

UPPSALA UNIVERSITY

European Master's Degree in Human Rights and Democratisation
A.Y. 2015/2016

Euthanasia, one's final human right?

The case of euthanasia for children

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Abstract

This thesis deals with the case of euthanasia for children. In the context of my research, euthanasia refers to the situation in which a physician ends the life (euthanasia in the strict sense) or helps ending the life without undertaking the lethal action (physician-assisted suicide) of a person who is suffering in an unbearable way, whether physically or mentally due to an accident or disease, without prospect of improvement, at the latter's explicit request. First, this thesis uncovers possible signs indicating that the existence of a human right to euthanasia could be derived on the ground of other rights. Hereby, I focus on the human rights systems as established at the level of the United Nations and the Council of Europe. I argue that there are clear indications towards acceptance of a right to passive euthanasia. Also for active euthanasia, I detect some interesting grounds and developments. However, the latter still remains very controversial in the eyes of human rights courts and bodies. Therefore, it seems highly unlikely that a human right to active euthanasia and physician-assisted suicide will be established soon. Answering whether a universal human right to euthanasia would be desirable, I argue that the worldwide insufficient access to health care is an important obstacle. Furthermore, this thesis deals with the question how a possible human right to euthanasia would apply to minors. I argue that totally excluding minors from the scope of this law is a violation of the principle of non-discrimination. Nevertheless, as children are a vulnerable group, they should be granted additional protection when exercising their right to euthanasia. In this context, it seems essential to find the balance between protection and participation. Last, I conduct a comparative law analysis on the implementation of children's human rights regarding the legal systems on euthanasia for minors in the Netherlands and Belgium. Here, I argue that both countries have clearly positive and clearly negative points towards finding the balance between protection and participation on this issue.

Acknowledgment

First I would like to express my sincere gratitude towards Anna-Sara Lind for her great feedback as a supervisor and her over-all support as our E.MA Director in Uppsala. Tack så mycket!

Furthermore, I would like to thank my fellow E.MA students for their open minds, their interesting insights and, above all, their friendship. Besides the fact that I gained a lot of academic knowledge during this year, I have grown as a person, due to each and every one of them. A special thanks goes to 'Belgian girls' Alisa and Eva and 'Uppsala girls' Irina and Joana.

Last, I thank my parents for providing me with this opportunity and for always supporting me.

List of abbreviations

UDHR	Universal Declaration on Human Rights
UN	United Nations
CoE	Council of Europe
ICCPR	International Covenant on Civil and Political Rights
CRC	Convention on the Rights of the Child
ECHR	Convention for the Protection of Human Rights and Fundamental Freedoms
ECHR	European Convention on Human Rights
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
ICESCR	International Covenant on Economic, Social and Cultural Rights
CRPD	Convention on the Rights of Persons with Disabilities
ECtHR	European Court of Human Rights
HRC	UN Human Rights Committee
Convention on Human Rights and Biomedicine	Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine
ESC	European Social Charter

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Prologue

Kina, a 13-year-old Belgian girl, had suffered from bacterial meningitis whereby she fell into a coma.¹ When she woke up, she was totally paralysed and suffered from the so-called locked-in syndrome. Her mental functions were perfectly fine, but she was not able to convert stimuli anymore into breathing independently, talking, moving and so on. The only things she could still do were blinking her eyes and moving her mouth. Through these small movements, she and her parents developed a system to communicate to make herself understandable by using the alphabet to form words or sentences. One day, Kina formed the words ‘I want to die’.

¹ This is a translation of the story of Kina as told in the Belgian documentary ‘Ook kinderen sterven’ (‘Children die too’) of 12 January 2015 in which different cases of euthanasia for minors are discussed. This documentary is available (only in Dutch, without subtitles) on the following link: deredactie.be/cm/vrtnieuws/videozone/programmas/koppen/2.37172 (last consultation on 5 May 2016).

1. Introduction

1.1. Introducing the subject of the thesis

This master's thesis on euthanasia for minors deals with cases such as the one presented above. Worldwide, many people suffer mentally and physically as a consequence of a disease or accident. When this suffering becomes unbearable and there is no longer hope for improvement of the person's situation, some of these people express the wish to die in a peaceful and painless way with the help of a physician. In other words, they want to commit euthanasia.² Whether states should or should not decriminalise or legalise this practice raises ethical, medical and legal questions. Therefore, it seems extremely difficult to reach a universal consensus.

The subject becomes even more controversial when euthanasia is considered for minors. As a consequence, the debate on this issue is often not taking place. However, reality shows that some children unfortunately do find themselves in situations in which they suffer in an unbearable way without any hope of improvement.³ Therefore, the primary motivation for writing my thesis on euthanasia for minors is to break the silence and to initiate further discussion.

Euthanasia is strongly connected to the notion of human dignity. As this is the ultimate foundation and goal for human rights,⁴ it does not come as a surprise that the discussion on this subject is often conducted on the ground of fundamental rights and freedoms. However, these are invoked at both sides of the debate. Whereas opponents argue that

² This is only one conception of what the concept of euthanasia means. For a more detailed elaboration on euthanasia as interpreted in the context of this master's thesis, see chapter 2.

³ To give one example of many: every year, 1691 children are diagnosed with cancer in the UK of which an estimated 252 die. See www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers (last consultation on 5 June 2016).

⁴ We can see e.g. that many international and regional human rights texts and instruments refer to this concept, including amongst others: (1) the preambles of the ICCPR and the ICESCR. Furthermore, also Article 10 of the former and Article 13 of the latter refer to human dignity, (2) the preamble of the CAT Convention, (3) the preamble, Art. 23, Art. 28, Art. 37, Art. 39 and Art. 40 of the CRC, (4) the preamble, Art. 1, Art. 3, Art. 8, Art. 16, Art. 24 and Art. 25 of the CRPD, (5) the preamble of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine and (5) the preamble of the ECHR.

euthanasia is a violation of human rights, proponents state that committing euthanasia is or should constitute a human right. This thesis will elaborate on both points.

The case of euthanasia for minors serves as an indicator for a tension regarding children that is often addressed as the ‘protection *v.* participation’-debate’.⁵ Children are considered particularly vulnerable to violations of their fundamental human rights as they have specific needs, are often highly dependent on adults and have not yet reached the level of adult maturity. Therefore, children enjoy special protection. On the other hand, children must also be considered autonomous subjects of rights with respect for their own views. Therefore, a question that arises is whether it would be possible to establish a human right to euthanasia for minors and how this should be organised to be in compliance with the fundamental rights of these children.

1.2. Research questions

This thesis aims to answer several questions with regard to euthanasia for minors from a human rights perspective.

The first and most fundamental question that should be addressed is about the possible existence of a human right to euthanasia. This question could be divided in several components, namely (1) ‘does a human right to euthanasia exist within the current human rights framework?’ (2) or, if not, ‘are there any signs for a future development of a human right to euthanasia?’ and (3) ‘should there be a human right to euthanasia?’.⁶

Second, this research aims to answer how a human right to euthanasia would apply to minors. In other words, how should this practice be organised to be in conformity with children’s human rights? The answer to this question does not only have the purpose to discuss the option of a fundamental human right for minors but could also form a basis of a framework for states that want to hold a debate on or decriminalise euthanasia for minors, regardless of whether it must be considered a human right or not.

⁵ Marshall, 1997, p. 1.

⁶ There is also a negative aspect to this research question that I will explain further in chapter 4.

1.3. Methodology

This master's thesis mainly focuses on the field of law. However, euthanasia is a complex and multi-layered subject that brings law and ethics together. Therefore, the thesis also touches upon the field of ethics regarding end-of-life decisions whenever this is relevant.

To start my research, I conduct an analysis of several human rights treaties and documents, as well as case law of the corresponding human rights courts and bodies. Hereby, I focus on the international human rights system as established at the level of the United Nations (hereafter: UN) and the regional human rights system as established at the level of the Council of Europe (hereafter: CoE). The choice for an analysis of the UN system is motivated by the purpose of this thesis, namely to formulate answers regarding a universal human right to euthanasia that transcends borders or particular regions. The focus on the European system stems from the fact that the European Court of Human Rights (hereafter: ECtHR) is the only human rights court until now that established case law on end-of-life-decisions, even though in a modest amount. Moreover, another reason for this focus is that I chose to conduct a comparative analysis between the Netherlands and Belgium on their implementation of the UN Convention on the Rights of the Child (hereafter: CRC) regarding euthanasia. These are two European countries that are both members of the United Nations and the Council of Europe.

Within these systems, I mainly examine the International Covenant on Civil and Political Rights (hereafter: ICCPR), the CRC and the Convention for the Protection of Human Rights and Fundamental Freedoms (hereafter: ECHR). The reason for this is that both these documents are the most extensive and discussed human rights treaties regarding the rights that are examined throughout this thesis. Sometimes however, I study other treaties if they add an important dimension to the issue. For this reason, I also involve the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (hereafter: CAT), the International Covenant on Economic, Social and Cultural Rights (hereafter: ICESCR), the Convention on the Rights of

Persons with Disabilities (hereafter: CRPD), the UN Declaration on Human Rights and Bioethics and the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (hereafter: Convention on Human Rights and Biomedicine) and the European Social Charter (hereafter: ESC).

As human rights law is part of the broader field of international law, the principles of interpretation of international treaties in Articles 31 to 33 of the Vienna Convention on the Law of Treaties apply.⁷ However, due to the characteristics of human rights treaties, some specific rules apply. Thereby, an important notion is the object and purpose of human rights treaties, which is the protection of the human person. Hence, three principles should be taken into consideration. First, the effectiveness rule applies, which means that human rights should be interpreted in such a way as to serve the purpose in an effective manner. Second, the evolutive interpretation should be taken into account. As human rights are dynamic, “effective protection of these rights involves taking into account developments in law and society.”⁸ It is e.g. often expressed by the ECtHR that the Convention is “a living instrument, which must be interpreted in the light of present day conditions.”⁹ Third, the interpretation should happen in an autonomous way. This entails that human rights should be interpreted according to their meaning in international law, not according to their meaning in national law.¹⁰ In chapter 6, I will discuss the way in which the rights enshrined in the CRC should be interpreted. However, I would already like to highlight that a specific way of interpreting each article was established, namely in the light of the four guiding principles of the Convention.

⁷ First, a treaty shall be interpreted in good faith. Furthermore, this will take place in accordance with the ordinary interpretation, the literal interpretation, the systematic interpretation and the teleological interpretation of the treaties. On the ground of Article 32 VCLT, one should not only look at the text of the treaty itself, but also “its preamble and annexes, any agreement or instrument in connection with the conclusion of the treaty and any subsequent agreement and practice regarding its interpretation”; Icelandic Human Rights Centre, ‘Interpretation of human rights treaties’, available at www.humanrights.is/en/human-rights-education-project/human-rights-concepts-ideas-and-fora/part-i-the-concept-of-human-rights/interpretation-of-human-rights-treaties (last consultation on 11 July 2016).

⁸ Ibidem.

⁹ ECtHR, *Tyrer v. the United Kingdom*, no. 5856/72, 25 April 1978, para. 31.

¹⁰ Icelandic Human Rights Centre, ‘Interpretation of human rights treaties’.

