, Marie stated considering every life equally valuable, including Michael's. Right after stating this, however, she clarified that this did not compromise the morality of Michael's euthanasia: *''...if I compare the value of Michael's life with other lives, his life is just as valuable, but Michael has decided that he suffers endlessly and unbearably, and that he wants to die because of that. The value of a life does not compromise that.''* When it comes to one's value to others, Marie again said all lives are equally valuable. She expressed some doubts about the impact of a euthanasia request and substantial suffering on one's social environment, whilst stating with certainty that some kind of impact for the social environment is definitely there: *''If someone lets people know that they want to die, that has many consequences. That summons emotion. That needs time to be processed.''*

In line with the previously given moral prerequisite for euthanasia (proper deliberation on the patient's behalf), Marie gave a careful and lengthy euthanasia procedure as the sole consideration that could transcend euthanasia. The wants and needs of family and friends, too, did not transcend the importance of autonomy for Marie; *''The euthanasia patient must be able to go about things autonomously. If the family doesn't agree, that shouldn't be leading in the decision.''* This sentiment was repeated for Robin despite Robin's tighter familial bonds and greater responsibility. Marie did add to this that family considerations would make it harder to commit to receiving euthanasia, anecdotally saying *''How I look at myself with this - I also have a euthanasia statement in the works - if a child says 'I don't want to lose you'. That would make it harder to make the decision, but I'd still do it. And I would talk more to that child.''* Thus, Marie also stresses the importance of proper communication throughout the process of choosing for / receiving euthanasia.

Interviewee #6, alias: Alan

Alan once started the euthanasia process because of his struggle with depression, and stopped this process because his quality of life increased. At the moment of interviewing, he is still unsure about his future in regards to euthanasia. As could be expected of someone who started this process himself, Alan found Michael's euthanasia to be moral: *''I believe that if you are mentally competent, and you have some kind of suffering that bothers you, you should be able to decide if you want euthanasia or not.''* When asked to elaborate on the kind of suffering that would in Alan's eyes morally validate euthanasia, Alan suggested that there is at the same time a personal element to pain perception, and an objective sort of 'minimum suffering' for euthanasia to be moral: *''That [pain] limit is personal, but if you're hand is bothering you a bit I don't think that's enough.''* When asked about euthanasia legislation, Alan expressed favoring a more lenient system that enabled people to end their lives themselves, without the presence of medical staff, after being checked for mental competence.

In regards to Michael's value of life, Alan confidently stated that *''Every person's life is worth just as much.''* When it comes to Michael's value to others, Alan said the following: *''I think it's difficult for people […] but I think they appreciate him just as much, regardless of whether he wants to stop going on or not.''* Alan followed this up by reflecting on his personal experience of telling his friends about starting the euthanasia process: *''It didn't change much […] the contact between us has maybe gotten stronger. Because we thought 'we don't have much time left together, so we should make the best of it.''* Thus, Alan suggests having a mildly positive outlook on the effect that one's euthanasia wish has for their social relationships.

When asked about the importance of Michael's autonomy in decision-making compared to the importance of other matters, Alan gave two matters that in his eyes morally trump Michael's euthanasia. Firstly, the earlier-mentioned concern of mental competency, and secondly the well-being and autonomy of medical staff: *''If a physician says 'I don't want to do this', than you have to respect that, because carrying out an euthanasia is a very unburdening thing to do.''*

Alan again drew from his personal experience when asked about the involvement of family and friends in euthanasia decision-making, saying: *''I think that's a difficult question. I found it difficult to request*

the [euthanasia] procedure because I didn't want to leave my friends behind […] and that's a difficult moment because you're thinking 'I have to be selfish, I can't take life anymore so I'm stopping.'' Alan then framed this doubt he experienced as an indicator that he didn't 'want euthanasia enough': *''Well maybe the euthanasia wish is quite strong, but not strong enough to think 'I'm dropping everything and I'm just going to do it.''* Later, Alan added on the basis of this sentiment that it wouldn't be immoral for Michael to be talked out of euthanasia by their family; for if they were able to talk Michael out of it, he did not desire the euthanasia strongly enough. Yet, after switching to Robin's case, Alan did seem to change his tune. When asked if it would be unethical if Robin decided not to request euthanasia to help her daughter, Alan responded as follows: *''That's a difficult question […] I think that it's unethical. Because I think that euthanasia is your choice […] others shouldn't be allowed to influence that.''* Thus, Alan did in the end, although hesitantly, morally prioritize personal autonomy above considerations of how much the patient desires for euthanasia as shown by their (un)willingness to disregard the needs of the people around them.

Interviewee #7, alias: Andrew

Andrew is deeply involved with euthanasia, dedicating a significant portion of his time to pro-euthanasia institutions and services as volunteer. In line with this, Andrew expressed convincingly pro-euthanasia sentiments when asked about the ethics of Michael's euthanasia: *''Even if he wasn't wheelchair-bound, and didn't have any pain, my stance is still that in a developed and emancipated society people make all of their choices on their own, all throughout life, and that's the same when it comes to death.''* When asked about the euthanasia legislation in the context of Michael's case, Andrew also said he would like to see more loose legislation. More centrally, however, he argued that he would like to see more single-actor self-killing: *''When people say that they want to maintain control over the end of their lives, I primarily have an urge to say 'you have to take responsibility for that'. And the problem with euthanasia is that you place a burden on someone else.''* Here, Andrew objects more generally to the reality of euthanasia placing a 'burden of killing' on a person other than the patient.

