

Should Young Children Be Involved in the Decision-Making Process about Their Active Life Termination?

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Abstract

On February 1st 2024, the Dutch government introduced the possibility for doctors to perform active life termination in terminally ill and suffering children, aged 1 to 12, under strict legal requirements. Although the ethical discussions about whether it is justified to terminate the life of a young child are still ongoing, this thesis argues under the assumption that under certain legal requirements, it is justified to terminate the life of a young child. Building on this argumentation, this thesis explores whether the young children, to whose situation active life termination would apply, should be involved in the decision-making process about their active life termination. Using Beauchamp and Childress' '*Four Principles Approach*', this thesis analyses the involvement of young children in this decision-making process, focussing on the biomedical principles of *respect for autonomy*, *beneficence*, and *non-maleficence*. This thesis argues that when the principle of respect for autonomy is taken into account, it could be considered desirable and perhaps morally necessary to involve the young child, if this child is deemed capable of making an autonomous decision. However, when the principles of beneficence and non-maleficence are taken into consideration, it could be argued that involving young children in the decision-making process about their active life termination may not be in their best interest and could potentially cause harm to these children. This thesis elaborates on the moral dilemma that arises when these biomedical principles seem to conflict with each other.

Keywords: active life termination, children, respect for autonomy, beneficence, non-maleficence.

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1. Introduction

In general, we do not get to decide how and when we die. However, advancements in medicine have enabled doctors with the possibility to hasten a terminally ill patient's death with minimal suffering, with different forms of end-of-life care, among which euthanasia and active life termination. Euthanasia and active life termination are strictly regulated medical interventions which are only permitted in a few countries, including The Netherlands (Gupta & Bansal, 2023; Cuman, 2017). Since the topic of this thesis is focused on an issue at the intersection of euthanasia and active life termination, I will start by explaining both practices in the following section.

1.1 Euthanasia and Active Life Termination

The medical practices of euthanasia (the term euthanasia originates from the Greek words 'eu' and 'thanatos', which means 'good death') and active life termination refer to compassionately allowing, hastening, or causing someone's death with minimal suffering (Gupta & Bansal, 2023). In The Netherlands, both practices require distinct legal approaches, which are tailored to different age groups.

On the one hand, the euthanasia regulation, which was introduced in 2002 by the Dutch Ministry of Health, Welfare and Sport and the Ministry of Justice and Security, only applies to cases involving terminally ill adults and children with a minimum age of 12 years, who are suffering unbearably and hopelessly, and have made an explicit request for euthanasia (Rijksoverheid, n.d.; Expertisecentrum Euthanasie, n.d.; Brouwer, 2021)

On the other hand, the active life termination regulation includes life-ending without an explicit request (Brouwer, 2021). On February 1st 2024, the Dutch government, specifically the Dutch Ministry of Health, Welfare and Sport and the Ministry of Justice and Security, introduced the possibility for doctors to perform active life termination to all terminally ill and suffering children younger than 12 years, but only under very strict legal requirements (Minister van Veiligheid en Justitie en de Minister van Volksgezondheid, Welzijn en Sport, 2024). The reason that all children less than 12 years of age fall under a separate legal regime is because they are deemed unable to make an explicit request, which is a requirement for euthanasia (Brouwer, Maeckelberge & Verhagen, 2024; Kloosterman, 2024). Further details on the historical and legal establishment of this regulation will be provided in section 2.1 and 2.2.

1.2 Ethical Concerns

The development of regulations surrounding active life termination for all terminally ill and suffering children younger than 12 years has sparked an ethical debate both about whether it is justified to terminate the life of a young child as about the broader societal implications of introducing such regulations. This is because at the core of this issue lies a tension between respecting individual autonomy and protecting vulnerable individuals from harm. While proponents could argue that active

life termination provides a compassionate end to suffering, opponents could express concerns about the potential for abuse and coercion, particularly when the decision involves persons who cannot fully comprehend or consent (Brouwer et al., 2018). Some ethicists raise their concerns about the development of the Dutch regulations surrounding end-of-life regarding making (life-or-death) decisions on behalf of others and claim that the broader societal and moral implications of involving young children in such a decision-making process need to be addressed (Boer, 2024). These ethicists fear that introducing regulations on active life termination could potentially lead to a slippery slope, posing a risk to other vulnerable groups in society who are unable to make an explicit request, such as patients with dementia or patients with mental disabilities (NOS.nl, 2023; van Rijn, 2023; Cuman, 2017).

In reaction to these ethical concerns, the Dutch government emphasised that active life termination in young children would only be possible when both doctors and parents or caregivers consider it to be the only reasonable alternative to end the child's hopeless and unbearable suffering (NOS.nl, 2023). Dutch legislators state that the reason that developments surrounding active life termination are present in The Netherlands is because parents and doctors (mainly paediatricians) have expressed the need to have such measures implemented and regulated, as they too often witness severe suffering in young, terminally ill children during their dying process (NOS.nl, 2019a; Kruse, 2019; Kloosterman, 2023). The implementation of this regulation was thus advocated for by a group (parents or caregivers of terminally ill and suffering young children and doctors) that are closely involved in the care of these children (NOS.nl, 2023; Nu.nl, 2023).

In the Netherlands, criteria are still being developed to clarify the regulations for active life termination in young children. These criteria aim to ensure that doctors who actively end the life of a young child under specific circumstances will not face legal prosecution (Brouwer, Maeckelberge & Verhagen, 2024; Kloosterman, 2024). So far, the available literature mainly discusses the view of parents and doctors, but rarely the choice of the child itself (Brouwer, Maeckelberge & Verhagen, 2024).

As there is a lack of existing (ethical) literature about whether young children should be involved in the decision-making process about their active life termination, this thesis aims to begin addressing this gap, by considering the child's perspective.

Although the ethical discussions about whether it is justified to terminate the life of a young child are still ongoing, this thesis will start from the assumption that, in exceptional cases, and under strict legal requirements, it can be justified to terminate the life of a young child. Hereby solely focussing on cases where there are good reasons to conclude that the requirements are met. Building on this argumentation, this thesis explores whether young children, to whose situation the criteria of active life termination would apply, should be involved in the decision-making process about their active life termination. Arguing under the assumption that the active termination of a young patient's life can be

justified allows for the discussion in this thesis to concentrate on the specific moral issue of whether children should be involved in such a decision-making process.

1.3 Research Question

Along the lines of this reasoning, the research question for my thesis is: *Should young children be involved in the decision-making process about their active life termination?* To answer this question, this thesis will be constituted as follows. After this introduction, in the first section called *Active Life Termination in The Netherlands*, I will provide further details on the legal and historical context regarding euthanasia and active life termination in The Netherlands, in order to lay an informational foundation for the topic of my thesis. In the second section, *Theoretical Framework*, I will present the argumentative framework, the ‘*Four Principles Approach*’ to biomedical ethics by Beauchamp and Childress, which will structure my ethical analysis. The third section, *Respect for Autonomy: Should Young Children Be Involved?*, will be devoted to outlining their biomedical principle of *respect for autonomy* and to applying this principle to the case of whether young children should be involved in the decision-making process about their active life termination. This section formulates an answer to the question whether it is desirable or even morally necessary to include young children in this decision-making process. The fourth section, *Beneficence & Non-Maleficence: Is it Desirable to Involve a Young Child?*, continues elaborating on the research question, mainly focusing on the principles of *beneficence* and *non-maleficence*. Furthermore, the fifth section, *Addressing the Moral Dilemma*, will highlight the moral dilemma that arises when these biomedical principles are in conflict with the principle of respect for autonomy and will provide a potential solution to this moral dilemma. Finally, a summary of the arguments will be presented in the conclusion, with an answer to the research question.