Finally, I conduct a comparative law analysis on the implementation of children's human rights regarding euthanasia for minors of two countries, namely the Netherlands and Belgium. This is a logical choice in the sense that these are the only two countries in the world that decriminalised active euthanasia for minors under precise circumstances and conditions. However, I am fully aware of the fact that these countries are 'pro euthanasia' minded. As my analysis focuses on the function of the law, namely finding the balance between protection and participation regarding euthanasia for minors, I use the functional method within comparative law.¹¹ However, due to space restrictions, I will mainly focus on the legal systems. Other aspects such as history, public opinion and practice will only shortly be addressed.

1.4. Delimitations

Article 1 of the CRC offers a universal understanding of who is meant by 'minor' or 'child', namely "every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier." However, this thesis solely focuses on minors who are able – which is not per se the same as being capable in the legal understanding of the word - to express a request to commit euthanasia. As the discussion with regard to euthanasia and human rights often revolves around the notion of autonomy, I wanted to highlight this fact by only taking the situation in consideration where the euthanasia request comes from the person who wishes to die. For this reason, I did not study e.g. the case of neonates with severe birth defects that make them suffer unbearably and cause them to live for a very short period of time or the case of patients who are living in a so-called vegetative state.

An element that is not discussed is the relation between euthanasia and the freedom of religion. The main motivation for this choice is that I do not want to present euthanasia as a story of religion against non-religion as this would simplify what is going on in reality. However, this relation could be subject of further research.

¹¹ Michaels, 2006, pp. 339-382.

Moreover, the scope of this thesis is further determined by other aspects that are included in or excluded from the concept of euthanasia in the context of this master's thesis, which will be further discussed in chapter 2.

1.5. Structure of the thesis

Due to various perceptions on the content of the term 'euthanasia', some ambiguities may arise when reading this thesis. Therefore, it starts with a chapter in which I elaborate on the interpretation of euthanasia in the context of this thesis and the arguments for including or excluding certain elements.

After this, the focus lies on the possible existence of a human right to euthanasia. As a point of departure for this analysis, I discuss the notion of human dignity regarding end-of-life decisions. This concept forms the ultimate foundation and goal for the existence of human rights. Hence, an examination of this concept is essential to be able to scrutinise the discussion on euthanasia and human rights. In the next chapter, different aspects of a human right to euthanasia are studied. More in particular, I aim to address the three aspects of the first research question, namely (1) 'does a human right to euthanasia exist within the current human rights framework?' (2) or, if not, 'are there any signs for a future development of a human right to euthanasia?' and (3) 'should there be a human right to euthanasia?'. This will take place through an examination of five human rights that are most frequently invoked with regard to euthanasia, namely (1) the right to life, (2) the right to privacy, (3) the prohibition of torture, inhuman and degrading treatment, (4) the non-discrimination principle and (5) the right to health.

In the next chapters, children play the central role as I address the question how this possible human right to euthanasia would apply to them. To start off, I focus on the evolutionary position of the child in international law and the difficulties we face today in balancing their rights against each other, the so-called protection *v.* participation debate.¹² In chapter 6, I examine whether euthanasia for minors is possible from a human rights perspective and if so, how this practice should be organised ideally. As an

¹² Marshall, 1997, p. 1.

ending point, I offer two case studies, namely the Netherlands and Belgium, in which I examine their conformity with children's human rights against each other.

Finally, an over-all conclusion is made in which both research questions are addressed.

2. A definition of euthanasia

2.1. Introduction

Many different views exist on the meaning of the term euthanasia.¹³ This is e.g. indicated by the fact that not many states provide a clear definition of the practice in their national legal systems.¹⁴ Some argue that this is striking in a domain “which is so ridden by controversy.”¹⁵ For this reason, the purpose of this chapter is to provide clarity for the reader by elaborating on how the concept of euthanasia is interpreted in the context of this thesis and why certain choices were made.

2.2. Further distinctions regarding euthanasia

Before formulating an interpretation, some frequent distinctions that are made in the matter of euthanasia will be discussed as well as their relevance for this thesis.

2.2.1. Active v. passive euthanasia

Traditionally, a further distinction is made between active and passive forms of euthanasia.¹⁶ In case of active euthanasia, a third person¹⁷ undertakes a lethal action to help someone die. Usually, this takes place by administering an injection with a lethal medicine.¹⁸ Passive euthanasia implies that “nothing” is done anymore. These are e.g. situations in which the third person stops treating the patient¹⁹ or turns off the artificial respiration of the patient.

¹³ Griffiths, Weyers and Adams, 2008, p. 2.

¹⁴ However, there are exceptions, such as e.g. Belgium. See Article 2 of the Belgian Act on Euthanasia of 28 May 2002.

¹⁵ Groenhuijsen, 2007, p. 4.

¹⁶ CoE, 2003, p. 18.

¹⁷ In the context of this master’s thesis, the third person is considered a physician.

¹⁸ Griffiths, Weyers and Adams, 2008, p.2.

¹⁹ Delbeke, 2012, p. 21.

Passive euthanasia is often more accepted because of the psychological reason that people find it harder “to inject a medicine than to stop a ventilator.”²⁰ Some academics have argued that in the case of active euthanasia, the intent of the physician is to kill the patient. In the case of removal of life sustaining treatment, the intent of the physician may only be to respect the patient’s wishes.²¹ However, I strongly agree with some who state that there is no difference between both forms from an ethical perspective.²² In both cases, the attempt has been to fulfil the request of the woman in a way as humane as possible. The intention is the same. The only difference is the used technique. Moreover, it is difficult to label passive euthanasia absolutely ‘passive’. One still has to undertake an action in order to help the person concerned die.²³

Because of the clearly outdated character of this division, no further distinction will be made between active and passive euthanasia in this thesis when it is not relevant.

2.2.2. *Voluntary v. involuntary euthanasia*

Another frequently made distinction is the one between voluntary and involuntary euthanasia. In case of voluntary euthanasia, the person who is killed has explicitly requested to be killed. In case of involuntary euthanasia, the person who is killed made no request and gave no consent.²⁴

In this thesis, I will only focus on voluntary euthanasia. This choice is motivated by the fact that the discussion regarding human rights and euthanasia often revolves around the principle of autonomy. Furthermore, the question of competence to make autonomous choices is one of the major discussions when talking about minors. As this thesis lays a strong emphasis on children, I highlight this issue.

²⁰ Distelmans in Cornelis, 2010, pp. 16-17.

²¹ See amongst others Gorsuch, 2006.

²² See amongst others Wim Distelmans, 2010 and Hopkins, 1997.

²³ Distelmans in Cornelis, 2010, pp. 16-17.

²⁴ www.euthanasia.com/definitions.html (last consultation on 24 June 2016).

2.2.3. *Euthanasia v. physician-assisted suicide*

When using the term euthanasia ‘in the strict sense’, it refers to the situation in which a physician undertakes a lethal action to make his patient die. Physician-assisted suicide however is the situation in which “suicide by a patient is facilitated by means or information (as a drug prescription or indication of the lethal dosage) provided by a physician aware of the patient's intent.”²⁵

I choose to include both of them in my interpretation of euthanasia as the purpose is in fact the same, namely relieving a patient of unbearable and continuous suffering by helping him or her to die (whether it is by taking the ‘last’ step or a step in between) when the latter explicitly requests this. Moreover, this choice is motivated by the fact that the European Court on Human Rights (which is the only Court that established case law on end-of-life-decisions) does not seem to make a difference between both forms from a human rights point of view.²⁶ However, case law on this issue is limited to this is a careful statement.

2.2.4. *Euthanasia as interpreted in this thesis*

As a consequence of the choices I made as described above, the term euthanasia refers to the situation in which a physician ends or helps to end the life of a patient who is suffering in an unbearable way without prospect of improvement, whether physically or mentally, at the latter’s explicit request. As can be derived from this interpretation, the patient does not necessarily have to be in a terminal state, which means that he does not per se have to die within a reasonable time.

Now that the meaning of euthanasia in the context of this master’s thesis has been clarified, the examination of a possible human right to euthanasia will be conducted in

²⁵ www.merriam-webster.com/medical/physician%E2%80%93assisted%20suicide (last consultation on 15 April 2016).

²⁶ Indications can be found in the cases of *Koch v. Germany* (ECtHR, no. 497/09, 19 July 2012) and *Pretty v. the United Kingdom* (ECtHR, no. 2346/02, 29 April 2002), according to BUIJSEN in M. Buijsen, 2015, p. 12.

the following chapters. For this analysis, the point of departure will be human dignity as explained in the next chapter.

3. The notion of human dignity as a point of departure

3.1. Introduction

As human dignity can be considered the foundation and goal of human rights law,²⁷ a possible human right to euthanasia should serve this notion. Therefore, chapter 3 briefly touches upon its meaning.²⁸

3.2. An under-defined notion

In the debate on euthanasia, human dignity is invoked as an argument by both proponents and opponents.²⁹ In relation to this, SMITH described: “Sometimes, it appears to be a sword; other times it is used as a shield.”³⁰ However, not much clarity exists on the meaning of this concept. Therefore, one of the major challenges is defining human dignity.

Also human rights documents do not offer an explicit definition. Nonetheless, they provide some guidance to make the notion more comprehensible. In this section, I focus on the language used in the Universal Declaration on Human Rights (hereafter: UDHR) as this Declaration clearly formed an important source of inspiration as many later human rights documents refer to the notion of human dignity in an identical way.³¹ First of all, it seems that human dignity is something basic to any human being.³² This aspect can be detected in the preamble of the UDHR, which proclaims that “dignity is inherent

²⁷ We can see e.g. that many international and regional human rights texts and instruments refer to this concept, including amongst others: (1) the preambles of the ICCPR and the ICESCR. Furthermore, also Article 10 of the former and Article 13 of the latter refer to human dignity, (2) the preamble of the CAT Convention, (3) the preamble, Art. 23, Art. 28, Art. 37, Art. 39 and Art. 40 of the CRC, (4) the preamble, Art. 1, Art. 3, Art. 8, Art. 16, Art. 24 and Art. 25 of the CRPD, (5) the preamble of the Convention on Human Rights and Biomedicine and (5) the preamble of the ECHR; Feldman, 1999, pp. 682-702.

²⁸ For a more detailed discussion on the meaning of human dignity, see Smith, 2012.

²⁹ Some find euthanasia contrary to human dignity as they argue that it violates the sanctity of life and endangers vulnerable groups. Others find it undignified to not be able to choose how and when they want to die or that they have to remain in suffer. These aspects will be further discussed in-depth in chapter 4.

³⁰ Smith, 2012, p. 128.

³¹ See e.g. the text and instruments referred to in footnote 28.

³² Spiegelberg, 1971, pp. 55-56, cited in Beyleveld and Brownsword, 2001, p. 50; R. Spaemann, 1996, p. 13.