When asked about the Michael's euthanasia wish in relation to the value of his life, Andrew responded by rejecting the idea of Michael's value of life being lower whilst repeating his perceived importance of Michael's autonomy: *''No, his life isn't worth less. But if it's his decision to stop, I respect that.''* Andrew also added later that the value of another life is not something he should be the judge of, anyway. In regards to the value of Michael's life to others, Andrew stated that the euthanasia wish could have either a positive or a negative on Michael's value to and relationships with others, and that any kind of shift in Michael's relationships would be natural. Before coming to this response, though, Andrew initially reframed the question, saying: *''It would mean a lot to me if I'd notice that he carefully manages his relationships in regards to the end of his life. He doesn't have to ask anyone for permission, but I think he should carefully interact with his environment in regards to that.''* In this quote, Andrew emphasizes the importance of proper communication regarding the end of one's life, while also making clear what his stance is on family involvement in euthanasia decision-making; one does not need to 'ask anyone for permission'. Later, in response to questions specifically about family involvement, he indeed reaffirmed this sentiment: *''When push comes to shove, I think he [Michael] should be the only one to make a final decision.''*

Interestingly, when asked the same question about Robin, Andrew refused to make a statement about the ethics of Robin's choice, making an appeal to non-invasiveness and the importance of careful conduct as a central value: *''Both as an advisor and in private I wouldn't say 'you can't chose that'. I don't want to be so invasive.''* And *''I think she should conduct it [the euthanasia process] carefully. That's what sets the limits.''*

Given the above, it seems that Andrews ethical perspective on euthanasia and self-killing is built on three principles: non-invasion of outsiders, personal autonomy, and careful patient conduct. It seems somewhat unclear which of the latter two Andrew finds more important; while saying that no other

matter should trump a patient's autonomy in how they choose to (not) end their lives, careful conduct in regards to the patient's social environment was simultaneously positioned as a central value that determines the morality of the decision-making.

Interviewee #8, alias: Sylvia

Sylvia's older sister and close friend received euthanasia in the past. She thinks of those euthanasia procedures in positive terms, and would also like to see her younger sister's wish for euthanasia fulfilled in relation to her younger sister's mental health issues. This euthanasia-positive viewpoint is also clear in her stance on the ethics of Michael's euthanasia: *''Yes, I would find that ethical. It's his decision, and you should respect that.''* She repeated this sentiment when asked about her stance on the legality of Michael's euthanasia, further supporting it by saying *''If you decide to request that [euthanasia], you have a reason for it, you wouldn't do it otherwise.''* And *''If someone requests it he also thought about it a lot, then I find it ethical for him to do that.''* Thus, Sylvia states that the desire to receive euthanasia ethically by itself supports receiving euthanasia, and expresses trust in how people reach the decision of requesting euthanasia.

When asked about the value of Michael's life, Sylvia responded *''You know, this is also part of life, an euthanasia request. And I wouldn't say that that makes one's life lesser.''* Thus, Sylvia defended an equal value of Michael's life by arguing that the (desire for) euthanasia is an inherent part of his life, and not an outside factor that compromises the value of his life. Sylvia also rejected the notion that Michael's value to others would in general decrease: *''If they [Michael & peers] truly love each other, they will respect that. [...] That doesn't influence how you interact or whatever. I think that may even give a deeper relationship.''* However, Sylvia did present a specific situation in which Michael's relationship with others could become less positive, namely when *''he doesn't talk about that [euthanasia] openly and honestly.''* As such, Sylvia stresses the importance of proper communication of euthanasia patients and their peers. She later reaffirmed this by, after stating that personal conflicts between euthanasia patients and peers are common, saying *''I think that if you throw it [euthanasia] out in the open, you can figure it out together.''*

When asked whether anything could trump the importance of Michael's autonomy, Sylvia only named timing: *''...there can still be some things that he [Michael] hadn't considered yet, because of that it's good that there's a procedure, and not like 'alright let's do it then'.''* Sylvia rejected the notion of some kind of suffering being a necessity for moral euthanasia, arguing that it is an improper requirement due to substantial inter-personal differences: *''You can't take that [suffering] as a criterium. For example, suffering for me is very different from suffering for you.''*

Sylvia again emphasized the importance of communication when discussing family involvement in euthanasia, while also confidently stating that Michael's autonomy should remain: *''The person with the [euthanasia] request is the person who decides. And you have to involve the family that surrounds that person. There's no other way.''* Still, when asked whether it would be ethical if Michael's decision was to be changed out of considerations for his family, Sylvia said yes: *''Because it's his choice.''* Though, Sylvia did say that she would prefer to see Michael acting independently of the concerns of peers. As such, Sylvia expressed a nuanced view on the ethics of family involvement in Michael's euthanasia decision-making, wherein an independently-acting Michael is considered preferable, but morality is ultimately determined by whether Michael's decision-making remains autonomous. Sylvia repeated this sentiment after switching to Robin's case, framing the difficulties with Robin's responsibilities as a practical issue rather than a moral one: *''That dependency [of Robin's daughter], you have to do something about that, that's a practical matter.''* As such, Sylvia does not consider Robin's responsibility to her daughter to be a reason against her euthanasia decision.

Interviewee #9, alias: Sandra

Sandra's mother received euthanasia, a process which Sandra supported and was involved in extensively. Two of Sandra's friends committed suicide in the past. In line with the former, Sandra stated that it would be moral for Michael to receive euthanasia: *''...I see his age, and I see that he slowly can't bear the pain anymore [...] And he's also not responsible for anyone in his environment. Then he's allowed to do that in my eyes.''* Here, Sandra also suggests that if Michael were responsible for others, that would compromise the morality of his euthanasia in some way. Regarding the legality of Michael's euthanasia, Sandra expressed wanting Michael's euthanasia to be legal: *''If it isn't legally allowed, someone is going to help kill Michael and that's very terrible of course.''* And elaborating with *''And then it's difficult to prove if it [Michael's self-killing] was justified. [...] And if Michael takes pills himself, it's suddenly become suicide instead of euthanasia, and that is very [negatively] loaded.''* Here, Sandra raises concerns about 'informal' self-killing practices, and presents euthanasia as a solution to these practices occurring.

After the initial question about the value of Michael's life in light of his euthanasia wish, the interview steered away somewhat, instead leading to Sandra making a general points about the ethics of euthanasia. She further supported Michael's euthanasia by saying *''It's clear that Michael has tried everything. He thought about it extensively, it's not like he woke up and thought 'I'm not feeling it today'.''* And Sandra elaborated on the point of proper consideration: *''I think you can make demands with euthanasia that someone discusses it with a psychologist or doctor first. But at some point most people will express that they've considered it properly. And if you can confirm that, that should be enough.''* When asked about the value of Michael's life to others in regards to his euthanasia wish, Sandra did give a direct response: *''I think his value for the environment stays the same. I think that if he didn't have the idea yet of 'I'm going to quit', he would have the same contact with his peers.''*

Regarding the importance of Michael, Sandra presented the earlier-mentioned proper consideration and some degree as suffering as the only matters that trump the importance of one's autonomy in their euthanasia decision-making. Considering the latter, she did acknowledge what she perceives to be a challenge to that requirement - 'measuring' psychological suffering: *''...with psychological suffering a troop of psychologists will approach, 'we can fix this' [...] I do think you should be suffering. I don't know how you should assess that when it comes to psychological suffering.''*