1.4 Thesis Scope, Research Method & Objectives

The scope of this thesis is thus to give an answer to the research question about: *Should young children be involved in the decision-making process about their active life termination?*. Due to this limited scope, certain argumentative areas are deliberately excluded. For instance, this thesis will not elaborate on cases involving children who are unable to speak and therefore cannot verbally communicate directly. Neither will it expand on cases involving children who are so young that they cannot competently and consciously deliberate and take part in discussions about their active life termination. Moreover, it is beyond the scope of this thesis to go extensively into the practicality of how to involve young children or how to explain to a young child that their¹ life is going to terminate. Furthermore, although making a connection to the regulations surrounding this topic in other countries would make for an interesting comparison, due to the limited scope of this thesis, I am only going to focus on the

¹ In this thesis, I use both singular and plural references for the purpose of proper sentence construction, as they/them/their have been officially accepted as gender-neutral personal pronouns in English. Find more information on <https://internationalwriterscollective.com/how-to-use-gender-neutral-pronouns-in-your-writing/>

situation in The Netherlands. Hereby, it is important to note that the relevance of this thesis topic arises only in a context where there is room for practices such as active life termination in young children. Additionally, although it seems relevant to this topic, it is beyond the scope of this thesis to analyse the position of parents, especially after the child's passing. In circumstances where parents have to decide about the active life termination of a young child and about the child's involvement in this decision, parents may feel the need to justify their decision to their child. When a child passes away through active life termination, it could be the case that their parents and doctors want to be able to look at themselves in the mirror and know that, in hindsight, the right choice was made. After the child is deceased, there is no possibility to talk to the child anymore. Therefore, parents (and doctors) could go through a process of wanting to justify this decision to themselves but also to their surroundings. Although the present thesis acknowledges this thought-process, as already mentioned, it is beyond the scope of my thesis to elaborate further on this. However, future investigation into this topic could be necessary, as I believe that there lies value in the parent's perspectives as well.

In this thesis, the research method used is a comprehensive literature review. Although the specific research question of this thesis has not been explored so far, literature that concerned related topics allowed me to gain a deeper understanding of the subject matter.

The main objective for this thesis is to examine existing guidelines and regulations regarding active life termination regarding young children in The Netherlands and to establish an ethical framework for involving these children in the decision-making process about their active life termination. Secondary objectives include both assessing the moral implications of involving young children in a decision-making process about their active life termination as evaluating the potential benefits and risks of incorporating children in such a decision-making process.

2. Active Life Termination in The Netherlands

As mentioned in the introduction, end-of-life care can only be carried out under certain legal requirements. However, what exactly do these requirements entail? And how were they developed? Additionally, understanding how the Dutch regulations have evolved over time provides a chronological framework for this thesis. Therefore, I have outlined both the legal and historical context of end-of-life care in the sections 2.1 and 2.2 below.

2.1 The Legal Context

It is important to note that, in The Netherlands, end-of-life care is *not* legalised. However, strict regulations have been established, which include that when doctors comply with certain legal requirements, they will not be prosecuted (Kloosterman, 2024; Expertisecentrum Euthanasie, n.d). The justification for establishing these requirements was, and still is, the possibility for doctors to alleviate unbearable suffering in terminally ill patients (EuthanasieCode, 2022).

With regard to euthanasia, these requirements are documented in the Euthanasia Code (2022, 11) of the Dutch Regional Euthanasia Review Committees and specify that a doctor can only perform euthanasia when this doctor:

1. is convinced that the patient's request was voluntary and well-considered.
2. is convinced that the patient was suffering unbearably and hopelessly.
3. has informed the patient about their situation and prospects.
4. has concluded with the patient that there was no reasonable alternative solution for their situation.
5. has consulted at least one other independent doctor, who saw the patient and gave a written opinion on the abovementioned care criteria.
6. has carried out the termination of life or assisted suicide with due medical care.

These six requirements apply to patients with a minimum age of 12 (Expertisecentrum Euthanasie, n.d.; EuthanasieCode, 2022; Brouwer, 2021). Several regional review committees have been appointed to assess whether doctors have satisfied all of the above-mentioned requirements, after the end-of-life care was executed. If this committee decides that a doctor has not complied with one or more requirements, the law claims that not only the doctor will be notified in writing, but that the committee must inform the Dutch Public Prosecution Service and the Health and Youth Care Inspectorate of its judgement. These authorities will then assess which further steps they consider to be necessary in the case (EuthanasieCode, 2022).

Furthermore, the Euthanasia Code provides specific information on how to approach cases of children aged 12 to 18. For instance, it states that in cases where a patient is 16 years or older and can no longer express his or her wishes but was previously capable of making a well-considered decision and had written a request for active life termination, a doctor can honour this request. Additionally, the Euthanasia Code clarifies that if a patient is between 16 and 18 years and is deemed capable of making a well-considered decision, the doctor can comply with their request for euthanasia, after involving the parents or caregivers in the decision-making process. Moreover, the Euthanasia Code explains that if a patient is between 12 and 16 years and is considered capable of understanding their own situation and interests, the doctor can proceed with the patient's request for euthanasia, provided that the parents or legal guardians also agree to it (EuthanasieCode, 2022, 46).

Since the euthanasia regulations only apply to patients aged 12 years and older, previously there were no regulations in place regarding euthanasia or active life termination for children under 12 years. This was because euthanasia requires an explicit request from the patient, something that was considered not applicable to young children, due to their age and cognitive development (Kema, 2019). As a result, young children who were terminally ill and suffering unbearably without any prospect of improvement fell into a legal gap.

This gap was only partially filled after the *Groningen Protocol* was established in 2005. This protocol included that doctors could perform active life termination in newborns up to the age of 1, if these children were experiencing unbearable suffering with no prospect of improvement (Brouwer, 2021). As doctors encountered cases where newborns had a very poor prognosis, and given that from the approximately 1200 children that die in The Netherlands each year, nearly 50 percent of these deaths occur around birth and within their first year of life, due to serious congenital conditions, the protocol only included this age group (Kruse, 2019). The same duty of care construction as in the euthanasia regulation was applied to this protocol. This construction includes that although active life termination in newborns was not legalised, doctors could still execute it under strict conditions, in the hope not to get prosecuted.

This meant that in The Netherlands since 2005 regulations and protocols have been established for euthanasia (upon explicit request) for adults and children with a minimum age of 12 and for active life termination in children under 1 year (Nu.nl, 2023; Brouwer, Maeckelberge & Verhagen, 2024). As for young children, aged 1 to 12, no regulations were developed yet, up to 2024 there existed a legal gap in Dutch regulations for children aged between 1 and 12 to pursue active life termination (Kruse, 2019; Kema, 2019; Nu.nl, 2023). This gap is also illustrated in figure 2 below.