[...] to all members of the human family.” The use of the word ‘inherent’ further indicates that this is a pre-existing value that cannot be legitimately taken away by authorities.³³ Furthermore, Article 1 UDHR states that “all human beings are free and equal in dignity and rights.” A consequence of this idea is that it applies to all people, “regardless of any disabilities, conditions, illnesses, etc., which might adversely impact them in others ways.”³⁴

Even though these elements indicate some characteristics of human dignity, the notion remains vague. Most of the time, the meaning of human dignity is therefore “left to intuitive understanding, conditioned in large measure by cultural factors.”³⁵ In this context, the CoE pointed out that “the end of life and the questions it raises in terms of dignity of the person is one of the current concerns of Council of Europe Member States, despite variations in cultural and societal approaches.”³⁶

3.3. The importance of a universal notion of human dignity for a possible human right to euthanasia

Human rights are considered to be universal minimum standards as they are grounded on the assumption that basic rights transcend cultural diversity: “all people have and should enjoy them, and [human rights are] independent in the sense that they exists and are available as standards of justification and criticism whether or not they are recognised and implemented by the legal system or officials of a country.”³⁷ As Andorno remarks justly: “In such a sensitive field as bioethics, where diverse sociocultural, philosophical, and religious traditions come into play, the importance of having principles of universal validity should not be underemphasised.”³⁸

³³ Schachter, 1983, p. 853; Sulmasy, 2008, p. 476.

³⁴ Citate from Smith, 2012, p. 132 who refers to Sulmasy, 2008, p. 473.

³⁵ Schachter, 1983, p. 849; Andorno, 2009, p. 229.

³⁶ CoE, 2014, p. 6.

³⁷ Nickel, 1987, p. 561.

³⁸ Andorno, 2009, p. 235

As mentioned in the beginning of this chapter, a human right to euthanasia should serve human dignity. Hence, if there would be a universal notion of human dignity in favour of euthanasia, this could form a ground for the existence of a human right to euthanasia.

In practice, this implies that people could invoke international human rights law to enforce their claim to commit euthanasia, even though the legal system of their own country prohibits this practice.

Now that the notion of human dignity as a point of departure has been examined, the analysis on a possible existence of a human right to euthanasia will be conducted further in the next chapter.

4. A human right to euthanasia?

4.1. Introduction

This chapter focuses on the possible existence of a universal human right to euthanasia. In the context of this thesis, a right to euthanasia should not be interpreted as an absolute right to die. Rather, it refers to a right to die with dignity in specific circumstances and under strict conditions. As described in chapter 2, throughout this master's thesis, 'euthanasia' refers to the situation in which a physician ends the life (euthanasia in the strict sense) or helps ending the life without undertaking the lethal action (physician assisted suicide) of a person who is suffering in an unbearable way, whether physically or mentally due to an accident or disease, without prospect of improvement, at the latter's explicit request.

Current human rights treaties and documents do not provide an explicit human right to euthanasia. Some argue however that this right could be derived on the ground of several existing human rights. Therefore, I conduct research on signs indicating that a human right to euthanasia could indeed be derived from other rights. Furthermore, I aim to detect developments towards a future human right to euthanasia. As an important aspect of a human right to euthanasia would be that it does not violate other human rights, also this negative relation between euthanasia and human rights will be examined.

As already mentioned, these aspects will be discussed through an analysis of human rights that are often invoked with regard to euthanasia, namely (1) the right to life), (2) the right to a private life, (3) the prohibition of torture, inhuman and degrading treatment, (4) the prohibition of non-discrimination and (5) the right to health. As will become clear from the analysis below, all rights are highly interconnected and interdependent when discussing euthanasia from a human rights point of view. I will come back to this towards the end of this chapter. However, it is interesting to study them separately because they all emphasise particular elements of the issue.

4.2. Euthanasia and the right to life

4.2.1. Introduction

The first human right that is included in this research is the right to life. Multiple times, human rights bodies have emphasised that this right should be considered the supreme right from which no derogation is permitted. The Human Rights Committee has stated that the right to life ought not to be given a narrow construction.³⁹ This is justified by the fact that the right to life “has profound importance both for individuals and for society as a whole.”⁴⁰ Furthermore, “[i]t is most precious for its own sake, but also serves as a basic right, facilitating the enjoyment of all other human rights.”⁴¹ The right to life has a ‘two-dimensional relationship’ with euthanasia in the sense that it is both invoked as an argument *pro* as well as an argument *contra*.

4.2.2. The right to life at the level of the UN and the CoE

Some argue that the right to life contains a right to die with dignity.⁴² In 1982 and 1984, the UN Human Rights Committee drafted General Comments No. 6⁴³ and No. 14⁴⁴ on the interpretation of Article 6 ICCPR. These documents do not clarify or specify whether the right to life as understood in the purpose of this Convention could contain a right to die with dignity.

However, a procedure has been started for the adoption of a new general comment on Article 6 ICCPR, which will replace the earlier ones.⁴⁵ During the general discussion on 14 July 2015, one of the issues addressed was the right to life in relation to end-of-life decisions. In the draft of the General Comment, it is clearly stated that ‘deprivation of

³⁹ UNHRC, *General Comment No. 6 on the Right to Life*, para. 5, available at www.refworld.org/docid/45388400a.html (last consultation on 23 April 2016). In further footnotes, this source will be referred to as ‘UNHRC, *General Comment No. 6 on the Right to Life*.’

⁴⁰ UNHRC, *Draft General Comment No. 36*, para.1.

⁴¹ UNHRC, *General Comment No. 14 on Nuclear Weapons and the Right to Life*.

⁴² General Comment No. 6 on the right to life, para. 1 and 5.

⁴³ UNHRC, *General Comment No. 6 on the Right to Life*.

⁴⁴ UNHRC, *General Comment No. 14: Article 6 (Right to Life) Nuclear Weapons and the Right to Life*.

⁴⁵ www.ohchr.org/EN/HRBodies/CCPR/Pages/GC36-Article6Righttolife.aspx (last consultation on 23 April 2016).

life’ “involves a deliberate⁴⁶ or otherwise foreseeable and preventable infliction of life-terminating harm or injury that goes beyond mere damage to health, body integrity or standard of living.”⁴⁷ As an example, the Committee explicitly refers to euthanasia. However, further in this document, it determines that “[S]tates Parties may also allow medical professionals to assess on a case-by-case basis whether or not to accommodate, on a highly exceptional basis⁴⁸ and as a method of last resort, explicit, unambiguous, free and informed requests for the termination of life-prolonging treatment made by mortally wounded or terminally ill adults, who experience intolerable pain and suffering and wish to die with dignity.⁴⁹ The assessment of such requests must be based on medical, psychological and ethical considerations, and any decision taken must be subject to robust legal and institutional safeguards in order to prevent pressure and abuse.”⁵⁰ Although this statement shows that euthanasia is not considered a violation of Article 6 ICCPR when it is committed under very precise conditions as described above, the UN Human Rights Committee does not recognise the fact that the right to life includes a right to die with dignity. This becomes clear by its carefully chosen language. Instead of choosing constructions such as ‘should allow’ or ‘must allow’, the Committee uses the words ‘may allow’. Another interesting point is that the Committee only refers to mortally wounded or terminally ill adults. Although this does not necessary entail that euthanasia for non-terminal people and children is a violation of the right to life, it shows the reluctance of the Committee to carefully consider these options as it did for terminal adults.

At the European level, the analysis starts with an examination of the case *Pretty v. the UK* of the ECtHR. Ms. Pretty suffered from a severe motor neurone disease affecting the muscles for which there is no cure. She wished to control how and when she died because she experienced the final stages of her disease as distressing and undignified. As she was almost totally paralysed, Ms. Pretty did not have the physical ability to

⁴⁶ UNHRC, Communication no. R.11/45, *Suarez de Guerrero v. Colombia*, 31 March 1982, para.13.2.

⁴⁷ UNHRC, *Draft General Comment No. 36 on the Right to Life*, para.5.

⁴⁸ UNHRC, *Concluding Observations: the Netherlands*, 2001, para.5.

⁴⁹ UN Committee on Economic, Social and Cultural Rights, *General Comment 14 on the Right to Health*, para. 25.

⁵⁰ UNHRC, *Concluding Observations: the Netherlands*, 2009, para.7.

commit suicide herself. Therefore, she wanted assisted suicide with the help of her husband. However, this practice was forbidden under UK law. Therefore, her husband would be prosecuted if he decided to help her die.⁵¹ Ms. Pretty submitted that the right to life, as enshrined in Article 2 ECHR, contains a right to die with dignity. She argued that the right to life is not more than a ‘right’ to life, not a duty to live. According to her, the sentence within the article concerning deprivation of life is designed to protect people from arbitrary killing by the State and other public authorities, not to protect people from themselves. Thus, the right to life acknowledges the fact that the individual has a right to choose whether or not to live any longer. As mentioned above, the main purpose of human rights in general is to safeguard human dignity. Therefore, she argued that this right should grant the individual a right to “avoid inevitable suffering and indignity as the corollary of the right to life.”⁵² In its defence, the UK Government submitted that Article 2 ECHR could indeed create positive obligations for the State.⁵³ However, the appropriate steps that a state should take to fulfil these obligations have the purpose of safeguarding life.⁵⁴

The ECtHR stated in its assessment that Article 2 ECHR sets out the limited circumstances when deprivation of life may be justified.⁵⁵ The Court found that states also have a positive obligation to safeguard the lives of individuals within their jurisdiction by taking all appropriate steps.⁵⁶ Therefore, public authorities have the duty “to take preventive operational measures to protect an individual whose life is at risk from the criminal acts of another individual.”⁵⁷ The Court was not persuaded by the argumentation of Ms. Pretty on a negative aspect of Article 2 ECHR, “as the consistent

⁵¹ ECtHR, Factsheet - End of life and the European Convention on Human Rights, 2015, p. 1.

⁵² Icelandic Human Rights Centre, Euthanasia and abortion; ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para.35.

⁵³ ECtHR, *Keenan v. the United Kingdom*, no. 27229/95, 3 April 2001; European Commission of Human Rights, *X v. Germany*, no. 10565/83, 9 May 1984.

⁵⁴ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 36.

⁵⁵ ECtHR, *McCann and Others v. the United Kingdom*, no. 18984/91, 27 September 1995, para. 149-150.

⁵⁶ Hereby, the Court referred to ECtHR, *L.C.B. v. the United Kingdom*, no. 23413/94, 9 June 1998, para. 36.

⁵⁷ The Court referred to ECtHR, *Osman v. the United Kingdom*, no. 23452/94, 28 October 1998, para. 115 and ECtHR, *Kiliç v. Turkey*, no. 22492/93, 28 March 2000, para. 62 and 76; ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 38.

emphasis in all the cases has been the obligation of the state to protect life.”⁵⁸ Moreover, the right to life in the Convention is not concerned with issues regarding the quality of living. Therefore, “Article 2 cannot, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.”⁵⁹

With regard to euthanasia as a possible violation of the right to life, Ms. Pretty submitted that permitting her to be assisted in committing suicide would not be in conflict with Article 2 ECHR. According to her, this could be deduced from the fact that those countries in which several forms of euthanasia was legal would be in breach of this provision. In other words: “a failure to acknowledge a right to die under the Convention would place those countries which do permit assisted suicide in breach of the Convention.”⁶⁰ The Court answered this claim by stating that “it is not for the Court in this case to attempt to assess whether or not the state of law in any other country fails to protect the right to life.”⁶¹ Furthermore, it finds that euthanasia “may raise conflicting considerations of personal freedom and the public interest that can only be resolved on examination of the concrete circumstances of the case.”⁶²

In the case of *Lambert and others v. France*,⁶³ the applicant’s son’s artificial hydration and nutrition had been withdrawn on the ground of a medical report drawn up by a panel of three doctors. Here, the Court found no violation of the positive obligations of the State under Article 2 ECHR. It reasoned that there was no consensus among the Member States of the CoE in favour of permitting the withdrawal of life-sustaining treatment. Therefore, States have a wide margin of appreciation on this matter. It examined the legal framework regarding this case and decided that this was clear and precise enough to regulate the doctor’s decision. Also, the decision-making-process had

⁵⁸ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 39.