When asked about the nature of family involvement in euthanasia decision-making, Sandra clearly expressed a pro-independency sentiment: *''...too bad for friends and family, I do think that the person themselves plays the main role in that.''* And *''As much as I understand that all those friends and family want Robin there, I also understand if Robin says 'guys, I can't go on'.''* Sandra did not oppose the notion of family and friends expressing their discontent with Robin's euthanasia, however: *''I think everyone should be allowed to say that. When Robin explains what her plans are, I'd maybe even say you're obligated to say how you feel.''* Instead, Sandra believes that the morality hinges on Robin's decision remaining autonomous, regardless of whether she's being influenced by friends and family: *''...if she can hold out longer despite the suffering than that's her decision, and that's fine.''* Still, Sandra would prefer to see Robin act independently, a sentiment she repeated when discussing Robin's responsibilities to her daughter: *''I don't think she should let herself be led by those kinds of feelings.''*

Interviewee #10, alias: Robert

Robert's mother received euthanasia, and Robert is currently considering euthanasia options in light of his most likely increasingly severe medical problems, in particular fearing the bodily degradation and 'meaningless life' that could follow. When asked about Michael's euthanasia decision, Robert reasoned that it is ethical for Michael to receive euthanasia: *''My rule is that you yourself determine what endless is, and I don't like others determining what is unbearable for you, and deciding what*

you're going to do for you.'' As such, Robert is defending personal freedom and attacking what is perceived as a 'nosy' attitude from outsiders towards a patient's suffering and euthanasia decisions. In a later comment, he added to this sentiment by complaining about doctors' reductionist ways of approaching euthanasia: *''Doctors say 'you can move your hand and watch the sun rise, so you can still live'. If that counts as living, I don't know what the meaning of life even is.''* Furthermore, he added that he perceives a double standard in how animals are put to sleep when they are clearly suffering, yet humans are forced to stay alive, a fact that Robert finds even stranger in the face of increasing health care expenditures.

When asked about the relation between Michael's euthanasia plans and value of life, Robert responded by saying *''I don't think anyone else should be allowed to determine that. People that request euthanasia have their reasons, but they're still worth as much as anyone else.''* Here, Robert is rejecting the notion that a desire for euthanasia compromises the value of one's life on two dimensions: not only are their lives worth just as much, it isn't up for anyone but the patient themselves to decide anyway, meaning that the question itself is invalid to begin with.

When asked about Michael's euthanasia in regards to the value of Michael's life to others, Robert unknowingly 'jumped the gun', making a comment about the balance between family considerations and autonomy: *''I don't think you can look at it that way. In moments like those, you think differently, you look at yourself more […] I think you should prioritize your own comfort. That is a selfish thought, though.''* The switch to Robin's case did not change this clear-cut position; Robert, whilst acknowledging that they may certainly change Robin's decision, considered neither Robin's richer social life or responsibilities relevant for the morality of her decision to receive euthanasia. In fact, Robert at multiple points expressed a relatively cynical view of the involvement of family and friends. As a moral prerequisite for euthanasia he stated that *''The coffee has to be pure, no matters like 'if you die, we can buy that house'.''* And a general point about familial involvement: *''I don't think family should mix themselves into that [euthanasia] process. They have other desires.''* As such, Robert is expressing a negative view on the involvement of family in euthanasia decision-making.

Aside from the concern of morally perverse familial involvement in the euthanasia decision, Robert only mentioned a patient's mental clarity as a factor that could transcend autonomy. Closing the interview, Robert made a general statement about his perspective on euthanasia: *''I'm not fond of people who create enormous health care costs in order to stall. I have a practical mentality: what is doable, what may a human life cost?''* As such, Robert suddenly introduced a concrete economic concern to an interview that had only regarded abstract moral concepts; interestingly, although Robert did not consider familial considerations and value of life valid moral grounds for doubting someone's wish for euthanasia, he did consider economic concerns a moral ground for doubting one's decision to 'stall' the end of their life.

General analysis

In this section, the most common and relevant sentiments expressed for each topic by all interviewees are taken together are presented. As mentioned before, analysis is framed along the lines of prevalent euthanasia ethics themes and the bioethics / family ethics conflict that also determined interview questions. Specific interviewees are referenced with their aliases and numbers (#1-#10) found at the top of their interview transcripts and individual analyses.

General Stance on Euthanasia

The majority of interviewees thought it was ethical for Michael to receive euthanasia. One, Justin (#1) did not; notably the only interviewee who was not recruited through the NVVE. Justin was confident that euthanasia was only meant for those who suffer unbearably and endlessly. The other nine

participants agreed Michael's euthanasia was ethical, but still presented diverse stances regarding what the requirements for ethical euthanasia are. On one end, Andrew (#7) said that neither suffering nor handicap are requirements for ethical euthanasia, because people should be able to make their own choices regarding their deaths regardless of such circumstances. On the other end, most other participants did state some kind of substantial suffering is a requirement for ethical euthanasia. Multiple participants in this latter group, and also Justin (#1), did add similar caveats about the nature of a patient's suffering, which can roughly be divided into three elements: (1) suffering is subjective in how it is experienced and expressed by patients, (2) suffering is subjective in how it is perceived by a physician, and (3) because of these reasons, a patient's suffering cannot be measured with total fairness and reliability. To some participants, this caveat seemed quite a challenge to their euthanasia ethics, whilst others did not seem to believe it compromised their ethical perspective on euthanasia in any significant way.

Still, all participants except Justin (#1) presented a moral and legislative stance on euthanasia that is substantially less restrictive than the current moral and legislative norms in The Netherlands. Expectedly, the main argument for this stance is based on one's right to autonomy in the end of their lives. Although the perceived importance of this autonomy did turn out to vary substantially, all participants expressed finding that it was highly important that people enjoy great freedom in choosing how their lives end. Some participants supported this point by referencing the high value our society places on the autonomy we hold when we choose how to *live* our lives, and arguing that this value should also be placed on the autonomy we hold when we choose how to *end* our lives. As such, participants positioned euthanasia as a natural extension of the other decisions we make throughout life. Many participants presented another pro-euthanasia argument, which was most often secondary to the autonomy argument: when someone chooses that they want their lives to be ended via euthanasia, the fact that they desire this on its own ethically validates them receiving euthanasia. This argument rested on the assumption that a decision as consequential as ending one's life will naturally have a proper reasoning behind it; someone does not want to have their life ended without good reason, after all. A third argument made by some participants in favor of a less restrictive stance on euthanasia regarded the practical reality of the 'alternatives to euthanasia'; the 'nastier' self-killing (suicide) methods that people choose, and perhaps would not choose if they were able to receive euthanasia instead. Participants argued that in comparison to common suicide methods, euthanasia is much more humane for both the individual with the death wish and everyone that would otherwise be traumatized or inconvenienced as a byproduct of those common suicide methods. Under the assumption made by participants that more loose euthanasia legislation would lead to euthanasia being chosen over suicide methods, it follows in this line of reasoning that outcomes would improve.