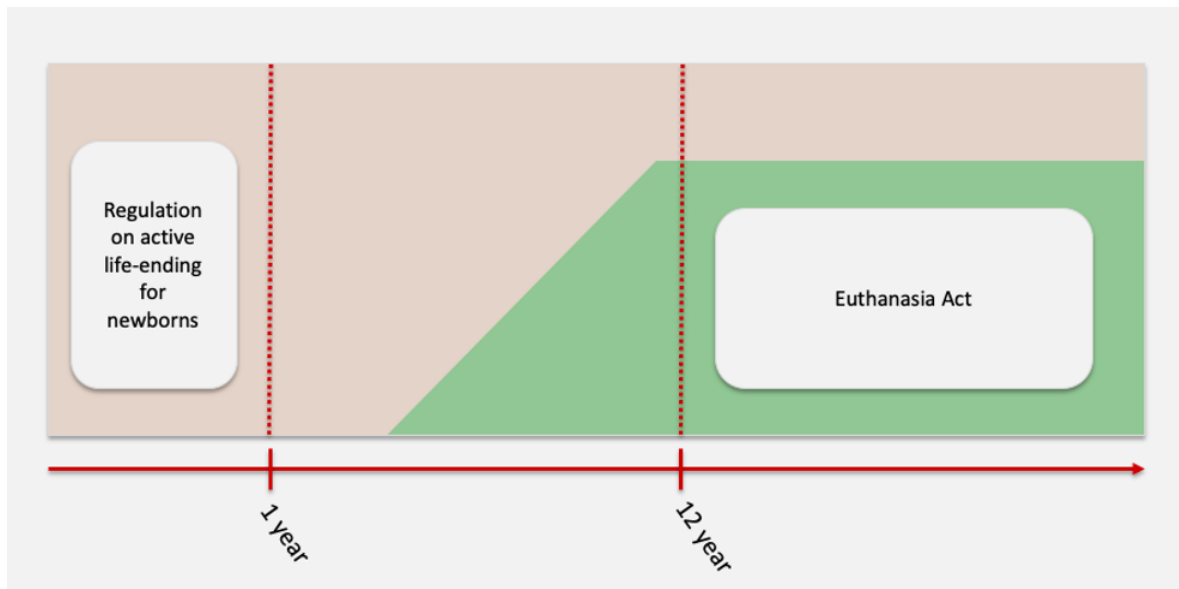


Figure 2. The legal gap between Dutch regulations on active life-ending (Brouwer, 2021, 11)

In fact, Brouwer (2021) stated that this legal gap consisted of two legal gaps, concerning both a group of children that could be considered capable of requesting euthanasia for themselves and a group of mentally incompetent children that cannot make such a request for themselves. The implications for the children who were caught in this legal gap will be discussed in section 2.2.

However, as a result of the advocacy by parents and doctors who were involved in the care of these children, this year, on February 1st 2024, a Dutch regulation came into effect that allows doctors to actively terminate the life of terminally ill and suffering children aged 1 to 12, under certain criteria (NOS.nl, 2023; Nu.nl, 2023; Brouwer, Maeckelberge & Verhagen, 2024; Kloosterman, 2024). This regulation is introduced by the Dutch Ministry of Health, Welfare and Sport and the Ministry of Justice and Security as an amendment to the existing regulation for the Assessment Committee for Late Pregnancy Termination and Life Termination in Newborns in The Netherlands (Minister van Veiligheid en Justitie en de Minister van Volksgezondheid, Welzijn en Sport, 2024). Both these governmental institutions state that these changes are based on an evaluation of this previous regulation and now includes provisions for assessing life termination in children aged 1–12 years (Overheid.nl, 2024).

Currently, the criteria for this regulation are being further developed, aimed at guiding doctors through situations in which it would be legally permissible to actively terminate the life of these children (Kinderpalliatief.nl, n.d.; Brouwer, Maeckelberge & Verhagen, 2024; Kloosterman, 2024).

2.2 The Historical Context

As outlined in section 2.1, regulations in The Netherlands surrounding end-of-life care have evolved significantly since the introduction of the euthanasia regulations in 2002. In this section, I will highlight the historical developments, mainly focussing on the considerations that led to the implementation of the active life termination for children aged 1 to 12 in The Netherlands.

Previously, as young children aged 1 to 12 fell into a legal gap between the Groningen Protocol and the euthanasia regulations, parents, in cases where they were confronted with their child's unbearable and hopeless suffering and approaching death, sought to alleviate their child's suffering in other ways. In consultation with doctors, parents could choose between the following options:

- *Palliative sedation*: this involves giving the child patient a sedative via an injection or IV drip to put them to sleep. This is the most common practice.
- *Discontinuing further treatment*: by putting a halt on a child's treatment, such as medication, this implies that the child would eventually die a 'natural' death as a result of their illness.
- *Abstinence from (artificial) nutrition and hydration*: this includes letting the child starve and dehydrate to initiate the dying process (NOS.nl, 2023; NOS.nl, 2019b).

Decisions surrounding these three medical interventions, such as starting palliative sedation or stopping life-prolonging treatments, are considered routine medical practices and therefore do not require strict regulations like those for euthanasia (Brouwer, Maeckelberge & Verhagen, 2024). Although these interventions can hasten death, the dying process for a child can still take days or even weeks, meaning that their life could be prolonged unnecessarily, causing them to suffer inhumanely (NOS.nl, 2019b; Kruse, 2019; Kloosterman, 2023). Witnessing this, according to parents '*undignified way of dying*', was something that was experienced by parents as very distressing (NOS.nl, 2019a; NOS.nl, 2019b; Brouwer, 2021; Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, 2022). Some parents stated that they deemed this further suffering as unnecessary, as modern medicine has the technical means to relieve the child's suffering through active life termination (NOS.nl, 2023; NOS.nl, 2019b). Parents and doctors wished for an option to accelerate or shorten this process (Kruse, 2019). Because if the parents and doctors of the terminally ill child have already agreed that it is acceptable to let the child die, why not opt for active life termination to prevent further suffering? Both doctors and parents thus felt that sometimes the lives of these children were unnecessarily prolonged (NOS.nl, 2023; NOS.nl, 2019b).

For instance, the Dutch paediatrician Prof. Dr. Eduard Verhagen, head of the Department of Paediatrics at the University Medical Center Groningen (UMCG) who has been advocating for the active life termination regulation for years, said on the Dutch news platform called '*Nieuwsuur*' that he believes that young children, who fall into the age group of 1 to 12 years, also have the right to a dignified end of their life (NOS.nl, 2023). Prof. Verhagen further elaborated that active life termination is mostly advisable in cases where it concerns children with congenital abnormalities such as brain, lung, or heart defects, or metabolic disorders (Kema, 2019; NOS.nl, 2023; Kloosterman, 2023). He continued by explaining that these conditions eventually lead to complex situations involving epilepsy and respiratory problems. Prof. Verhagen finally claimed that doctors cannot cure these children and

that they cannot prevent their death (Kema, 2019). But he clearly underscores that active life termination should always happen after thorough consultation with the involved parents or caregivers, and after experts have expressed their opinions (Nu.nl, 2023).