⁵⁹ *Ibidem*, para. 39-40.

⁶⁰ *Ibidem*, para. 41.

⁶¹ *Ibidem*, para. 41.

⁶² *Ibidem*, para. 41.

⁶³ ECtHR, *Lambert and others v. France*, no. 46043/14, 5 June 2015.

been conducted “in meticulous fashion.”⁶⁴ It seems as if the Court was permissive towards a right to die as it held that there was no violation of Article 2 of the Convention. TRETYAKOV pointed out that “it seems appropriate to conclude that the ECHR has made a cautious, but a very important step in the direction of recognizing that the individual autonomy in end-of-life decision-making is to be protected, and if the state chooses to protect it and establishes appropriate safeguards around it, this does not constitute a violation of the Convention.”⁶⁵ I agree on the fact that this judgement may have an important influence on the position of the Court on end-of-life decisions in the present and the future. However, it should be mentioned that the Court strongly emphasised that this case was not about active euthanasia or assisted suicide, but about the withdrawal of life-sustaining treatment.⁶⁶ Therefore, I would argue that the impact may be limited to passive euthanasia.

4.2.3. *Developments at the national level regarding the right to life*

Quite recently, some significant cases were ruled on the national level in which several courts found that the right to life does contain a right to die with dignity, contrary to the current conception of international human rights bodies.

One of these is the *Carter Case*, ruled by the Supreme Court of Canada on 6 February 2015.⁶⁷ In this case, the Court found that the prohibition on physician-assisted suicide “infringes the right to life [...] in a manner that is not in accordance with the principles of fundamental justice.”⁶⁸ Even though it did not want to expand the scope of the right to life to issues concerning quality of life, the Court stated that the right to life does not create ‘a duty to live’. It recognised that the main purpose of this prohibition was to protect vulnerable groups “from being induced to commit suicide at a time of weakness.”⁶⁹ Therefore, the law that prohibited this practice did not have an arbitrary character. However, a total ban on physician-assisted suicide “catches people outside

⁶⁴ ECtHR, Factsheet - End of life and the European Convention on Human Rights, 2015, p. 3.

⁶⁵ Tretyakov, 2015.

⁶⁶ ECtHR, *Lambert and others v. France*, no. 46043/14, 5 June 2015 Lambert, para. 141;

⁶⁷ Supreme Court of Canada, *Carter v. Canada (Attorney General)*, No. 35591, 6 February 2015.

⁶⁸ *Ibidem*, para. 56.

⁶⁹ *Ibidem*, para. 90.

the class of protected persons.”⁷⁰ Hence, this limitation is not always connected to the objective. Consequently, the Court found that the law violates the principle against gross disproportionality and, thereby, the right to life as enshrined in s. 7 of the Canadian Constitution.⁷¹

Another recent judgement is the South-African case of *Stransham-Ford v. Minister of Justice and Correctional Services and Others*, ruled by the Pretoria High Court on 4 May 2015.⁷² The judge highlighted that the right to life is strongly connected to human dignity. Previously, the Constitutional Court had already argued that the right to life is not simply ‘a right to exist’, but also ‘a right to a life worth living’.⁷³ As the notion of human dignity is subjective in nature, it is irrelevant whether others believe that the natural consequences of (in this case) cancer permit a dignified death. Furthermore, the Court found that the right to life “cannot mean that an individual is obliged to live, no matter what the quality of his life is.”⁷⁴ For these reasons, the High Court found a violation of the right to life by prohibiting euthanasia.

These ‘events’ could be important for the future development of a human right to euthanasia on the international level or a constitutional right to euthanasia on the national level of other states. Influenced by the phenomenon of judicial globalisation, a “diverse and messy process [is taking place] of judicial interaction across, above and below borders, exchanging ideas and cooperating in cases involving national as much as international law.”⁷⁵ Judicial globalisation is taking place at the vertical level, between national and supranational courts. POLAKIEWICZ and JACOB-FOLTZER witness e.g. “the beginning of a true dialogue between the [European Court of Human Rights] and national jurisdictions.”⁷⁶ as well. However, also between national courts and especially between constitutional courts, there is transnational judicial cooperation and influence.

⁷⁰ Ibidem, p. 335.

⁷¹ Ibidem, p. 336.

⁷² Pretoria High Court, *Stransham-Ford v. Minister of Justice and Correctional Services and Others*, no. 27401/15, 4 May 2015.

⁷³ Constitutional Court of South-Africa, *S v. Makwanyane*, no. CCT 3/94, 6 June 1995.

⁷⁴ Pretoria High Court, *Stransham-Ford v. Minister of Justice and Correctional Services and Others*, no. 27401/15, 4 May 2015, para. 27.

⁷⁵ Slaughter, 2000, p. 1104.

⁷⁶ Polakiewicz and Jacob-Foltzer, 1991, pp. 65-66.

SLAUGHTER describes this beautifully as the ‘cross-fertilisation’ of national courts. A striking and relevant example of this process is the fact that the Pretoria High Court explicitly referred to the *Carter case* in its judgement on the *Stransham-Ford* case. It did not only refer to the case but closely examined the reasoning of the Canadian Supreme Court to reach its conclusion.⁷⁷ This could be seen as evidence of the fact that the highest national courts are influencing each other regarding the matter of euthanasia. SLAUGHTER described in this context: “Constitutional courts – or any courts concerned with constitutional issues – will be forging a deeply pluralist and contextualised understanding of human rights law as it spans countries, cultures and national and international institutions. The interactions between these courts and formal human rights tribunals established by treaty will indirectly involve national and international legislators on vital questions reflecting both the universality and diversity of humanity.”⁷⁸

4.3. Euthanasia and the right to privacy

4.3.1. Introduction

Death is one of the most intimate and humane events during a human’s life. Therefore, some individuals feel the need to have a choice about the manner of their dying and the timing of their death as a consequence of taking responsibility for their own lives. They want to be able to die in a dignified way, according to their own conceptions. In this context, Dworkin described: “Making someone die in a way that others approve, but he regards as a horrifying contradiction to his life is a devastating odious form of tyranny.”⁷⁹ According to the famous utilitarian philosopher John Stuart Mill this choice can only be limited against a human being’s will to prevent harm to others.⁸⁰ Hence, one

⁷⁷ Pretoria High Court, *Stransham-Ford v. Minister of Justice and Correctional Services and Others*, No. 27401/15, 4 May 2015, para. 18.

⁷⁸ Slaughter, p. 1124.

⁷⁹ Dworkin, 1993, p. 46.

⁸⁰ Mill in Warnock, Bentham and Mill, 1986, pp. 126 and 135.

of the main principles to occur in the euthanasia debate is the principle of autonomy, often enshrined in the right to respect for private life and the right to autonomy.⁸¹

4.3.2. *The right to privacy at the level of the UN and the CoE*

At the level of the UN, it is the ICCPR that mainly protects the right to privacy through its Article 17. This provision determines that “no one shall be subjected to arbitrary or unlawful interference with his privacy [...]” Therefore, two questions arise: (1) does committing euthanasia fall under the scope of ‘privacy’ and (2) if so, is the prohibition of euthanasia a form of arbitrary or unlawful interference with a person’s privacy? The UN Human Rights Committee drafted General Comment No. 16 on the interpretation of the right to privacy. However, this document does not offer any specifications or clarifications to be able to answer these questions.⁸² Also, the Committee did not establish any case law on end-of-life decisions yet. Before analysing both aspects further, we look whether the ECtHR offered some answers that may be useful.

At the European level, the same questions emerge on the ground of Article 8 ECHR. This provision states the following: “(1) Everyone has the right to respect for his private and family life, his home and his correspondence. (2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.” However, the difference with the UN level is that the case law of the ECtHR does offer some answers.

In the case of *Pretty v. the United Kingdom*, the applicant submitted a violation of Article 8 ECHR. She argued that this provision contained the right to self-determination, which encompasses the right to make decisions about one’s body and what happens to it. According to her, “this included the right to choose when and how

⁸¹ Amarasekara and Bagaric, 2002, p. 21.

⁸² UNHRC, *General Comment No. 16 on the right to privacy*, para. 1.

to die.”⁸³ As dying is one of the most intimate moments in human life, she stated that “there must be particularly serious reason for interfering [...]”⁸⁴ The Government had failed to show that this interference was justified (or, to put it in the language of the ICCPR, ‘arbitrary’). Furthermore, the applicant argued that the interference was not proportional because of the blanket ban imposed by the UK Government without taking her individual circumstances into consideration. The Government replied that Article 8 ECHR was not engaged “as the right to private life did not include a right to die.”⁸⁵ Therefore, it only covers the manner in which a person conducted its life, not its death. Even if Article 8 ECHR could be rightfully invoked, the interference would be justified on the ground of the wide margin of appreciation that the State has to decide on issues where no European consensus exists. During its assessment, the ECtHR first focused on the question whether euthanasia could fall under the scope of ‘private life’, as protected by Article 8 ECHR. It stated that “the concept of private life is a broad term not susceptible to exhaustive definition.”⁸⁶ Furthermore, “the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.”⁸⁷ The Court observed “that the ability to conduct one's life in a manner of one's own choosing may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned.”⁸⁸ Furthermore, it recognised that the right to privacy includes notions on the quality of life, contrary to the right to life as discussed above. Therefore, the Court was not prepared to exclude that the blanket ban on euthanasia did not interfere with Ms. Pretty’s right to respect for private life. The second part of the Court’s assessment focused on whether this interference was justified. Therefore, this limitation had to be in accordance with the law. As the prohibition of assisted suicide was prescribed by British law, this element was present. Furthermore, the limitation has to (2) pursue a legitimate aim and (3) be necessary in a democratic society, which also implies that the interference must be proportional to the aim pursued. The Court found that this interference indeed pursued a

⁸³ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para.59.

⁸⁴ *Ibidem*, para.59.

⁸⁵ *Ibidem*, para.59.

⁸⁶ *Ibidem*, para.61.

⁸⁷ *Ibidem*, para.61.