Value of life - on its own

When asked about the value of Michael's life in the light of his euthanasia considerations, two types of responses were popular among participants. The first of these responses was a fundamental rejection of the question; participants argued that they could not answer the question, because they are not fit to judge the value of one's life as an outsider. The reasoning for this as provided by participants was twofold: firstly, making a judgement about the value of someone else's life was considered intrusive and meddlesome. This concern about being intrusive and meddlesome also aligns with the general pro-autonomy stance that participants held, since this stance is naturally individualistic. Secondly, participants said that they lack any deep insight into other people's lives, which they would consider a requirement to make a judgement about someone's life. Whenever a single participant provided both lines of reasoning, the latter point was naturally secondary to the former; ignorance only becomes a concern if you consider yourself morally fit to make a judgement to begin with.

Still, secondly, some participants did make a statement about the value of Michael's life compared to any other person that is not considering euthanasia. Among these participants, almost all confidently stated that the value of Michael's life was the same as anyone else's, and that him considering euthanasia did not compromise the value of his life. A minority did argue that the value of life was lower than that of others, but not because Michael was considering euthanasia: instead, they suggested that the value of Michael's life was compromised by the general pain and discomfort that he suffered. This stance is reminiscent of pragmatic approaches that assess the value of life through measures like Quality-Adjusted Life Years (QALY's), wherein a decrease in one's health indeed entails a decrease in the value of one's life.

Value of life - to peers

Regarding the value of Michael's life for peers in light of his euthanasia considerations, multiple participants again objected to answering the question. In doing so, they applied the same reasoning they used in their objection to question 1: firstly, that it is invasive and meddlesome to comment on the value of someone's life as an outsider, and secondly, that they lack the knowledge about Michael's life to make any kind of judgement anyway. However, this objection was a bit less common in response to Question 2, and more participants did make a judgement about the value of Michael's life for this peers in regards to his euthanasia wish. Participants tended to frame the value of an euthanasia patient's life for their peers in terms of the quality and positivity of their social relationships. A minority stated that Michael's euthanasia wish wouldn't affect these relationships in any significant way. The majority, then, did believe that considering one's euthanasia would have some effect on their social relationships. This majority did not necessarily agree on whether this effect would be positive or negative, however. A few participants believed it could have a positive effect, viewing the euthanasia matter as an opportunity for relationships to become deeper and closer due to the heavy nature of the matter. On the other hand, a few participants believed that a negative effect was more likely, reasoning that the peers of an euthanasia patient would struggle to maintain a relationship: peers could struggle to process the euthanasia patient's pains and expressions of existential dread, or negatively internalize the fact that a close friend or family member wishes to die despite their relationship existing. Finally, some participants believed that the effect on social relationships could either be positive or negative, differing on a contextual basis. These participants commonly noted quality of communication as a determinant of whether the effect would be positive or negative.

Autonomy

Although not always when they were asked about it directly, all participants mentioned matters or concerns that they believed could morally outweigh one's autonomy in receiving euthanasia. Two of these concerns were centered around a single central sentiment: that the patient's proper deliberation of their euthanasia decision is a moral requirement for their euthanasia, and a requirement that transcended their right to autonomy. Firstly, multiple participants expressed concerns about the possibility of impulsive euthanasia decisions; in this regard, participants appreciated the forced delays in the current conventional euthanasia procedures as a means for preventing impulsive decision-making. Secondly, some participants expressed that they wanted the euthanasia patient to be mentally competent when they made the decision. As such, mental ill-health in the case of, for example, depression and dementia would compromise the morality of the patient's euthanasia decision. Most of the participants that touched on mental competency added that they believe the matter of mental competency and autonomy to be quite challenging morally.

It should be noted that the proper deliberation requirement seems to clash with a previously described popular statement: that one's euthanasia is naturally properly deliberated due to the major consequences that this decision has for someone's life (or death). One could suggest that if this is the

case, that would invalidate concern about such a proper deliberation. Still, multiple participants both made this former statement and expressed this latter concern.

A categorically different concern regarded the autonomy and well-being of medical staff that could be tasked with conducting euthanasia. Most participants expressed some sentiment about how medical staff shouldn't be forced to conduct euthanasia procedures, for the sake of their well-being - multiple participants believed that conducting an euthanasia is a heavy task - and in particular for the sake of their autonomy in itself. This sentiment was also used to formulate support for an euthanasia system with less involvement from medical staff, which was favored by some participants.

Lastly, a few participants were concerned with the patient's motivations for deciding to not receive euthanasia, the sentiments being that one's euthanasia-related decision would not be moral if the motivations for it were considered immoral. This was touched in an off-handed general sense a few times, and only one specific hypothetical example of such an 'immoral motivation' was presented in the ten interviews: a hypothetical situation where the euthanasia patient decides to receive euthanasia because their children wanted to receive their inheritance more quickly. Of course, the ethical perspective with which the ethics of someone's motivations for (not) receiving euthanasia are judged, is likely similar to the ethical perspective of participants regarding the ethics of euthanasia as a whole; if one participant in general values autonomy greatly, he is likely to only consider an autonomously motivated euthanasia decision as ethical.

Autonomy & Family involvement

Among almost all participants, one general message about familial involvement in euthanasia decision-making was presented highly consistently: family and friends ought to be involved, but the decision should be made by the patient alone. This 'hands-off' form of familial involvement was very important to participants; as mentioned in the *Question 2* analysis, many participants considered proper communication between the euthanasia patient and their peers a factor that contributed to positive relationship building leading up to and during the process of receiving euthanasia; it would reduce conflict and deepen interpersonal understanding, both in light of the euthanasia matter and in general. Most participants stated that euthanasia patients like Michael and Robin have an obligation to discuss to communicate with their family about their euthanasia requests, out of respect for the relationships they hold with their family members. A few participants suggested that this is a two-way street; an euthanasia patient's family would also have an obligation to engage a meaningful conversation with the euthanasia patient after finding out about the matter, again out of respect for the relationship that they hold. The few participants that did not say they found communication (very) important tended to hold a negative overall view on the influence of family on euthanasia patients; in these cases, family was seen as potentially obstructionist or coercive in regards to the euthanasia patient's wishes. Communication was generally also found less important when discussing Michael's case in comparison to Robin's, because participants often linked the importance of communication to how close the relationships are to begin with; Robin's closer family relationships entailed a greater importance of proper communication regarding her euthanasia wish.