As outlined in section 2.1, on February 1st 2024, a Dutch regulation came into effect that allows doctors to actively terminate the life of terminally ill and suffering children aged 1 to 12 only under certain criteria (NOS.nl, 2023; Nu.nl, 2023; Brouwer, Maeckelberge & Verhagen, 2024; Kloosterman, 2024). Regarding how many children this regulation would apply to, former Minister of Health, Welfare and Sport of The Netherlands Prof. Dr. Ernst Kuipers estimated that per year this active life termination would concern around 5 to 10 young terminally ill children between the ages of 1 to 12, who suffer without any prospect of improvement, and for whom palliative care is deemed insufficient to relieve them from their suffering (Nu.nl, 2023; Nederlandse Vereniging voor Kindergeneeskunde, 2020; NOS.nl, 2019b; Kruse, 2019). The above-mentioned Dutch regulation will thus concern children with such severe illnesses or conditions that death is inevitable, and who are expected to die within a foreseeable timeframe (NOS.nl, 2023; Nederlandse Vereniging voor Kindergeneeskunde, 2020).

To be more precise, the Dutch regulation regarding active life termination in children aged 1 to 12 states the following: *‘It goes without saying that, to the extent possible and appropriate for their understanding and age, the child will be asked for their opinion and that this opinion will be taken into account in the decision-making process’* (Overheid.nl, 2024). This also aligns with *The Convention on the Rights of the Child*, which requires that a child, regardless of age, is optimally involved in the decision-making process that directly affects them (Héman, 2022). It could be argued that, in practice, actively involving children between the ages of 1 to 12 in the decision-making process about their active life termination applies to the oldest children in this age group, who are most likely better able to deliberate and participate in discussions about their active life termination, compared to the youngest children. Nevertheless, they are still young children.

3. Theoretical Framework

With the knowledge of both the legal and historical context of end-of-life care, two main questions necessarily arise. For instance, from a moral point of view, would it be in the best interest of a young child to be involved in the decision-making process about their active life termination? Or should children be excluded from participating in this decision-making process altogether?

To answer both these questions, I will examine whether young children should be involved in the decision-making process about their active life termination through the ethical lens of the '*Four Principles Approach*' to biomedical ethics.

This 'Four Principles Approach', established by American philosophers Tom Beauchamp and James Childress, will guide my ethical analysis on whether children should be involved in the decision-making process about their active life termination. I will elaborate on what their biomedical principles entail in section 3.1 below.

3.1 Four Principle Approach

Beauchamp and Childress have gained significant popularity in medical research, as they laid the groundwork for which ethical principles are important to consider in medicine. In answer to the Hippocratic medical tradition, which neglected many problems of for instance truthfulness, privacy, justice, communal responsibility, and the vulnerability of research subjects, Beauchamp and Childress initiated the debate on moral principles, practices and virtues within the medical practice (Beauchamp, 2007).

The principles for biomedical ethics that Beauchamp and Childress came up with are *respect for autonomy, beneficence, non-maleficence* and *justice*. While the principle of respect for autonomy requires respect for the decision-making capacities of autonomous persons, thus respecting and supporting their autonomous decisions, the principle of beneficence encompasses a group of principles that include preventing, lessening, or relieving harm, providing benefits and balancing benefits against risks and costs. Additionally, non-maleficence is a principle that requires not causing harm to others and the principle of justice incorporates a group of norms that require a fair distribution of benefits, risks and costs. Finally, the principle of justice, this principle includes that people in a (civilised) society, that constitutes of a cooperative venture structured by moral, legal and cultural principles of justice that define the terms of cooperation, are treated justly if treated according to what is fair, due or owed. According to (distributive) justice, several resources, such as economic goods, political rights and burdens, should be distributed appropriately throughout society (Beauchamp, 2007; Beauchamp & Childress, 2001).

This approach of Beauchamp and Childress, also called *principlism*, suggested shifting from a healthcare ethics model, focused solely on the principle of beneficence, or doing good, to a model that also recognizes patient autonomy (Beauchamp, 2007; Beauchamp & Childress, 2001). Additionally,

these American philosophers highlighted the importance of addressing broader societal concerns, particularly social justice. According to Beauchamp and Childress, the objective of the social institution of morality is to promote human flourishing by counteracting conditions that cause the quality of people's lives to worsen, such as problems of indifference, conflict, suffering, hostility, scarce resources, limited information, and the like. Besides, they state that the four principles are part of a framework of foundational norms for common morality with which to get started in biomedical ethics and that serve in moral reasoning, guiding many other moral claims and judgements. These authors argue under the assumption that their framework of four principles should incorporate and articulate the most general values of the common morality (Beauchamp, 2007).

Beauchamp and Childress further address that their principlism does not just include a mere list and analysis of four abstract principles, but that it is rather a theory about how principles link to and guide practice (Beauchamp & Childress, 2001). In his chapter, called '*The Four Principles Approach to Healthcare Ethics*', Beauchamp (2007) elaborates on the fact that these principles need to be specified to meet the needs and challenges of particular contexts. This specificity allows the principles to overcome their lack of content, address moral conflicts, and provide practical guidance. For instance, without further specification, '*do no harm*' is too abstract to help navigate complex issues such as whether doctors may justifiably hasten the death of the terminally ill. Applied to the case of involving a terminally ill young child in the decision-making process about their active life termination, '*do not harm*' could for example be specified as '*terminally ill young children should not be involved in the decision-making process about their active life termination if there is doubt about whether they can adequately participate in deliberations or if there is reason to believe that it will cause fear or stress in the child*'. This example illustrates the need for a specific application of a general principle to a particular context. Moreover, Beauchamp and Childress' principles are considered *prima facie* valid, which means that one cannot overrule the other. This means that when different principles conflict with each other in a specific context, a balance between these principles must be found. According to the authors, this involves specifying or balancing the principles in such a way that the dilemma is resolved (Beauchamp & Childress, 2001). By specifying the above-mentioned principles, this thesis aims to develop a normative framework around the inclusion of young children in the decision-making process about their active life termination.

Since my hypothesis suggests that the principle of justice may not be relevant to the topic of involving young children in decisions about their active life termination, I will not further discuss this principle in the upcoming sections of my thesis. This is because these situations require individual, case-specific analyses rather than a broad consideration of societal fairness (Cuman, 2017). It could even be argued that young children cannot be considered citizens who actively participate in society, as they mostly participate in what society, such as their parents or caregivers, expects of them, such as attending school or playing sports. Also, the Dutch legal system is mostly structured under the premise that children under the age of 12 do not have the capacity to make decisions for themselves. Therefore,

although it is important to note that the principle of justice is a crucial aspect of biomedical ethics, my assumption is that it is not directly relevant to the particular issue that is being examined in this thesis. Thus, considerations of justice will not be included in my analysis.

In the following sections, I will elaborate on the three remaining principles of Beauchamp and Childress, namely the principle of respect for autonomy, the principle of beneficence and the principle of non-maleficence. Moreover, I will discuss their significance for the involvement of young children in the decision-making process about their active life termination. In particular, I will explore how each of these principles can be applied and specified to address the challenges and moral dilemmas that arise regarding the question whether young children should be involved in the decision-making process about their active life termination.

4. Respect for Autonomy: Should Young Children Be Involved?

In this section, the principle of respect for autonomy is explained, specified, and applied to the case of whether young children should be involved in the decision-making process about their active life termination.