⁸⁸ *Ibidem*, para.62.

legitimate aim, namely safeguarding life and thereby protecting the rights of others. When deciding on the necessity of this prohibition in a necessary democracy, the Court applied its margin of appreciation doctrine. This system implies that it leaves the evaluation of the necessity within the respective society to the state itself. The broadness of the margin of appreciation will vary in accordance with the nature of the issues and the importance of the interests at stake. The Court decided, keeping in mind that there is no European consensus on the subject and that euthanasia is seen as inherently connected to ethics that can vary from state to state, the margin of appreciation has to remain broad. Last, the ECtHR found the interference proportional to the aim pursued, which is the protection of the rights of others (in particular vulnerable groups). Therefore, it did not find a violation of Article 8 ECHR.⁸⁹

Later cases on end-of-life-decisions before the ECtHR in which Article 8 ECHR was invoked show that no ground breaking evolutions took place regarding the right to privacy. However, an important development regarding the scope of Article 8 ECHR is that the ECtHR now fully acknowledges that end-of-life-decisions are an aspect of the right to life. Whereas the Court stated in *Pretty v. the UK* that it “was not prepared to exclude” that the prohibition of assisted suicide constituted an interference with the right to life, it found in *Haas v. Germany* that “an individual’s right to decide the way in which and at which point his or her life should end, provided that he or she was in a position to freely form his or her own judgment and to act accordingly, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention.”⁹⁰

Hereafter, I would like to highlight and discuss two aspects that frequently occur in judgements of the ECtHR on end-of-life decisions in relation to article 8 ECHR, namely the margin of appreciation doctrine and the argument of the slippery slope.

⁸⁹ Ibidem, para.59-78.

⁹⁰ ECtHR, *Haas v. Switzerland*, no. 31322/07, 20 January 2011.

4.3.3. *The margin of appreciation*

Although the ECtHR can be considered one of the most authoritative international courts,⁹¹ it has received significant amounts of criticism. Hereby, one of the Court's highly debated mechanisms is the margin of appreciation doctrine.⁹² As mentioned above, this doctrine is frequently invoked in cases where morals are involved.⁹³ According to SADURSKI, "the use of the margin of appreciation is likely to continue and even increase in the near future."⁹⁴ This is due to the rising number of Council of Europe Member States, which "has expanded from twenty-three states in the 1990s to forty-seven Member States in less than twenty-five years."⁹⁵ Therefore, the search for consensus on this level will become even more difficult.

One could distinguish two types of criticism regarding the margin of appreciation. The first category of criticism relates to the overuse of this mechanism, thereby threatening the rule of law and becoming "a judicial platitude, a misleading metaphor that can be unpacked to the point where it becomes redundant."⁹⁶ The second category focuses on its unpredictability.⁹⁷

Some state that the Court is facing an existential crisis⁹⁸ as its legitimacy is under serious attack, not only by Member States but also by media and civil society.⁹⁹ In my view, it is not impossible that the Court is put under pressure by this phenomenon. As a consequence, it takes on a rather prudent position regarding controversial issues, invoking the margin of appreciation even in cases where minimal standards of rights are violated.

⁹¹ Stone Sweet and Keller, in Stone Sweet, Keller eds., 2008, p. 3.

⁹² This doctrine was established in ECtHR, *Handyside v. the United Kingdom*, No. 54933/72, 7 December 1976; See amongst others Kratochvil, 2011; Letsas, 2006; Brauch, 2004-2005; Benvenisti, 1999.

⁹³ Zoethout, 2014, p. 310.

⁹⁴ Sadurski, 2012, pp. 2-3.

⁹⁵ *Ibidem*, pp. 2-3.

⁹⁶ Letsas, 2007.

⁹⁷ Kratochvil, 2011, pp. 324-357; Merrills, 1993.

⁹⁸ Dzehtsiarou and Greene, 2011.

⁹⁹ *Ibidem*, p. 1707.

A second criticism one is about the lack of a uniform or coherent application of the doctrine by the Court.¹⁰⁰ In this context, BREMS stated the following: “How is one to determine on which controversial ethical issues different societies may legitimately adopt different approaches? Societies and values change. [...] Somewhere in between, international human rights court must stop tolerating the latter position as an expression of legitimate ethical diversity among states and must bring recalcitrant states in line with a pro-human rights position.”¹⁰¹ An example of this latter position is the evolution through the case law of the Court regarding LGBT rights, where it was less and less willing to invoke the margin of appreciation doctrine as a justification for limitation of these rights.¹⁰² However, one has to take into account that this was the consequence from a greater European consensus on the subject, established during the last few years.

As the idea of consensus is central to the operation practice of the margin of appreciation, one would expect that the greater the consensus, the narrower the margin of appreciation. However, reality sometimes shows a different picture. In my view, the case of abortion serves as an indicator for this issue. The Court has previously held that Article 8 ECHR cannot be interpreted as a right to abortion.¹⁰³ This is supported by the fact that it is an ethical topic on which a broad margin of appreciation is granted to Member States.¹⁰⁴ However, following the reasoning as expressed by several judges formulating their partly dissenting opinions in *A, B and C v. Ireland*, “[since] there is an undeniably strong consensus among European States [...] to the effect that, regardless of the answer to be given to the scientific, religious or philosophical question of the beginning of life, the right to life of the mother, and, in most countries’ legislation, her well-being and health, are considered more valuable than the right to life of the

¹⁰⁰ See R. MacDonald, 1993, p. 85.

¹⁰¹ Brems, 2010, p. 689.

¹⁰² A clear example is the recognition of same-sex relationships. In 2001, the Court decided in the case of *Mata Estevez v. Spain* that ‘family life’ in the context of Article 8 ECHR is still an area in which states enjoy a wide margin of appreciation, despite a growing European consensus on the matter. In 2010 however, the Court revisited this position in *Schalk and Kopf v. Austria* in 2010; ECtHR, *Mata Estevez v. Spain*, no. 56501/00, 10 May 2001; ECtHR, *Schalk and Kopf v. Austria*, no. 30141/04, 24 June 2010.

¹⁰³ ECtHR, *A, B and C v. Ireland*, no. 25579/05, 16 December 2010.

¹⁰⁴ ECtHR, *P and S v. Poland*, no. 57375/08, 30 October 2012, p. 133.

foetus”,¹⁰⁵ the margin of appreciation becomes narrower. Furthermore, this consensus even transcends the level of the Council of Europe member states.¹⁰⁶

Nevertheless, only a few states in the world decriminalised or legalised some forms of euthanasia. Hence, it is clear that these are still in an isolated position. Therefore, it seems highly unlikely that the position of human rights bodies will change soon. If the consensus would become stronger, the discussion above illustrates that it will be difficult to predict when and what kind of influence this would have on the invocation of the margin of appreciation doctrine.

4.3.4. *The argument of the slippery slope*

A frequently occurring argument against euthanasia is the one of a slippery slope. This argument can be discussed in a very detailed way as many different conceptions exist. In this section, I will only shortly highlight two aspects of it.

Traditionally however, two types of slippery slope arguments can be distinguished, namely the conceptual version and the empirical version.

The conceptual version implies that “allowing something (A) whose justifying principle necessarily also justifies something else (B), the force of logic will require one to allow B as well.”¹⁰⁷ Therefore, if autonomy is considered the justifying principle for a human right to euthanasia, this could allow a right to die for those who simply wish to die, regardless of whether there is suffering involved or not. The same reasoning takes place when taking the principle of beneficence as the justifying principle which could create a

¹⁰⁵ ECtHR, *A, B and C v. Ireland*, Joint partly dissenting opinion of judges Rozakis, Tulkens, Fura, Hirvelä, Malinvern and Poalelungi, no. 25579/05, 16 December 2010, para. 2-3.

¹⁰⁶ Furthermore, this consensus transcends the level of the CoE. Many other human rights bodies recognised a right to abortion in specific circumstances. See e.g. amongst many others Committee on the Rights of the Child, *Concluding Observations on Chad*, 1999, p. 30; UNHRC, *Concluding Observations on Guatemala*, 2012, p. 20; Committee against Torture, *Concluding Observations on Peru*, 2006, p. 23; Committee on Elimination of Discrimination Against Women, *Concluding Observations on Sri Lanka*, 2002, p. 283; Committee on Economic, Social and Cultural Rights, *Concluding Observations on Costa Rica*, 2008, p. 46.

¹⁰⁷ Griffiths, 2008, p. 513.

right to die, regardless of the patient's consent or not.¹⁰⁸ SMITH argues that this argument is not as strong as it may appear as there are more interests at stake than only autonomy and beneficence. Furthermore, he states that even when these two principles would be the only interests at stake, "there is particular reason why both together are not necessary for the required justification to work."¹⁰⁹

The empirical version of the slippery slope argument is "based upon whether the move from A to B will happen irrespective of whether it is logically required." In this context, it is frequently stated that a right to euthanasia will endanger vulnerable groups. According to GRIFFITHS, there is however "no evidence that members of any of the supposedly vulnerable groups more frequently die from euthanasia than anyone else."¹¹⁰ Here, he criticises opponents of euthanasia by remarking that "the place to look for the danger is among the very large numbers of deaths due to pain relief, palliative or terminal sedation and abstention from life-prolonging treatment, in many of which the patient or his representative are not involved in the decision-making."¹¹¹

4.4. Euthanasia and the prohibition of torture, inhuman and degrading treatment

4.4.1. Introduction

A third argument in favour of a human right to euthanasia could be found in the prohibition of torture, inhuman and degrading treatment. In my opinion, this provision forms the strongest ground for a human right to euthanasia within the current human rights system. This is mainly because of the absolute character of the prohibition, which means that no derogation is possible under any circumstances, not even the most difficult ones.¹¹² The ECtHR has declared that it is "one of the most fundamental values

¹⁰⁸ This is relevant for the examination of the prohibition of torture, inhuman and degrading treatment; Keown, 2002, pp. 78-79

¹⁰⁹ Smith, 2012, p. 268.

¹¹⁰ See Battin, 2007 for an analysis of the data from the Netherlands and Oregon; Griffiths, 2008, p. 516.

¹¹¹ Griffiths, 2008, p. 516.

¹¹² Committee against Torture, *General Comment No. 2 on the Implementation of Article 2.*

within democratic society.”¹¹³ Furthermore, the Court stated in the case of *Gäfgen v. Germany* that “[t]he philosophical basis underpinning the absolute nature of the right under Article 3 [ECHR] does not allow for any exceptions or justifying factors or balancing of interests.”¹¹⁴ Some argue that prohibiting euthanasia in the context as described in chapter 2 could constitute torture or inhuman and degrading treatment. Hereafter, I examine both options.

4.4.2. Torture

Torture is another concept within human rights that is difficult to define as it is “subject to ongoing reassessment in light of present-day conditions and the changing values of democratic societies.”¹¹⁵ However, the first paragraph of Article 1 CAT provides a definition of torture for the purpose of this Convention. Overall, four essential elements can be derived: (1) an act, inflicting severe pain or suffering, whether physical or mental, (2) the element of intent, (3) a specific purpose, and (4) the involvement of a state official, at least by acquiescence.

4.4.2.1. Could the prohibition of euthanasia be categorised torture?

To examine whether the prohibition of euthanasia could be categorised torture, we have to review if all the necessary elements are present.

- a. An act, inflicting severe pain or suffering, whether physical or mental

Even though the Government cannot be held reliable directly for the suffering of the patient, it could be argued that the State neglects its positive obligation to protect citizens of torture by not decriminalising or not legalising euthanasia.

¹¹³ ECtHR, *Chahal v. United Kingdom*, no. 22414/93, 15 November 1996.

¹¹⁴ ECtHR, *Gäfgen v. Germany*, no. 22978/05, 1 June 2010, para. 107.