All ten participants agreed, although sometimes somewhat hesitantly, that family members should never be involved directly in the decision-making process of euthanasia patients like Michael and Robin; familial involvement should never compromise their autonomy in their euthanasia decision-making. But the ethical sentiments of familial involvement in euthanasia decision-making did not stop at this simple dichotomy of involvement - no involvement; reasoning from the assumption that the euthanasia patient is the only one making decisions, some participants made comments about whether and to which degree an euthanasia patient should consider the wants and needs of family when making their decisions. As such, these participants commented on what they considered ethically proper use of the patient's autonomy, rather than the morality of the autonomy itself. Participants' statements about this ethical use of autonomy can be divided into two similarly popular

categories. Firstly, some participants believed that people in Michael's and Robin's situation should make euthanasia decisions keeping only their own wants and needs in mind; the euthanasia decision was seen as something that should ethically be made considering only the patient themselves. A notable aspect of this statement is that participants often phrased it along the lines of '*the patient should be selfish*'. As such, this negatively loaded word is used to refer to how they believe euthanasia patients should motivate their decision-making. This suggests that the way they want patients to motivate their decisions would be frowned upon by participants if the decisions regarded a different matter, and that euthanasia alone is a matter that excuses one's selfish (self-centered) motivations for their decisions. Secondly, other participants stated that they would be ethically fine with seeing an euthanasia patient consider their family whilst making an euthanasia decision, but only when their autonomy remained uncompromised; the considerations for family should not be based on coercion. Here, moral priority is given to uncompromised autonomy over any ethical questioning of how that autonomy is used by a patient; as long as the patient's autonomy is maintained, any kind of motivations for the patient's euthanasia decision-making is considered ethical.

Conclusion

A general analysis and a case-specific analysis have been conducted to properly assess the ethical perspectives of the ten participants that were interviewed. Focus was put on participants' ethical perspective on familial involvement and autonomy in regards to euthanasia decision-making, in accordance to the research question of this thesis:

To which extent and in what way are bioethics and family ethics sentiments upheld by pro-euthanasia actors?

As explained before, bioethics and family ethics respectively hold patient autonomy and family considerations and involvement as core values in medical decisions. Based on the case-specific analysis and the general analysis, it was quite clear which of the two types of sentiments were held to a greater extent by the pro-euthanasia actors interviewed; they confidently assigned great ethical importance to the bioethics value of autonomy, and considered the wants and needs of family as regarded in family ethics a secondary - though still important - concern. The dominant bioethical prioritization of autonomy was most often reasoned by taking the value of autonomy that we conventionally uphold in our society throughout life, and extending it to the context of dying. No direct family involvement in a patient's euthanasia decision-making was often argued for two-fold: by emphasizing that the decision has a huge consequence for the patient and should therefore be his alone to make, and by expressing a fear for immoral types of family involvement, such as coercion. Any family ethics sentiments that were expressed by participants primarily took the form of concerns about proper communication between patient and family throughout the euthanasia decision-making process and the euthanasia process on its own. The main reasons participants cited for finding this communication important were to reduce conflict between patient and family, deepen their relationships, and potentially make their relationships more positive than before the matter of the patient's euthanasia. In conclusion, although participants clearly were more concerned with the bioethics value of autonomy than family ethics, participants did make clear that they had paid much mind to family dynamics and the need for proper communication. Participants also considered those impacted by a death in a broader sense, in a way that arguably extends out of the scope of family ethics; one common argument in favor of euthanasia claimed that it would serve as a replacement for self-killing (suicide) methods that have a much greater negative emotional and economic impact on society at large. In conclusion, family ethics thinking was substantially present in the ethical perspectives of participants; it just got trumped in terms of priority whenever it would clash with a patient's autonomy.

Strengths & Limitations

Background

Despite the absence of literature about the specific topic of Dutch euthanasia ethics and the relation between family ethics and euthanasia, this thesis established a background and analytical framework by deducing family ethics and bioethics positions about euthanasia, and observing Dutch euthanasia discourse. These efforts were crucial in how they provided a structure for interview guides and transcripts analysis. The analysis of Dutch euthanasia ethics could have been more thorough, however, considering more and more various sources to establish a complete view on the Dutch euthanasia ethics discourse.

Recruitment

Both the recruitment through the NVVE Facebook group and through personal connections was done without requiring a form of compensation. This recruitment method was efficient; it required minimal resources or time on the sides of both the researcher and possible participants. However, its effectivity is lacking; in the end, only 10 were interviewed. This perhaps resulted in some unique medical-ethical perspectives being missed out on. This limited reach issue also resulted in the initially posed research question being abandoned:

What are notable differences in the popularity of family ethics and bioethics sentiments between various types of actors?

This question could not be answered in a meaningful way given the highly limited diversity - in terms of type of actor - of the recruited participants. As such, the definitive research question specifically regarded pro-euthanasia actors.

Still, the findings in the personal experience group seem sufficiently saturated; only few sentiments expressed by participants were meaningfully unique, suggesting that the vast majority of types of ethical sentiments that are held by pro-euthanasia actors were on display in this thesis. Furthermore, given the substantial amount of data collected (66 pages of transcript), the minimal expenditures of this thesis is a quite notable strength.

Data collection

There are some notable strengths regarding the applied interview methodology. Interview questions were guided by a background analysis to ensure a degree of structure for interviews that was informed by relevant euthanasia ethics topics. This also allowed for great degree of contextualization around the bioethics / family ethics conflict. The hypothetical case-based structure allowed for a more concrete and unambiguous discussion of euthanasia ethics, which has likely saved time during interviews and improved the quality and comparability of collected data. However, a few interviewees expressed having difficulties with the case-based structure of the interviews, saying that it was difficult to imagine a hypothetical scenario that was different from the real-life Dutch scenario that they had operated in for many years. Also, the contextualization via the topics of general stance, value of life and autonomy may have been excessive; the questions representing each individual topic absorbed a similar amount of time in interviews to the question about the central bioethics / family ethics conflict. Also, interviews generally took substantially longer than expected, resulting in some parts of some interviews being cut short, and some comments made by participants being under-examined.