4.1 The Principle of Respect for Autonomy

In his (earlier mentioned) chapter called '*The Four Principles Approach*' to Health Care Ethics', Beauchamp (2007) explains that the principle of respect for autonomy is rooted in the liberal moral and political tradition, which values individual freedom and choice. He highlights that, in moral philosophy, personal autonomy refers to self-governance while remaining free from controlling interference by others and from personal limitations that prevent choice. Conversely, a person who has diminished autonomy is a person who is controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans. Beauchamp argues that, in order to respect people's autonomy, it is essential to their capacities and perspectives, including their right to hold certain views, make certain choices, and take certain actions based on their personal values and beliefs. Moreover, he explains that '*respect (...) involves acknowledging the value and decision-making rights of persons and enabling them to act autonomously, whereas disrespect for autonomy involves attitudes and actions that ignore, insult, demean or are inattentive to others' rights of autonomy*' (Beauchamp, 2007, 4). Examples of disrespecting someone's autonomy range from manipulative under-disclosure of relevant information to disregarding a refusal of medical interventions (Beauchamp, 2007; Childress, 1990).

Furthermore, the principle of respect for autonomy of Beauchamp and Childress imposes both negative and positive moral obligations. While the negative obligation entails that autonomous actions should not be subjected to controlling constraints by others, the positive obligation requires a respectful treatment in disclosing information and actions that foster autonomous decision making (Beauchamp, 2007). Regarding the principle of respect for autonomy, Beauchamp (2007) presses the healthcare workers' obligations to disclose information, ensure understanding and voluntariness, and foster adequate decision making. However, what is the role of the respect for autonomy principle in end-of-life decisions, particularly in active life termination? The answer to this question will be explored in the following sections.

4.2 Exploring the Principle for the Thesis Case

Respecting autonomy thus means acknowledging the right of individuals to make decisions about their lives, based on their own values, beliefs, and preferences. With regard to adults in a healthcare context, the principle of respect for autonomy emphasises the importance of being able to make an autonomous choice. Respecting this choice includes that a medical treatment should only be initiated if that person is well-informed and can make a voluntary decision to give consent for or against it (Childress, 1990).

However, in cases regarding end-of-life decisions for adults, how can the principle of respect for autonomy be applied? The answer to this question will be discussed here below.

4.2.1 The Meaning of the Principle in General End-of-Life Decisions

As mentioned in section 2.1, the Dutch legal framework places a strong emphasis on an autonomous choice when it comes to the acceptability of euthanasia. According to Beauchamp and Childress, an autonomous choice should consist of three elements, namely that a subject acts intentionally, with understanding, and voluntary, thus without controlling influences that determine their action (Beauchamp and Childress, 2001, p. 59). They thus argue that respect for autonomy requires that individuals have the right to make their own decisions about their medical care, and this includes the right to be fully informed about the risks, benefits, and alternatives of any proposed intervention.

Yet, in the case of euthanasia, it is not merely about the patient consenting to a treatment proposed by the doctor. Rather, as explained in section 2.1, it involves an explicit request from the patient for a medical intervention that is far from an ordinary medical treatment. This means that the requirements for euthanasia go a step further compared to regular medical treatment. Furthermore, it indicates who has to initiate the conversation, as the explicit request should be made by the patient. In sum, with regard to the principle of respect for autonomy within the general healthcare context, informed consent is an important practical application of respect for autonomy, but in specific situations regarding euthanasia, the capacity of the patient to make an autonomous decision, together with an explicit request from the patient, form the practical application of the principle. Nevertheless, this specification of the principle of respect for autonomy focuses solely on medical practices involving adults. This leaves room for the question to what degree these elements could be applied to cases involving children. This question will be addressed in the following section.

4.2.2 The Meaning of the Principle for Young Children

With regard to young children, the question could be raised if the principle of respect for autonomy is applicable to them at all. As children's cognitive and emotional development varies significantly between the ages of 1 to 12, receiving an informed consent or an explicit request from a young child could be seen as a complex issue with regard to medical treatments. Legally, there are often age-based restrictions designed to protect minors, reflecting societal concerns about their decision-making capacity (Cuman, 2017). Furthermore, regarding (very) young children, it could be argued that they have not yet reached a decent level of competence and autonomy, making application of the principle potentially irrelevant for them (Childress, 1990). For older children, particularly those approaching 12 years of age, involving them in discussions about their medical treatment and considering their wishes could be a way to respect their emerging autonomy. Therefore, involving these 'older' children in the decision-making process about their medical treatment, to the extent that they are able, could be the appropriate and potentially necessary thing to do (Héman, 2022; Koninklijke Nederlandsche

Maatschappij tot bevordering der Geneeskunst, 2022). The specification of the principle of respect for autonomy could thus include that if young children show that they possess the capacity to make an autonomous choice, they should be included in the decision-making process about their medical treatment. However, could this specification of the principle of respect for autonomy for young children regarding their medical treatment also be applied to the involvement of young children in the decision-making process about their active life termination?

4.2.3 The Meaning of the Principle for End-of-Life Decisions in Young Children

When the principle of respect for autonomy is applied to the case of involving these children in the decision-making process about their active life termination, the following ethical considerations come to the surface. As outlined in section 4.2.2, one of the considerations is the complexity of to what extent a (wise) young child has the competence to make an autonomous choice. Additionally, it could be argued that it will always remain partially unclear to what extent a young child understands their (medical) situation. Besides the fact that young children are essentially still developing their understanding of the world and their ability to communicate, how can a child, who has seen so little of life, make an autonomous choice about their life? It is questionable whether the answers lie within the concept of autonomy. While respect for autonomy is a key consideration for euthanasia in adults, for young children between the ages of 1 to 12 it is complicated by the developmental stage and maturity of the child.

The question thus remains, should young children be involved in the decision-making process about their active life termination? For what reasons would it be a good thing, or even justified, to involve them? When thinking about the specification of the principle of respect for autonomy, it could be formulated along the lines of: if a child is capable of making an autonomous choice, involving them in the decision-making process about their active life termination does not just seem to be a matter of desirability, but perhaps even a moral obligation. Nevertheless, there may be principles that conflict with this specification, for instance, the principle of non-maleficence, which I will elaborate on in section 5.2.

4.3 Provisional Conclusion

When looking at the principle of respect for autonomy applied to the topic of whether young children should be involved in the decision-making process about their active life termination, it seems that under certain conditions, it could potentially be necessary to involve the child. These conditions include that the young child is able to gain a clear understanding of his or her situation and is capable of making an autonomous decision. However, there are uncertainties whether these conditions can be met when it comes to young children. Because, although it could seem like a child understands a lot, when can doctors and parents or caregivers know if they actually do? Even a wise child may not possess the

emotional and cognitive maturity required to weigh the complexities of active life termination. It could be argued that leaving children in the dark about their active life termination, especially when they can communicate very well, is not desirable. While younger children may lack the ability to fully understand the concept of death and the permanence it entails, older children might have a better grasp of their situation and the implications. Yet, their understanding and decision-making capacity are still developing. Thus, determining whether a child possesses sufficient cognitive and emotional maturity to understand the implications of active life termination is, and perhaps will always remain, a complex matter.

In sum, although it can be argued that involving young children can be deemed necessary, under certain conditions, often there will remain a certain level of uncertainty about whether the child possessed the relevant skills to be involved in such a decision-making process. Furthermore, involving the child could potentially not be in the best interest of the child, or potentially cause harm to the child.