¹¹⁵ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment J.E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013, para.14; World Organization Against Torture, 2006, p. 107, citing Inter-American Court of Human Rights, *Cantoral-Benavides v. Peru*, No. 69, 2000, para. 99; ECtHR, *Selmouni v. France*, no. 25803/94, 28 July 1999, para. 101; Furthermore, the UNHRC stated in its General Comment no. 20 on Art. 7 ICCPR that it is not necessary “to draw up a list of prohibited acts or to establish sharp distinctions between the different kinds of punishment or treatment. See UNHRC, *General Comment No. 20*, para. 4.

b. The element of intent

Generally, it is difficult to argue that the element of intent to degrade, humiliate or punish is present in the actions of the Government regarding health care. Therefore, important judgments of the ECtHR are *Peers v. Greece* and *Groni v. Albania*. In both cases, the Court has noted that “a violation of Article 3 ECHR may occur where the purpose or intention of the state’s action or inaction was not to degrade, humiliate or punish the victim, but where this nevertheless was the result.”¹¹⁶ This could imply that this condition is fulfilled when the suffering of the patient can be considered degrading or humiliating, even if the State does not prohibit euthanasia with this intention.

c. A specific purpose

Former Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment mentioned in his report that even though Article 1 mentions a list of purposes, this is a non-exhaustive list. However, only purposes that have “something in common with the purposes expressly listed are sufficient.”¹¹⁷ In practice, this means that the purpose of a state should relate to (a) obtaining information or a confession, (b) punishment, (c) intimidation or coercion or (d) discrimination. It seems difficult to argue that states prohibit euthanasia with a purpose related to one of these four options. As already mentioned, most of the time the purpose is to safeguard life and to protect vulnerable groups. One could argue that people who are not able to commit suicide themselves because of physical reasons are discriminated against people who are able to commit suicide themselves. Nonetheless, even though discrimination may be taken place as a result,¹¹⁸ it remains highly unlikely that this was the purpose of the Government.

¹¹⁶ ECtHR, *Peers v. Greece*, no. 28524/95, 19 April 2001, para. 68 and 74; ECtHR, *Groni v. Albania*, no. 25336/04, 7 July 2009, para. 125.

¹¹⁷ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Manfred Nowak, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2010, para.35.

¹¹⁸ This element will be discussed further in section 4.5.

d. The involvement of a state official, at least by acquiescence

The obligation to prevent torture applies to doctors and professionals, whether they work in public or private hospitals, other institutions and detention centres.¹¹⁹ Therefore, this criterion is fulfilled.

From this assessment, I conclude that all elements are clearly present to categorise the prohibition of euthanasia as torture, except for the specific purpose. However, neither this element nor the element of intent is a requirement for conduct to amount to inhuman and degrading treatment. Thus, this option (as will be examined in section 4.4.3.) might offer a stronger ground for a human right to euthanasia.

4.4.2.2. Report on abuses in health-care settings

In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Méndez published a report on certain forms of abuses in health-care settings that may cross a threshold of mistreatment which is tantamount to torture or cruel, inhuman or degrading treatment or punishment. He noticed that the conceptualisation of abuses in health-care settings as torture or ill-treatment is a relatively recent phenomenon.¹²⁰ However, “the international community has begun to recognise that torture may occur in other contexts than in those of interrogation, punishment or intimidation of a detainee.”¹²¹

Furthermore, the report of Méndez mentions some specific examples of treatment within the health care context where torture may occur, such as the following: “The mandate has recognised that medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person

¹¹⁹ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Manfred Nowak, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2008, para.51.

¹²⁰ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment J.E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013, para.15.

¹²¹ *Ibidem*, para. 15.

concerned.”¹²² This is very relevant in the sense that this explicit mentioning might offer a ground for a right to some forms of passive euthanasia, such as stopping futile medical treatments.

Often, dubious grounds of medical necessity are invoked to justify intrusive and irreversible procedures performed on patients without full free and informed consent. Therefore, the report refers to the doctrine of medical necessity, established by the ECtHR in the case of *Herczegfalvy v. Austria*.¹²³ In this case, the Court “found the situation in which a patient was continuously sedated and administered forcible feeding whilst being physically restrained by being tied to a bed for a period of two weeks was nonetheless consistent with Article 3 of the ECHR because the treatment in question was medically necessary and in line with accepted psychiatric practice at that time.”¹²⁴ Méndez acknowledges that this doctrine continues to be an obstacle to protection from arbitrary abuses in health-care settings. Therefore, he highlights that “treatment provided in violation of the terms of the Convention on the Rights of Persons with Disabilities [as this is a particular vulnerable group for this type of abuse] cannot be legitimate or justified under the medical necessity doctrine.”¹²⁵

4.4.3. *Inhuman or degrading treatment*

Article 16 CAT determines that “[e]ach State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in Article 1, when such acts are committed by or at the instigation of or with the consent or of a public official or other person acting in an official capacity.”

¹²² Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Manfred Nowak, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2008, para. 40 and 47.

¹²³ ECtHR, *Herczegfalvy v. Austria*, no. 10533/83, 24 September 1992, para. 27 and 83.

¹²⁴ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment J.E. Méndez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013, para. 34.

¹²⁵ *Ibidem*, para. 35.

The ECtHR determined that treatment must reach a minimum level of severity, and “cause either actual bodily harm or intense mental suffering”¹²⁶ to be categorised inhuman. However, an important difference with torture is that it does not have to be deliberate nor inflicted for a purpose.¹²⁷ Degrading treatment involves humiliation and debasement. Also in this case, intent is not a requirement.¹²⁸

In *Pretty v. the UK*, the applicant submitted that the suffering she faced qualified as degrading treatment under Article 3 of the ECHR. Ms. Pretty did not deny the fact that it was not the Government who was responsible for the disease that caused her suffering. However, she highlighted the positive obligation of the Government to protect her from the suffering she endured by taking reasonable steps.¹²⁹ As Article 3 ECHR is an absolute right, she argued that “there was no room for striking a balance between her right to be protected from degrading treatment and any competing interest of the community.”¹³⁰ Furthermore, she stated that even if this balance was present, it was a disproportionate one because the UK law imposed a blanket ban on assisted suicide, “regardless of the individual circumstances of the case.”¹³¹ Another aspect of her submission was that the absoluteness of Article 3 ECHR does not allow room for a margin of appreciation. Even if there was any, she stated, the Government was not entitled to determine that “all those who were terminally ill or disabled and contemplating suicide were by definition vulnerable and that a blanket ban was necessary so as to protect them.”¹³² The Government submitted that Article 3 ECHR was not engaged in this case as this prohibition had been found to comprise a primarily negative obligation, except for three exceptional circumstances which did not apply in this case. Furthermore, the Government stated that the Court’s case law indicates that positive obligations are not absolute “but must be interpreted in such a way as not to impose an impossible or disproportionate burden on the authorities.”¹³³ Even if Article 3

¹²⁶ ECtHR, *Ireland v. the United Kingdom*, no. 5310/71, 18 January 1978, para. 167.

¹²⁷ *Ibidem*, para. 167.

¹²⁸ ECtHR, *Price v. the United Kingdom*, no. 33394/96, 10 July 2001, para. 24-30.

¹²⁹ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 44.

¹³⁰ *Ibidem*, para. 45.

¹³¹ *Ibidem*, para. 45.

¹³² *Ibidem*, para. 46.

¹³³ *Ibidem*, para. 47.

were engaged, it did not confer a legally enforceable right to die because of the margin of appreciation that a state has in assessing the scope of any positive obligation.¹³⁴

The Court stated that Article 3 indeed creates a positive obligation for States “to take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman and degrading treatment or punishment, including such treatment administered by private individuals.”¹³⁵ The Court previously stated in its case law that “[w]here treatment humiliates or debases an individual, showing a lack of respect for, or diminishing, his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual's moral and physical resistance, it may be characterised as degrading and also fall within the prohibition of Article 3.”¹³⁶ Also suffering that is caused by naturally occurring illness may be covered where it is, or risks being, exacerbated by treatment for which the authorities can be held responsible.¹³⁷ According to the Court, the State had not inflicted any ill-treatment on the applicant, nor was there any complaint about the medical care that Ms. Pretty received from the State medical authorities.¹³⁸ However, the claim of the applicant was that the inhuman and degrading treatment existed of not decriminalising assisted suicide in her specific case whereby the state failed to protect her from the suffering she endured. The Court found that this claim placed a new and extended construction on the concept of treatment. Even though the ECHR is a living instrument, the interpretation of Article 3 must take place in accordance with the fundamental objectives of the Convention. In other words: Article 3 ECHR must be construed in harmony with Article 2 ECHR. The Court already decided, as described in section 4.2., that this right did not create any right for an individual to require a state to permit or facilitate his or her

¹³⁴ *Ibidem*, para. 48.

¹³⁵ ECtHR, *A. v. the United Kingdom*, 23 September 1998, no. 100/1997/884/1096, para. 22; ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 51.

¹³⁶ ECtHR, *Price v. the United Kingdom*, no. 33394/96, 10 July 2001, para. 24-30.

¹³⁷ European Commission of Human Rights, *D. v. the United Kingdom*, 2 May 1997; ECtHR, *Keenan v. the United Kingdom*, 4 March 2001; *Bensaid v. the United Kingdom*, no. 44599/98, 6 February 2001.

¹³⁸ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para.53.

death.¹³⁹ Therefore, the Court concluded that no positive obligation as requested by the applicant arises under Article 3 of the Convention.¹⁴⁰

In my view, the case of *Pretty v. the UK* is a perfect example of the fact that the ‘absoluteness’ of Article 3 ECHR is not always interpreted in an absolute way by the ECtHR¹⁴¹ If the Court would fully respect the absolute character of this Article, the application of would purely be a matter of scope.¹⁴² This implies that the only question should be whether the suffering of people who want to commit euthanasia but cannot attain a minimum level of severity that is high enough to fall under the scope of inhuman and degrading treatment. However, judging from the language that is used by the Court, there was a clear balancing of interests.

A possible problem with a human right to euthanasia on the ground of the prohibition of torture, inhuman and degrading treatment is that it might grant a right to euthanasia to everyone who suffers, irrespective of their consent or not. This is the previously mentioned issue of the slippery slope as discussed in section 4.3.4. This could e.g. form the basis to euthanise neonates with severe birth defects because of which they will only live very shortly and under extreme suffering. Even though one could discuss if this would indeed be the most humane option from an ethical point of view, this goes beyond the scope of the right to euthanasia as described in Chapter 2.

4.4.4. *A comparison with the case of abortion*

Another interesting development is that the denial of abortion may constitute torture or ill-treatment. In the landmark decision of *KNLH v. Peru*, the UN Human Rights Committee found that the denial of a therapeutic abortion was a violation of the individual’s right to be free from ill-treatment.¹⁴³ Furthermore, the Committee explicitly stated that breaches of Article 7 ICCPR include the denial of access to safe abortions to

¹³⁹ Ibidem, para.54.

¹⁴⁰ Ibidem, para.56.

¹⁴¹ The case law of the Court on its non-refoulement principle, as embedded in Art. 3 ECHR shows the same issue. See e.g. H. Battjes, 2009.