Another notable methodological strength of this thesis is that during data collection, extra attention was paid to the personal nature of interviews; at the beginning of interviews, it was emphasized to the interviewee that the goal of the interview was purely to observe their perspectives, and not to judge

or challenge them. This likely made interviewees feel more comfortable and interviews go over more smoothly. Also, the interview disclaimer (see Appendix 1A) was sent to interviewees a few days before an interview was planned. This was deemed appropriate, since the disclaimer in part served as a warning for the possibly highly personal nature of the interviews. By sending the disclaimer in advance, interviewees could not be caught off guard by and were able to prepare for this personal aspect. In line with the effort to maximize the comfort of interviewees, Interviews were held in locations of the interviewee's choice, thus creating an interview space that felt safe to interviewees in which to share their personal stories. Two interviews (#5, #10) had to be conducted by telephone due to practical limitations however, meaning that transcripts were written on the spot and were likely less precise.

Data analysis

Interviews were transcribed, after which important segments were highlighted. Highlighted segments were not exclusively worked into the analysis, but did receive much more attention throughout the analyzing process. This method was applied consistently to all transcripts, and allowed for an efficient, robust and flexible analysis of the interview transcripts. This qualitative data analysis was, however, prone to author bias (see below), because both the interpretation of transcripts and the process of identifying what was 'important' enough to be highlighted are inevitably based on the author's predispositions in regards to euthanasia ethics.

Author bias

This thesis was written by a single author, rendering it prone to bias based on the author's personal ethical perspective on euthanasia. Although the fullest effort has been made to stay neutral, and there is no possibility of conflict of interest, the author's perspective may still have influenced this thesis in every stage: the framing of the Dutch euthanasia discussion, the recruitment process, and the interpretation of transcripts could all be subject to an author's subconscious bias. Yet, there is good reason to believe that author bias had a limited impact within this thesis; during interviews, participants generally were not hesitant to object to or reframe the questions that they were asked, suggesting that no significant manipulation of the participants' responses occurred. The interview disclaimer (Appendix) that was sent before interviews also helped achieve this. Furthermore, a specific analytical framework was used consistently to formulate interview questions and analyze transcripts, allowing only little room for author bias in that respect. Still, it is important that the author's viewpoint on the ethics of euthanasia is disclaimed, along with the author's personal experiences with euthanasia:

At the time of writing this, I am 23 years old. Logically, I have had little experience with deaths of people who were close to me. However, my father received euthanasia eight years ago due to suffering caused by advanced cancer. Because I did not really grasp what was going on at the time, my feelings about him receiving euthanasia are rather 'neutral'.

In terms of my general stance of euthanasia, I believe that euthanasia should be allowed and is ethical under certain conditions. Where I 'draw the line' is at a situation like Michael's or Robin's: a situation where the person has substantial medical suffering and/or some kind of severe handicap. When it comes to the main thesis of this thesis, I find myself sympathizing to a great extent with a family ethics perspective on euthanasia. I believe that the more one's life is devoted to another person, the more that person should be involved in the decision of whether or not to request euthanasia. Although the idea that anyone other than the euthanasia patient actively decides is still appalling to me, I do not find it ethically objectionable if a peer would try to persuade the patient out of a genuine and benevolent motivation. Considering the interview case of Robin, for example (see Appendix 1A), I would not ethically object to Robin's dependent daughter trying to persuade Robin to not request euthanasia out of a genuine need for Robin to stay alive to support her. I see a certain positive holisticism in such a honest human interaction and interdependence, and I would rather see that than a in my opinion blind fetishization of patient autonomy.

Further suggesting that author bias played a limited role is the clear fact that the author's medical-ethical perspective on euthanasia generally conflicts with that of participants; participants favored bioethics sentiments heavily, while the author has strong sympathies for family ethics thinking. This

suggests that the author's perspective did not lead to a representation of participants' viewpoints in a way that is biased towards the author's own viewpoint.

Recommendations for future research

On their own, the findings of this thesis about the ethical perspectives of those who have had experience with euthanasia are in some ways unfulfilling due to the earlier mentioned limitations. However, it can serve as a stepping stone for future research with more extensive findings. Recommendations for future research into the ethical perspectives of individuals about euthanasia are as follows:

- Employ a team of multiple researchers to minimize author bias throughout various stages of research.

- Perform a more systematic and diverse media analysis of euthanasia discourse to provide a stronger basis for interview questions and transcript analysis. Analyze politics, major social media, and a variety of papers and the responses they receive from the public.

- Recruit in a more potent and diverse way to get a substantial and diverse sample of both people with personal experiences and people with professional experiences. In particular, try offering compensation to participants and spreading flyers in public spaces of local communities.

- Pay extra attention to the highly personal nature of interviews, similar to this thesis. Emphasize that interviewees will not be judged or challenged for their input. Allow participants to prepare themselves for the personal nature of interviews.

- During interviews, use hypothetical or real-life euthanasia cases to contextualize and decrease ambiguity, similar to this thesis. Prioritize to a greater extent exploring the main thesis and maintaining a substantial level of depth throughout the interview, rather than excessively focussing on surface-level contextualization. Alternatively, make more time available for interviews to allow for both extensive contextualization and meaningful exploration of the main thesis.

- Explore the ethics of euthanasia in a more connective manner, establishing links between literature, results, and discourse.

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On a closing note, I would like to express my appreciation for those who made the writing of this thesis possible. I have great gratitude for the participants who, without being offered any type of compensation, sat down with a stranger to share greatly personal stories - stories that formed the backbone of this thesis. I can only hope that they will enjoy reading this thesis, so that they may receive some kind of reward for their support after all. Of course, I would also like to extend my gratitude to my supervisor, Hilje van der Horst. In the midst of major delays for this thesis, her attitude was relaxed as to not add further stress, whilst also disciplined as to not make me complacent.

You have my genuine gratitude for your support,

-Daniel

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Appendix

1: Interview guide

NB: below, an English and a Dutch version of the interview guide can be found. Since all interviewees were Dutch natives, that version of the interview was used exclusively. Translations from Dutch to English may not be entirely exact due to the absence of a professional translator.