These objections to involving young children in the decision-making process about their active life termination, with regard to the principles of beneficence and non-maleficence, will be discussed in the following section.

5. Beneficence & Non-Maleficence: Is it Harmful to Involve a Young Child?

In this section, the principles of beneficence and non-maleficence are explained, specified and applied to the case of whether young children should be involved in the decision-making process about their active life termination.

5.1 The Principle of Beneficence

The term beneficence means acts of mercy, kindness, charity, love and humanity and it includes all forms of action intended to benefit other persons (Beauchamp, 2007). A doctor who acts in the best interest of patients typically aims to create a positive balance of benefits over any potential harms. Beauchamp (2007) describes the principle of beneficence as referring to a positive moral obligation to act for the benefit of others. In the medical context, beneficence can be understood as actively taking into account the welfare of patients, whilst assisting those in need of treatment or in danger of injury and preventing, removing or minimising harms like pain, suffering and disability that come with injury or disease (Beauchamp, 2007).

In section 4.2.3, I have outlined several arguments about whether young children should be involved in the decision-making process about their active life termination, from an autonomy point of view. According to the principle of respect for autonomy, if a young child demonstrates the capacity to make an autonomous decision, they should be involved in the decision-making. However, this raises two questions. Namely, even if a young child is competent to make an autonomous decision, should this child actually be involved? Furthermore, is it justified, from a beneficence point of view, to involve a young child in this kind of decision-making process? The reason for including the principle of beneficence in my analysis, is because I deem it relevant to discuss whether involving young children in the decision-making process about their active life termination is beneficial for their well-being.

As decisions surrounding active life termination come with a lot of responsibility, this raises the question whether respecting a child's autonomy would also ensure their well-being. Despite the fact that a young child could demonstrate a certain level of autonomy, a child is still a child. This fact suggests that perhaps children should be allowed to maintain their innocence. This notion might be particularly relevant in cases involving seriously ill young children. It could also be argued that a young child should remain just that, a young child, who ideally should not have to worry about serious and difficult decisions. Perhaps these 'young child' considerations even play a role when the young child is terminally ill.

Following this line of reasoning, it could be argued that such a decision is better off being made by doctors and parents, in order to avoid causing (more) distress or anxiety. By essentially protecting these terminally ill young children from making heavy decisions, their emotional well-being could be preserved as much as possible, which is something that could be deemed important, given their situation

of being terminally ill and suffering. This perspective suggests that protecting a child's well-being is a priority, even in the face of terminal illness and active life termination.

Nevertheless, involving young children in the decision-making process about their active life termination could potentially also be beneficial for these children. For instance, by allowing a young child to participate in discussions about their condition and potential end-of-life decisions, this could provide a sense of control and understanding in the child. Involving the young child could empower them because it recognizes their ability to contribute to decisions about their own life, contributing to their well-being, even in the face of terminal illness. This form of acknowledgment of the child could provide a sense of dignity and self-worth at a very difficult time. Children, especially those experiencing severe and prolonged suffering, could potentially have a very clear sense of when their quality of life has deteriorated to an unbearable level. Involving the child in decision-making could ensure that their specific wishes and experiences are considered, potentially giving them relief and comfort. Additionally, the involvement of a young child in the decision-making process could potentially foster better communication and understanding within the family, reducing conflicts and misunderstandings. Moreover, this involvement could reduce anxiety and fear, as the young child is not left in the dark about their situation. Therefore, for some young children, given how they are, it could be a good thing for them to be involved, as it can give a sense of comfort and control.

Furthermore, there could be tensions between what is perceived as beneficial for the child and the child's own expressed wishes. Especially as children grow older, it could be considered important to involve them in decision-making processes about their active life termination. This could ensure that medical decisions contribute to a child's overall well-being, taking into account their physical, emotional, and psychological health.

Ultimately, it seems that the direction taken in involving the child should be guided by what is in the child's best interest. The principle of beneficence thus emphasises the duty to act in the best interest of the patient. However, beneficence could include that it would be better for a young child to be involved in the decision-making process about their active life termination *or* that it is better for the child not to be involved in this decision-making process. Determining what constitutes the 'best interest' can be complex, especially when dealing with young children who may have limited understanding or capacity to express their wishes in the first place. The question remains whether it is in the best interest of the young child to be involved in the decision-making process about their active life termination. Perhaps a young terminally ill child should not be burdened with all the weight that comes with the decision-making process about their active life termination. This argument is something that will be explored in the next section.

5.2 The Principle of Non-Maleficence

As one of the most quoted maxims in the history of codes of health care ethics states *primum non nocere*, or 'above all, do no harm', the principle of non-maleficence means 'do no harm' (Beauchamp,

2007, 4). In the medical context, this principle requires avoiding actions that cause unnecessary harm or suffering to a patient. Examples of failures of doctors to act non-maleficently involve abuses of persons or subtle and unresolved questions, which can be classified as fundamentally morally wrong as these actions intentionally or negligently cause harm to a patient (Beauchamp, 2007).

With regard to the topic of whether young children should be involved in the decision-making process about their active life termination, in the context of non-maleficence, the first question that comes up is whether active life termination itself constitutes harm. However, in this thesis, I argue under the assumption that in some cases, active life termination in young children is ethically and legally justifiable. Nevertheless, it could be argued that the way the process of euthanasia or active life termination is regulated can have a significant impact on the well-being of the patient. Considerations of potential psychological and emotional harms are crucial, particularly regarding whether and how decisions would be communicated and implemented.

When considering the principle of non-maleficence in the context of whether young children should be involved in the decision-making process about their active life termination, it can be argued that they should not be involved due to the significant mental burden this involvement could place on them. According to this principle, it is essential to avoid causing harm, which means that the specification of this principle could include that terminally ill young children should not be burdened with the responsibility of being involved in the decision-making process about their active life termination.

The reason for this could be the developmental capacity of young children. Young children, for instance around 4 years, lack the cognitive and emotional maturity to fully understand the concepts of life and death, let alone make decisions about them. However, even 'older' children, closer to 12 years, may struggle with the gravity of such decisions. The burden of these decisions could interfere with their ability to comprehend and meaningfully participate in discussions about their own end-of-life choices. Evaluating the potential harms of involving young children in the decision-making process about their active life termination includes considering the emotional and psychological impact on the child. If there is a chance that this impact will affect the terminally ill young child in a negative way, it might be better to avoid burdening them with such responsibilities.

Therefore, involving very young children in such a serious decision-making process raises ethical questions about their ability to understand and weigh such decisions, and the impact that involvement in the decision-making process about a young child's active life termination would have on their well-being.

5.3 Involving the Child

When the above-mentioned principles of beneficence and non-maleficence are applied to the case of involving terminally ill young children in the decision-making process about their active life termination, the focus is mainly on doing what is in the best interest of the child and avoiding harm.

Active life termination decisions must carefully weigh the potential benefits against the risks and harms, which includes considering the psychological and emotional impact on the young child.