¹⁴² Smet, 2014, p. 273; H. Battjes, 2009, pp. 587–588; Barak, 2012, p. 27.

¹⁴³ UNHRC, Communication *Karen Noelia Llantoy Huamán v. Peru* No. 1153/2003, 22 November 2005, para.6.3.

women who have become pregnant as a result of rape.¹⁴⁴ Also, the Committee against Torture has repeatedly expressed concerns about restrictions on access to abortion and about absolute bans on abortion as violating the prohibition of torture and ill-treatment.¹⁴⁵ In my view, the fact that the Special Rapporteur on Torture explicitly mentions in his report that denying abortion to women under certain circumstances, such as in case of rape, may constitute torture and ill-treatment could be important for the future development of a human right to euthanasia. Several arguments support this reasoning. First of all, I would argue that abortion and euthanasia show a lot of analogous characteristics. Traditionally, abortion is also considered a highly controversial issue on which no universal consensus exists. Such as euthanasia, the discussion on abortion lays on the crossroad of ethics, medicine and law. Furthermore, in this situation, the Government cannot be held directly responsible for the suffering of women who want to undergo an abortion. However, by denying the possibility of abortion, the State neglects its positive obligations on the ground of the prohibition of torture. This throws away the argument of governments who state that they cannot be held responsible for the suffering of euthanasia because they are not directly responsible for it.¹⁴⁶ Moreover, the same balancing of rights occur with regard to euthanasia and abortion: the right to life of the foetus is balanced against the right of the mother to be free from torture, inhuman and degrading treatment. The fact that this balance weighs in the advantage of the woman seems an important evolution. However, as I already mentioned, it should be stated that the European Court of Human Rights e.g. is very reluctant to recognise this human right to abortion. An important characteristic with regard to abortion is that the UN Human Rights Committee considers it as a form of gender discrimination.¹⁴⁷ This could have been an important element in the reasoning of the Committee to categorise the prohibition of abortion as torture under precise circumstances. This is a crucial element that lacks in the case of euthanasia. However, as discussed in the previous section, purpose and intent are not necessary for conduct to

¹⁴⁴ UNHRC, *General Comment No. 28 on the Equality of Rights Between Men and Women*, para.11; See also CCPR/CO.70/ARG, para. 14.; See also UNHRC, *Concluding observations*, 2000, para.14.

¹⁴⁵ Committee Against Torture, *Conclusions and recommendations*, Peru, 2006, para.23.

¹⁴⁶ This was e.g. argued by the UK Government in the case of *Pretty v. the UK*.

¹⁴⁷ This is e.g. stated in General Comment No. 28 of the UNHRC on Equality of rights between men and women.

amount to inhuman or degrading treatment. In this light, the fact that denial of abortion could be considered torture under certain circumstances could still create opportunities to categorise a denial of euthanasia as inhuman or degrading treatment.

4.5. Euthanasia and the principle of non-discrimination

4.5.1. Introduction

The principle of non-discrimination is regarded a tool to realise human rights as well as a tool to measure whether human rights are infringed upon. People with disabilities have send out important signals in relation to this matter.

In most states, committing suicide is not considered an offence under national criminal law. However, some people with disabilities who wish to end their lives are not physically able to kill themselves. They need the help of a third person. Nonetheless, this forces the latter to commit criminal activities. Therefore, some express that this is a violation of the non-discrimination principle in conjunction with the right to autonomy of people with disabilities and their equality before the law.

4.5.2. The principle of non-discrimination at the level of the UN and the CoE

As the denial of autonomy is a frequently occurring issue for this group, the CRPD strongly emphasises the protection of their right to autonomy in relation to respect for human dignity. Article 3 CRPD e.g. states that one of the principles of the Convention shall be “[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.”¹⁴⁸

Moreover, equality before the law is enshrined in Article 5 CRPD. States Parties have to take measures to guarantee people with disabilities “equal and effective legal protection against discrimination on all grounds.” If States discriminate people in the exercise of this right on the basis of disability, this is “a violation of the inherent dignity and worth

¹⁴⁸ Art. 3, a CRPD.

of the human person.”¹⁴⁹ What is meant with ‘on the basis of disability’ is “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.”¹⁵⁰

Even though these provisions do not automatically create a ground for a human right to euthanasia, it does show that evolutions are taking place within international law that emphasise the right to autonomy and equality for people with disabilities.

With regard to the ECHR, Article 14 states that “[t]he enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”. The words ‘or other status’ indicate that this is a non-exhaustive list.

In the case of *Ms. Pretty v. the UK*, the applicant argued that she was discriminated against people who were physically able to commit suicide without assistance, as this last practice is not a crime on the ground of UK law. According to her, she was treated in the same way as those whose situations are significantly different. The Government defended itself by invoking that the legitimate aim of the prohibition of assisted-suicide was to protect vulnerable groups, such as people with disabilities. Ms. Pretty argued back that she did not consider herself vulnerable or in need for protection. Therefore, there was no reasonable or objective justification for this difference in treatment as it was disproportional to the aim.¹⁵¹

The ECtHR found that Article 14 had to be considered as the applicant’s rights under Article 8 ECHR were engaged. States Parties “enjoy a margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a

¹⁴⁹ Preamble CRPD; Committee on the Rights of Persons with Disabilities, General Comment No. 1, para. 33.

¹⁵⁰ Art. 2 CRPD.

¹⁵¹ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 85.

different treatment.”¹⁵² However, discrimination can also arise in situations in which States fail to treat persons differently whose situations are significantly different.¹⁵³ Nonetheless, the Court considered that there was an objective and reasonable justification for not distinguishing both categories. It referred to its reasoning on Article 8 ECHR to determine this objective and reasonable justification, namely protecting vulnerable groups, and found that this justification similarly applies to Article 14 ECHR. Therefore, there was no violation of Article 14 ECHR.¹⁵⁴

From the reasoning of the Court, it can be derived that similar ‘burdens’ count for the principle of non-discrimination as for the right to privacy, namely the invocation of the margin of appreciation doctrine and the protection of vulnerable groups. As it does not seem to me that the position of the Court will soon change in relation to Article 8 ECHR, I would conclude the same in relation to Article 14 ECHR.

4.6. Euthanasia and the right to health

4.6.1. Introduction

If euthanasia is legalised, many fear that States may refuse or feel more reluctant to invest in health care.¹⁵⁵ In other words, the State could abuse euthanasia to not fulfil its duties on the ground of the right to health. This option will be discussed below.

4.6.2. The right to health at the level of the UN and the CoE

Firstly, the right to health will be discussed on the basis of Article 12, paragraph 1 ICESCR as this treaty provides “the most comprehensive article on the right to health in international human rights law.”¹⁵⁶

¹⁵² Ibidem, para. 88 in which the Court refers to the case of the ECtHR, *Camp and Bourimi v. the Netherlands*, no. 28369/95, 3 October 2000, para. 37.

¹⁵³ ECtHR, *Thlimmenos v. Greece*, no. 34369/973, 6 April 2000, para. 44.

¹⁵⁴ ECtHR, *Pretty v. the United Kingdom*, no. 2346/02, 29 April 2002, para. 87-90.

¹⁵⁵ Math and Chaturvedi, 2012.

¹⁵⁶ UN Committee Economic, Social and Cultural Rights, *General Comment No. 14 on the right to health*, para. 2.

On the ground of Article 12, every human being “is entitled to the enjoyment of the highest attainable standard of health [whether physically or mentally] conducive to living a life in dignity.”¹⁵⁷ The system that is used to measure state compliance with economic, social and cultural rights is called ‘progressive realisation.’ In short, it implies that States are obliged to “take steps to the maximum of their available resources to achieve progressively the full realisation”¹⁵⁸ of this right. This can happen by all appropriate means, including in particular the adoption of legislative measures.¹⁵⁹ Furthermore, Article 12 ICESCR foresees some core obligations for the State that must be respected immediately from the moment of ratification, such as e.g. the principle of non-discrimination and the obligation to take steps towards the full realisation of the right to health.¹⁶⁰ The right to health contains four dimensions. The first one is availability, which implicates that States should provide a well-functioning and quantitatively sufficient health care system, where “[t]he precise nature of the facilities, goods and services will vary depending on numerous factors, including the States Party’s developmental level.”¹⁶¹ The second principle, namely the one of accessibility, includes several elements, such as respect for the principle of non-discrimination, physical accessibility, economic accessibility and informational accessibility. The third one is acceptability, which means that “all health facilities, goods and services must be respectful of medical ethics and culturally appropriate.”¹⁶² The last principle is labelled quality and refers to provide medical care that is scientifically and medically appropriate.¹⁶³

The Committee states that one should make a distinction between the inability on the one hand and the unwillingness on the other hand of a state party to comply with its obligations under Article 12 ICESCR. When a state is unwilling to use the maximum of

¹⁵⁷ Ibidem, para. 1.

¹⁵⁸ Office of the United Nations High Commissioner for Human Rights, *Factsheet No. 33, Frequently Asked Questions on Economic, Social and Cultural Rights*, 2008, p. 11 (last consultation on 15 May 2016).

¹⁵⁹ Art. 2, para. 1 ICESCR.

¹⁶⁰ UN Committee Economic, Social and Cultural Rights, *General Comment No. 14 on the right to health*, para. 30.

¹⁶¹ Ibidem, para. 12.

¹⁶² Ibidem, para. 12, c.

¹⁶³ Ibidem, para. 12, a, b, c and d.

its available resources for the realisation of the right to health, then there is a violation. However, this distinction should not be made for the core obligations enshrined in Article 12 ICESCR as these are non-derogable.¹⁶⁴

In its General Comment on the right to health, the UN Committee on Economic, Social and Cultural Rights emphasises the interdependency between the right to health and other human rights as they “address integral components of the right to health.”¹⁶⁵ Furthermore, the Committee points out that the full enjoyment of the right to health remains a challenge for millions of people throughout the world. This goal becomes even more difficult to reach for them when belonging to a vulnerable group, such as people living in poverty.¹⁶⁶

At the level of the CoE, the Revised European Social Charter includes economic and social rights. The right to protection of health is enshrined in Article 11 of the Charter. To ensure this right, “the Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed inter alia: (1) to remove as far as possible the causes of ill-health, (2) to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health, (3) to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.” Article 11 is interpreted as containing physical and mental well-being, as proscribed by the World Health Organisation.¹⁶⁷ Also here, States must ensure the best possible state of health for the population according to existing knowledge. Furthermore, the European Social Committee declared that the health care system must be accessible to everyone without discrimination.

In this context, some argue that euthanasia forms a specific danger to the right to health of vulnerable people, as they often do not have sufficient access or even no access to health care at all. Therefore, a condition for decriminalising euthanasia without

¹⁶⁴ Ibidem, para. 47.

¹⁶⁵ Ibidem, para. 3.

¹⁶⁶ Ibidem, para. 5.

¹⁶⁷ European Committee of Social Rights, Digest of the Case Law on the European Committee of Social Rights, 2008, p. 324.

violating the right to health could be that a state has to possess an adequate health care system and a general willingness to implement the right to health, with additional attention for vulnerable groups.