Before the questions themselves are asked, two things are explained to the interviewee. Firstly, the interviewer tells the interviewee about the research and the interview procedure. This allows the interviewer to gain informed consent..

If at any time the interviewee appears to be or expresses being uncomfortable during the interview, the interviewee is reminded of his or her complete freedom to not answer certain questions or halt the interview altogether. If an interviewee is visibly highly uncomfortable or emotional, the interviewer puts a stop to the interview himself to with certainty avoid further distressing the interviewee. Interviewees do not see the interview guide at any point.

1A: Interview guide - English

STEP 1: INTRODUCTION
TEXT: This interview is conducted as part of research about the ethical perspectives regarding euthanasia that are held by people who have had close experiences with euthanasia. This interview will be audio-recorded and transcribed. All interviews are placed into the research anonymously, with only basic data (biological sex, age, kind of euthanasia experience) present. The research will be presented to other students, and might be published.

You are free to refuse to answer a question, or shut down the interview as a whole, at any time. The interview will take approximately 30 minutes.

If you have any questions for the researcher after the interview has been conducted, you can contact me by e-mail: daan.borkent@wur.nl

STEP 2: INTRODUCTORY QUESTION
Can you describe your professional and/or personal background with euthanasia?

STEP 3: FIRST CASE: MICHAEL
This case is about an imaginary man named Michael. Michael is 78 years old. Michael was involved in a serious car accident three years ago, which made him wheelchair-bound. Additionally, the physical trauma from that accident has put him into a constant state of substantial pain and discomfort. All available medical and holistic treatments have been attempted, without success; Michael will most likely remain in this state for the rest of his life.
He has retained a casual relationship with one granddaughter and a friend from his old job. He sees both around once per month. Michael does not provide for anyone financially, nor does he have substantial responsibilities towards anyone. He spends most of his time reading at home. Although Michael is generally satisfied with his life, the substantial pains and discomfort caused by the car accident have lead him to consider requesting euthanasia.

Make the following assumptions while considering Michael's case:
1: If Michael were to request euthanasia, it would be accepted due to the euthanasia legislation being less strict in this hypothetical scenario
2: Michael's substantial and endless suffering have been determined by medical professionals with the same rigorous methodology that is used to determine endless and unbearable suffering in contemporary Netherlands.

0A: Do you think it is ethical for Michael to request euthanasia? Why?
0B: Do you think Michael should be allowed to receive euthanasia by law? Why?

1: a) What is the value of Michael's life in comparison to that of an average person?
b) Is this influenced by Michael suffering from medical issues and considering requesting euthanasia? If so, how?

2: a) What is the value of Michael's life for others?
b) Is this influenced by Michael having a fulfilled life and considering requesting euthanasia? If so, how?

3: a) How important is it that Michael has complete freedom in deciding whether or not to request euthanasia?
b) Are there any other considerations that are more important than this freedom? If so, which?

4: To what extent should family and friends be involved in Michael's decision to request or not request euthanasia?

STEP 4: SECOND CASE: ROBIN
This case is about an imaginary woman named Robin. Robin is 75 years old. Robin was involved in a serious car accident three years ago, which made her wheelchair-bound. Additionally, the physical trauma from that accident has put her into a constant state of substantial pain and discomfort. All available medical and holistic treatments have been attempted, without success; Robin will most likely remain in this state for the rest of her life.
She has been married to her husband for 45 years. Robin has a brother and two children, and five grandchildren. She has regular contact with all of these family members. She also has friends that she talks to on a weekly basis. Robin works part-time to, together with her husband, provide necessary financial support to one of their children's households. Even though Robin is satisfied with her life, the substantial pains and discomfort caused by her struggle with cancer has lead her to consider requesting euthanasia.

Make the following assumptions while considering Robin's case:
1: If Robin were to request euthanasia, it would be accepted due to the euthanasia legislation being less strict in this hypothetical scenario.
2: Robin's substantial and endless suffering have been determined by medical professionals with the same rigorous methodology that is used to determine endless and unbearable suffering in contemporary Netherlands.

0A: Do you think it is ethical for Robin to request euthanasia? Why?
0B: Do you think Robin should be allowed to receive euthanasia by law? Why?

1: a) What is the value of Robin's life in comparison to that of an average person?
b) Is this influenced by Robin suffering from medical issues and considering requesting euthanasia? If so, how?

2: a) What is the value of Robin's life for others?
b) Is this influenced by Robin having a fulfilled life and considering requesting euthanasia? If so, how?

3: a) How important is it that Robin has complete freedom in deciding whether or not to request euthanasia?
b) Are there any other considerations that are more important than this freedom? If so, which?

4: To what extent should family and friends be involved in Robin's decision to request or not request euthanasia?

1B: Interview guide - Dutch

STEP 1: INTRODUCTION
TEXT: Dit interview wordt uitgevoerd voor een onderzoek naar de ethische opvattingen over euthanasie van mensen die te maken hebben gehad met euthanasie. Dit interview wordt opgenomen en uitgeschreven. De interviews worden anoniem in het onderzoek geplaatst, met alleen uw basale gegevens (geslacht, leeftijd, soort ervaring met euthanasie) erbij. Het onderzoek wordt gepresenteerd aan andere studenten, en er bestaat een kleine kans dat het gepubliceerd wordt.

U heeft volledig de vrijheid om naar wens een vraag niet te beantwoorden, of het interview in zijn geheel stop te zetten. Het interview duurt ongeveer 30 minuten.

Als u na het interview vragen heeft voor de onderzoeker, kunt u contact opnemen met de onderzoeker op: daan.borkent@wur.nl

STEP 2: INTRODUCTORY QUESTIONS
TEXT:
IF MEDICAL PROFESSIONAL
Wat is de titel van uw beroep?
Kan u uw beroep kort beschrijven?
Hoe is uw beroep verbonden aan euthanasie?
Wat is uw perspectief op euthanasie binnen uw beroep?

IF LAYMAN
Welke betekenis heeft euthanasie voor uw leven gehad?
Hoe kijkt u naar de betekenis van euthanasie in uw leven?