In line with the beneficence and non-maleficence considerations, it could be argued that it is in the best interest of the child not to be involved in the decision-making process about their active life termination. The reason for this is that it is uncertain whether they can participate meaningfully. Furthermore, as stated in section 5.2, it could be experienced by the terminally ill young children as a burdensome process, and therefore it could potentially be harmful for the child to be involved. However, it became clear in section 5.1 that the beneficence principle could be interpreted in two ways, as being involved in the decision-making process about their active life termination could also have a positive impact on the child's well-being. This creates an uncertainty about whether young children should or should not be involved in the decision-making process about their active life termination.

Thus, with regard to active life termination in young children, a moral uncertainty remains, which perhaps suggests that the perspective of the child is needed in order to justify active life termination. Parents or doctors could, in the uncertainty of their child's perspective, feel a strong desire to justify an active life termination decision about their child to themselves but also to others. Nevertheless, it could be argued that they should not be burdening the child with heavy decisions that are primarily their own concern. Yet, the need for justification remains, and perhaps the child is the one that could provide the ultimate answer as to whether active life termination should be executed.

Also, it could be argued that active life termination is too difficult of a decision to make without the young child involved. In an ideal scenario, a doctor could talk to the child about it and the child would choose, but at the same time, this is not an ideal scenario, given that the doctor is dealing with a child. Although there are very wise children, a child is still a child, not an adult. This dilemma raises crucial questions about whether children are able to fully oversee life in general, or whether children understand the consequences of their actions. However, do adults always understand the consequences of their actions? The questions that are raised with regard to the new active life termination regulation show that there is a lot of (ethical) uncertainty involved in how to approach this regulation.

In the sections above I have analysed the involvement of young children in the decision-making process about their active life termination through the ethical lens of Beauchamp and Childress 'Four Principles Approach'. Moreover, I have outlined what the principles of respect for autonomy, the principle of beneficence and the principle of non-maleficence entail, which are principles that seem to be conflicting with each other in this context. This conflict creates a moral dilemma, about which I will elaborate further in the following section.

6. Addressing the Moral Dilemma

Common to all forms of practical ethics is reasoning through difficult cases, some of which constitute moral dilemmas, and conflicting biomedical principles can create difficult moral dilemmas (Beauchamp & Childress, 2001). The moral dilemma that I explore in this thesis is whether young children should be involved in the decision-making process about their active life termination. This dilemma arises from a conflict between the principles of respect for autonomy and the principles of beneficence and non-maleficence. For clarity purposes with regard to the moral dilemma, I will briefly (re-)address the specifications of these three biomedical principles and why they would or would not conflict with each other below. Afterwards, I will elaborate on further considerations and present a potential solution to the moral dilemma before concluding this thesis.

6.1 Respect for Autonomy

The specification of the principle of respect for autonomy suggests that involving a young child in the decision-making process about their active life termination is a necessary condition for active life termination, if the child is deemed capable of making an autonomous decision, which would be assessed by the doctor in collaboration with the parents or caregivers. This would ensure that the child's autonomy is respected and that any decision made aligns with their interests and values. For active life termination to be ethically justified in light of the principle of respect for autonomy, it would not be sufficient to merely consider the child's involvement desirable; it would be morally necessary. However, a child of around 10 years may have the cognitive capacity but not enough life experience. Nevertheless, if a child meets the requirements for making an autonomous decision, then they *must* be involved, according to this thesis' specification of the principle of respect for autonomy.

6.2 Beneficence and Non-Maleficence

According to one of the specifications of the principle of beneficence, involving children in the decision-making process about their active life termination could be beneficial for their psychological comfort, sense of empowerment, and overall well-being. However, the other specification of the principle of beneficence includes that the involvement of a young child in the decision-making process about their active life termination could have a negative impact on the well-being of this child. When the specification of the principle of beneficence states that the involvement of the young child in the decision-making process about their active life termination has a positive impact on the well-being of the child, it could be argued that this principle would not necessarily be in conflict with the principle of respect for autonomy. This is because both the principle of respect for autonomy and the principle of beneficence would then suggest to involve the young child in the decision-making process about their active life termination. However, if the specification of the principle of beneficence indicates that involving the young child would have a negative impact on their well-being, it could be argued that this

principle could be in conflict with the principle of respect for autonomy. In such a scenario, while the principle of respect for autonomy might advocate for involving the child in the decision-making process, the principle of beneficence would then suggest that the child should not be involved. This creates a moral dilemma where it is unclear what would be best for the child. This thus shows that how the principle of beneficence is specified matters for whether there would exist a conflict between the principle of beneficence and the principle of respect for autonomy.

Finally, regarding the principle of non-maleficence, it could be argued that this principle could be in conflict with the principle of respect for autonomy. As the specification of the principle of non-maleficence could state that the involvement of young children in the decision-making process about their active life termination may impose a mental burden on the child, and could therefore potentially cause harm to the child, this specification could suggest that it might be desirable or even morally necessary in some situations for children to not be involved in the decision-making process about their active life termination. However, although it could be argued that this specification of this principle would conflict with the specification of the principle of respect for autonomy, if the principle of respect for autonomy advocates for involving the child in the decision-making process, the principle of non-maleficence more so seems to play into the fact that the main subjects of this matter are young children, and therefore vulnerable. The emphasis of the non-maleficence argumentation is thus on whether it is ethically appropriate to involve a young child in this kind of decision-making process *at all*. Moreover, the non-maleficence considerations explicate that doctors and parents or caregivers need to be very certain that the child will not become confused, stressed, or anxious, or experience too much of a sense of responsibility, because if there exists any uncertainty about this (in addition to uncertainty about whether the child is truly capable of making an autonomous choice), then the young children may be better off not being involved.

6.3 Balancing Biomedical Principles

As stated in section 3.1, the principles of respect for autonomy, beneficence and non-maleficence are *prima facie* principles, meaning that one principle cannot overrule the other, and when they are in conflict, an appropriate balance between these principles must be found. According to Beauchamp and Childress (2001), this thus involves specifying or balancing these three principles in such a way that the dilemma is resolved. However, the problem in the case of involving young children in the decision-making process about their active life termination, is that an appropriate balance is difficult to find. A doctor cannot both include and exclude a child from this decision-making process. Once a child is involved, the child cannot become ‘uninvolved’ again. Furthermore, the principles, and how they are specified in this thesis, do not provide a lot of room to balance against each other in order to solve this moral dilemma, when these principles are in conflict. Perhaps this could suggest that, when such a conflict between these principles arises, the moral dilemma that derives from it, at this moment in time, would not be solvable. This raises further questions about what to do when a moral dilemma seems

unsolvable. However, due to the limited scope of this thesis, there is no space to explore this question in more detail. Therefore, I will return to the content of the moral dilemma for the final paragraphs below.

Returning to the initial argumentation, finding a proper balance between the biomedical principles—for instance, protecting the child's emotional well-being while respecting their autonomy—poses a significant challenge. Perhaps balancing these principles requires an approach that considers each child's unique circumstances and capacities, rather than relying solely on age as a determinant (Cuman, 2017). Nonetheless, this dilemma seems to force us to choose among conflicting principles. According to Beauchamp and Childress, a way to solve a moral dilemma includes thinking through the alternatives and deliberate, to potentially reach a conclusion (Beauchamp & Childress, 2001). They further argue that even the morally best action in the circumstances may still be regrettable and may leave a moral residue, also referred to as a moral trace. Choosing a way of dealing with this moral dilemma, whether it is prioritising the young child's emerging autonomy or protecting the young child from potential harm, could thus still leave a moral trace. Regret and residue over what is not done can arise even if the right action is clear and uncontested (Beauchamp & Childress, 2001). But Beauchamp and Childress (2001) also argue that the feeling of regret or a sting of conscience have to make place for the realisation that there exists a duty to bring closure to a situation. Therefore, in a situation where a restriction of a patient's autonomy is in order, the justification could rest on some competing moral principle, such as beneficence or non-maleficence or vice versa (Beauchamp, 2007).

Ultimately, it could be argued that, if and when young children are involved in the decision-making process about their active life termination, each case must be approached with utmost sensitivity, recognizing the limitations and potential changes in the child's understanding and wishes over time. Additionally, even if a child has the cognitive abilities to comprehend their medical situation, they might not have sufficient life experience to fully grasp the implications of their active life termination decision. This lack of experience can impact their ability to make choices that are truly informed, and truly their own.

Nevertheless, it could still be considered crucial to involve the principle of respect for autonomy in decisions regarding the active life termination of a young child. This is because, if a child is cognitively capable of understanding their situation, and able to make an autonomous choice, it could be argued that their views and preferences should be respected as part of the decision-making process about their active life termination. Assessing a child's ability to make an autonomous choice involves considering both their intellectual capabilities and their emotional resilience and the primary goal of involving the child is to gain insight into the child's perspective and understanding of their situation, their feelings, and their wishes regarding their own end-of-life care. This can help in making decisions that truly consider the child's perspective. Furthermore, engaging in this dialogue could help in ethically justifying any decisions made. It ensures that the child's voice is part of the decision-making process, maintaining their dignity, and aligning with the principle of respect for autonomy. This approach

emphasises the child's right to be heard and involved in the decision-making process that profoundly affects their life.

6.4 Further Considerations

Nevertheless, additional questions emerge, such as *'To what extent does the idea of respecting a young child's autonomy actually provide a solid foundation for involving the child in the decision-making process about their active life termination?'* and *'How would this balance against arguments regarding whether such involvement is in the child's best interest or whether it could potentially harm the child?'*

Furthermore, when thinking about the practicality of active life termination in children younger than 12, two scenarios could be the case.

In the first scenario, a child might indicate that they want relief from suffering, stating something along the lines of: *'I want to sleep forever'* (keeping in mind that every child could say this in a different manner). This could be the scenario, where a child thus seems to take the initiative, which may prompt a discussion about active life termination with them. However, while a child might express a desire to 'sleep forever', this expression needs careful interpretation, as it may reflect a desire to escape pain rather than a true understanding of death.

The second scenario could be a situation in which doctors and parents are already contemplating active life termination for the child, and they are wondering whether they should involve the child. There may be other possible scenarios that are not addressed in this thesis. However, intuitively, the second scenario seems to be the most common situation in cases involving young children who would be considered eligible for active life termination.

Moreover, it is important to reflect on what parents or caregivers and doctors would hope to achieve by involving a young child in the decision-making process about their active life termination and whether they would succeed. Ideally, they would be able to talk to a child about active life termination, and the child would also say that active life termination is a good idea. However, it could be considered doubtful whether parents or caregivers and doctors would get such an answer, and even if they do receive such an answer, whether they can trust that child's perspective to remain the same overtime. Especially considering their developmental stage, it could also be considered doubtful whether young children would provide a clear and consistent answer about their wishes. Children's understanding and perspectives can change significantly over time, and their current wishes may not be the same in the (near) future. Children's cognitive and emotional development means their views are likely to evolve, making it difficult to rely on a single conversation as a definitive guide for long-term decisions. Realistically, expecting a child to provide a consistent and long-term perspective on such a profound issue is challenging, thus, trusting that a child's perspective will remain the same overtime is also challenging.

6.5 Potential Solution

The moral dilemma that is addressed in this thesis centres around balancing respect for the child's emerging autonomy with the duty to protect their well-being. To address this moral dilemma and the conflicting *prima facie* principles that arise because of the introduction of regulations regarding active life termination for young children aged 1 to 12 in The Netherlands on February 1st 2024, I used Beauchamp and Childress' approach to reasoning with conflicting principles, attempting to specify those principles in a way, trying to 'solve' the moral dilemma. The specification that would lead to a potential solution to the moral dilemma could be presented as follows: *a young child should only be involved in the decision-making process about their active life termination if there is a high level of confidence (i.e., minimal uncertainty) about the child's ability to discuss active life termination, and if there is a high level of confidence (i.e., minimal uncertainty) that such a discussion will not be harmful (emotionally burdensome or frightening) to the child, in order to achieve the child's best interest.* This still leaves a range of possibilities regarding how best to talk about active life termination with a young child. However, due to the limited scope of my thesis, I only got to address this part to a limited extent.

Besides, there also remains a significant open space where the dilemma seems to persist. For example, consider a situation where doctors with parents or caregivers believe the child is capable of being involved in discussions about active life termination, but they are too uncertain whether actually discussing it will frighten the child. In such cases, according to this thesis' specification of the principle of non-maleficence, doctors and parents or caregivers should not explicitly talk to the child about active life termination—but how can "keeping them in the dark" then be justified? This could be a question that could be explored in further research.

7. Conclusion

To conclude, in order to give an appropriate answer to the research question of this thesis, '*Should young children be involved in the decision-making process about their active life termination?*', I analysed how the biomedical principles of respect for autonomy, beneficence, and non-maleficence, as articulated in Beauchamp and Childress' 'Four Principles Approach', could be specified in order to answer this question. The above-mentioned analysis aimed to address the challenges and moral dilemmas surrounding whether young children should be involved in the decision-making process about their active life termination.

While this thesis' specification of principle of respect for autonomy implies that a young child must be involved in the decision-making process regarding their active life termination, if the child seems capable of making an autonomous decision, this principle may conflict with duties arising from the principles of beneficence and non-maleficence, which focus on doing what is in the best interest of the child and protecting the child from harm. However, regarding the specification of the principle of beneficence, it is also conceivable that involving a young child in the decision-making process about their active life termination might actually contribute to their well-being. The conflicting specifications of these three biomedical principles create uncertainty about what would be best for a young child, resulting in a moral dilemma. The potential solution to this moral dilemma, and thus a potential answer to the research question of this thesis, could include that a young child should only be involved in the decision-making process about their active life termination if there is a high level of confidence (i.e., minimal uncertainty) about the child's ability to discuss their active life termination, and if there is a high level of confidence (i.e., minimal uncertainty) that such a discussion will not be harmful (emotionally burdensome or frightening) to the child, in order to achieve the child's best interest.

Opting to answer the research question of this thesis meant that I have left some questions partially unanswered—or perhaps not unanswered, as there may not be a clear solution to this dilemma. For instance, what if a young child seems capable of being involved in the decision-making process about their active life termination, but there still exists uncertainty about whether this involvement would frighten the child? Furthermore, as stated in section 1.4, there are argumentative areas that I have deliberately excluded, due to the limited scope of this thesis, such as what to do when a child cannot verbally communicate or how to explain to a young child that their life is potentially going to terminate in practice. Therefore, further investigations are necessary to provide suitable answers to these unsolved questions and moral dilemmas.

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* Since the titles of most documents are in Dutch, the English translation is provided in the brackets.

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