STEP 3: FIRST CASE: MICHAEL
Deze case gaat over een denkbeeldige man genaamd Michael. Michaels is 78 jaar oud. Michael was drie jaar geleden betrokken bij een auto-ongeluk, waardoor hij in een rolstoel belandde. Ook bezorgt de fysieke schade van dat ongeluk hem nog steeds constant veel pijn en ongemak. Alle beschikbare medische en holistische behandelingen zijn zonder succes uitgeprobeerd. Michael blijft hoogstwaarschijnlijk in deze staat voor de rest van zijn leven.
Michael is nog zo af en toe in contact met een kleindochter en een vriend van zijn oude werk. Met beiden spreekt hij ongeveer eens in de maand af. Michael ondersteunt niemand financieel, en heeft geen enkele grote verantwoordelijkheden naar anderen. Hij besteed het grootste deel thuis lezend. Alhoewel Michael over het algemeen tevreden is met zijn leven, hebben de pijn en de last van het auto-ongeluk hem ertoe gebracht om te overwegen euthanasie aan te vragen.

Maak deze aannames terwijl je over Michaels case nadenkt:
1: Als Michael euthanasie aan zou vragen, zou dit geaccepteerd worden. Dit is het geval door de minder strikte wetgeving die aanwezig is in dit denkbeeldige geval.
2: Michaels substantiële en eindeloze lijden zijn met dezelfde uitgebreide methode vastgesteld als de methode die momenteel in Nederland wordt gebruikt om ondraaglijk en uitzichtloos lijden vast te stellen.

0A: Vind je dat het ethisch verantwoord is als Michael euthanasie verzoekt? Waarom?
0B: Vind je dat het wettelijk toegestaan zou moeten zijn dat Michael euthanasie kan ontvangen? Waarom?

1: a) Wat is de waarde van Michaels leven in vergelijking met dat van het gemiddelde persoon?
b) Wordt dit beïnvloed doordat zij een voltooid leven heeft en euthanasie overweegt? Zoja, hoe?

2: a) Wat is de zin van Michaels leven voor anderen?
b) Wordt dit beïnvloed doordat Michael euthanasie overweegt? Zoja, hoe?

3: a) Hoe belangrijk is het dat Michael vrijheid heeft in het maken van de keuze om euthanasie te verzoeken?
b) Zijn er overwegingen die belangrijker zijn dan deze vrijheid? Zoja, welke?

4: In welke mate zouden familie en vrienden betrokken moeten zijn bij Michaels keuze om wel of niet euthanasie te verzoeken?

STEP 4: SECOND CASE: ROBIN
Deze case gaat over een vrouw genaamd Robin. Robin is 75 jaar oud. Robin was drie jaar geleden betrokken bij een auto-ongeluk, waardoor ze in een rolstoel belandde. Ook bezorgt de fysieke schade van dat ongeluk haar nog steeds constant veel pijn en ongemak. Alle beschikbare medische en holistische behandelingen zijn zonder succes uitgeprobeerd. Robin blijft hoogstwaarschijnlijk in deze staat voor de rest van haar leven.
Robin is 45 jaar getrouwd met haar man. Ze heeft een broer, twee kinderen, en vijf kleinkinderen. Ze heeft regelmatig contact met al deze familieleden. Ze heeft ook vrienden waar ze wekelijks mee afspreekt. Robin werkt samen met haar man part-time om nodige financiële steun te bieden aan het huishouden van één van haar kinderen. Alhoewel Robin over het algemeen tevreden is met haar leven, hebben de pijn en de last die veroorzaakt zijn door haar strijd met kanker haar ertoe geleid om te overwegen om euthanasie aan te vragen.

Maak deze aannames terwijl je over Robins case nadenkt:
1: Als Robin euthanasie aan zou vragen, zou dit geaccepteerd worden. Dit is het geval door de minder strikte wetgeving die aanwezig is in dit denkbeeldige geval.
2: Robins substantiële en eindeloze lijden zijn met dezelfde uitgebreide methode vastgesteld als de methode die momenteel in Nederland wordt gebruikt om ondraaglijk en uitzichtloos lijden vast te stellen.

0A: Vind je dat het ethisch verantwoord is als Robin euthanasie verzoekt? Waarom?
0B: Vind je dat het wettelijk toegestaan zou moeten zijn dat Robin euthanasie kan ontvangen? Waarom?

1: a) Wat is de waarde van Robins leven in vergelijking met dat van het gemiddelde persoon?
b) Wordt dit beïnvloed doordat zij een voltooid leven heeft en euthanasie overweegt? Zoja, hoe?

2: a) Wat is de zin van Robin leven voor anderen?
b) Wordt dit beïnvloed doordat Robin euthanasie overweegt? Zoja, hoe?

3: a) Hoe belangrijk is het dat Robin vrijheid heeft in het maken van de keuze om euthanasie te verzoeken?
b) Zijn er overwegingen die belangrijker zijn dan deze vrijheid? Zoja, welke?

4: In welke mate zouden familie en vrienden betrokken moeten zijn bij Robins keuze om wel of niet euthanasie te verzoeken?

1C: Interview disclaimer

The following three-point disclaimer was sent to participants before interviews, and repeated to them at the start of interviews:

- The interview will take between 30 and 40 minutes. You have complete freedom in ending the interview at any time.

- The interview contains ethical questions about hypothetical euthanasia patients. The interview could get quite personal at times; you also have complete freedom to not answer specific questions.

- The interview is audio-recorded, and then transcribed for research purposes. You will remain anonymous in this process. The research will be accessible to other researchers and students.

Appendix 2: NVVE Recruitment Post

The following Dutch text was used to recruit interviewees on the NVVE Facebook page:

Beste leden van de NVVE Facebook groep,

Mijn naam is Daan Borkent. Ik studeer publieke gezondheid aan de Wageningen Universiteit, en ik ben een scriptie aan het schrijven over euthanasie. Voor dit verslag ben ik benieuwd naar de inzichten van mensen die te maken hebben gehad met euthanasie in hun sociale omgeving: vrienden, familie, enzovoort. Graag zou ik meer leren over de morele afwegingen die gemaakt worden rondom euthanasie.

Ik zou dit het liefst doen in de vorm van interviews van ongeveer 30 minuten. De interviews kunnen plaatsvinden waar en wanneer u wilt. Tijdens de interviews stel ik u een aantal vragen over de ethiek en moraal van euthanasie, en noteer ik wat uw inzichten zijn. Deze vragen gaan dan over de situaties van denkbeeldige euthanasie patiënten die ik aan u voorleg. Het interview wordt anoniem verwerkt in het onderzoek.

Zou u een interview willen doen, of heeft u vragen?
Ik hoor graag van u!

Met vriendelijke groet,
Daan Borkent