A specific aspect falling under the protection of the right to health that is often emphasised in the debate on euthanasia is the obligation for states to foresee in alternative options, such as palliative care. According to the Special Rapporteur on Torture, the denial of pain treatment could be considered cruel, inhumane or degrading treatment when the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment. In this context, he points out: “When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”¹⁶⁸ In a joint letter of the Special Rapporteur on the right to health and the Special Rapporteur on torture, it was reaffirmed that “Governments must guarantee essential medicines – which include, amongst others, opioid analgesics – as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment.”¹⁶⁹ These statements clearly indicate a strong link between respect for the right to health and the prohibition of torture, inhuman and degrading treatment. Also the Parliamentary Assembly of the CoE expressed the importance of a well-functioning palliative care system in its Recommendation 1418 on the Protection of the human rights and dignity of the terminally ill and the dying.¹⁷⁰ Therefore, an additional condition for decriminalising or legalising euthanasia could be that States have to invest in proper

¹⁶⁸ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment J.E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013, para. 54.

¹⁶⁹ Joint letter of the Chairperson of the fifty-second session of the Commission on Narcotic Drugs, 2008, p. 4; Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment J.E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013, para. 56.

¹⁷⁰ E.g. in sections 7, 8 and 9; Parliamentary Assembly CoE, Recommendation 1418 on Protection of the human rights and dignity of the terminally ill and the dying, 25 June 1999, available at assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=16722&lang=en (last consultation on 8 July 2016).

palliative care that is accessible to everyone to prevent that people would feel pressured to commit euthanasia.

However, I would like to briefly highlight another aspect of the relation between euthanasia and palliative care. The mere existence of palliative care is often invoked as an argument for the prohibition of euthanasia, as this would alleviate the suffering and is in accordance with human dignity (whereas euthanasia is not).¹⁷¹ As already stated, the ultimate purpose of euthanasia is to release someone from its unbearable suffering at the latter's request. To some, the option of palliative care does not facilitate this aim in a sufficient way because of physical and especially psychological reasons.¹⁷² In my point of view, it is therefore incorrect to present the relation between these two systems as a typical 'or...or...' -story.

4.7. Conclusion

In this chapter, I aimed to address whether there are any signs that a human right to euthanasia could be derived on the ground of existing human rights. Furthermore, I examined whether there are any developments towards a future human right to euthanasia.

A general remark I would like to make is that the traditional distinction between passive euthanasia on the one hand and active euthanasia and physician-assisted suicide on the other hand can be detected very clearly in the present position of human rights bodies towards euthanasia. As mentioned in chapter 2, I highly criticise this artificial division because there is no difference between these forms from an ethical point of view.

The first right that has been involved is the right to life. The language used by human rights bodies at the level of the UN and the CoE indicates that these are not prepared to recognise that the right to life includes a negative aspect, namely a right to die. However, a fascinating evolution is taking place at the national level. A range of high

¹⁷¹ billmuehlenberg.com/2010/09/25/palliative-care-versus-euthanasia/ (last consultation on 11 July 2016).

¹⁷² Quill and Battin, 2004, p. 214.

courts have recently judged that the right to life does contain a right to die with dignity. As it is clear that these courts are inspired by each other's judgements, it will be interesting to see whether a 'chain reaction' will occur and which influence this will have on the future position of international and regional human rights bodies. Regarding a human right to passive euthanasia, the recent case of *Lambert v. Others* forms a strong indication that the ECtHR does respect the right to autonomy of a patient when it comes to refusing treatment, whether lifesaving or not. Taking into account the strong emphasis of the Court on the fact that this case was not about active euthanasia or assisted suicide, it is highly unlikely that this judgement will create opportunities for these forms of euthanasia. Also the negative relation between euthanasia and the right to life has been examined. In this context, it is of great importance that the UNHRC stated that this practice does not necessarily have to violate the right to life if it takes place under very strict conditions. However, the Committee did exclude non-terminal people and minors from this statement. This indicates the reluctance of the Committee towards the possibility of euthanasia for these categories of people.

The right to privacy has been mainly discussed through the case law of the ECtHR. As shown in the case of *Pretty v. the UK*, the Court grants a wide margin of appreciation to States regarding euthanasia, based on the argument that there is no European consensus on the issue. Even if this consensus would become stronger in the future, practice illustrates that it will be difficult to predict when and what kind of influence this will have on the invocation of the margin of appreciation doctrine by the Court. Furthermore, the ECtHR emphasised that the limitation of the right to privacy was proportionate to the aim pursued, namely protecting vulnerable groups. A short examination of the slippery slope argument teaches us however that vulnerable groups do not necessarily have to be effected more by euthanasia than others. Nonetheless, the used statistics presented the situations in the Netherlands and Oregon, two countries that possess a high quality health care system.

As a third right, I chose to examine the prohibition of torture, inhuman and degrading treatment. I argue that this right forms the strongest ground for a human right to euthanasia because of its absolute character. In my view, the prohibition of euthanasia

does not amount to torture as it lacks a specific purpose in the context of this right. However, this purpose does not have to be present to categorise conduct as inhuman or degrading treatment. Therefore, the question is whether the suffering a person endures due to the prohibition of euthanasia reaches the requested level of severity. The case of euthanasia as judged in front of the ECtHR serves as a perfect indicator to identify the, sometimes, ‘disrespect’ for the absolute character of the prohibition of torture, inhuman and degrading treatment. With this, I mean that the Court still balances rights against each other, although the application of this principle should purely be a matter of scope. Therefore, the developments taking place regarding abortion could be of great importance. The fact that the Special Rapporteur on Torture stated that forced treatment could amount to torture might again be an important step towards a human right to passive euthanasia.

With regard to the prohibition of non-discrimination, people with disabilities have argued that the prohibition of euthanasia is discriminative as some are not physically able to commit suicide, which is no criminal offence. The Committee on the Rights of Persons with Disabilities indicates that many problems occur regarding disrespect for their autonomy and, thereby, human dignity. However, as the ECtHR refers to the same grounds and mechanisms as it does in case of the right to privacy to find that this difference in treatment is no discrimination, it seems unlikely that its position will change soon.

The last examined right was the right to health. According to me, this right forms the strongest ground against a universal right to euthanasia. Access to adequate health care and a general willingness to implement the right to health seem to be important conditions to ensure that the practice of euthanasia is not abused. As it is clear that many states do not meet these criteria today, a human right to euthanasia could indeed endanger the right to health.

As mentioned in the introduction of this chapter, the case of euthanasia shows how interconnected and interdependent all these discussed human rights are. A human right

to euthanasia is one that would come with many layers in the sense that it should be based on many human rights principles to be 'ideal'. A human right to euthanasia that would solely be based on autonomy could create a general right to die, without suffering involved. However, if one would take the principle of beneficence as the foundation, this could open a door for involuntary euthanasia. If justice is not respected as in that there is no equal access to health care, a human right to euthanasia could be abused and endanger vulnerable people's lives. Therefore, I conclude that all these elements have to be present and mutually enforce each other.

As can be derived from the conclusion above, there is no clear answer to the first research question. Whereas a human right to passive euthanasia seems to receive more and more support, active euthanasia and assisted suicide are still treated rather shabbily. Although some grounds can be found and developments are certainly taking place, a general right to euthanasia is not something that will happen soon. When answering the question if it would be desirable to create a universal human right to euthanasia at this moment in time, I would argue that the right to health forms an important obstacle.

The next three chapters will focus on the way in which a human right to euthanasia would apply to minors. As the case of euthanasia for minors serves as a perfect indicator for the broader 'protection v. participation'-debate, I will briefly discuss this in the next chapter.

5. Children as subjects in international law

5.1. Introduction

This chapter offers a general overview of the child as a subject of rights within international law. Their position as individuals and as a group in this area has undergone a significant evolution through time.¹⁷³ Today, children are still considered a vulnerable group within the human rights framework because they have specific needs, are often highly dependent on adults and have not yet reached the level of adult maturity. Therefore, additional protection is required to ensure that their human rights are fully respected, protected and fulfilled.¹⁷⁴ However, children are also autonomous subjects of rights who have the right to be heard and to have their views be taken into consideration regarding decisions that influence their lives.¹⁷⁵

Some cases show that state parties find difficulties in balancing those two elements, which is described as the so called ‘protection v. participation’-debate.¹⁷⁶ As the case of euthanasia for minors could be considered a perfect indicator of this issue, maybe even the ultimate one, the wider debate on finding the balance between protection and participation within children’s rights will be discussed more in-depth.

5.2. Before the UN Convention on the Rights of the Child

In the past, children were often treated as invisible members of society that were ‘seen but not heard’. This view was for example reflected in the fact that they lacked access to justice and complaints mechanisms and in the over-all denial of credibility “in the eyes of adults and the law.”¹⁷⁷ As stated by Parkes, “the litany of reports, inquiries and investigations [...] have all in some way highlighted the fact that these children were

¹⁷³ Parkes, 2013, p. 1.

¹⁷⁴ www.humanrights.is/en/human-rights-education-project/human-rights-concepts-ideas-and-fora/the-human-rights-protection-of-vulnerable-groups (last consultation on 25 June 2016).

¹⁷⁵ Ibidem.

¹⁷⁶ Marshall, 1997, p. 1.

¹⁷⁷ Parkes, 2013, p. 1.

powerless, vulnerable and had nobody to listen to them.”¹⁷⁸ Consequently, one could say that a general sense of responsibility had been established among adults and governments to strive for minimum standards of rights for children.¹⁷⁹

5.3. The arrival of the UN Convention on the Rights of the Child

In the light of the events mentioned above, the UN Convention on the Rights of the Child was established in 1989. This document is frequently considered “a landmark in the history of the United Nations standard-setting.”¹⁸⁰ A number of reasons rightly justify this statement. Firstly, the Convention was the first human rights treaty to include both civil and political rights as well as economic, social and cultural rights. This is of great importance for strengthening the idea of the indivisibility, interdependence and interrelatedness of human rights.¹⁸¹ Secondly, it brought with it a significant paradigm shift. Whereas a traditional welfare-based approach predominated towards children in the past, the CRC introduced a holistic rights-based approach “where all children have the right to be involved in all decisions affecting them.”¹⁸²

Today, there are 196 States Parties to the Convention. All but one of them¹⁸³ ratified it, which makes it “the most widely and rapidly ratified human rights treaty in history.”¹⁸⁴ The CRC consists of 54 Articles in which many human rights as those extended to adults are enshrined. Moreover, some rights were added that strongly relate to the specific needs of children due to their developmental stages and vulnerable status.¹⁸⁵

¹⁷⁸ Ibidem.

¹⁷⁹ Ibidem.

¹⁸⁰ Santos Pais, 2000, p. 93.

¹⁸¹ For more information on these general principles, see

www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx (last consultation on 28 May 2016).

¹⁸² Parkes, 2013, p. 1.

¹⁸³ Only the United States of America did not ratify the CRC;

treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&lang=en (last consultation on 28 May 2016).

¹⁸⁴ www.unicef.org/crc/ (last consultation on 28 May 2016).

¹⁸⁵ Lurie, 2003.

Several systems were established to categorise these rights, amongst which the ‘3 P’s, namely ‘provision’, ‘protection’ and ‘participation’.¹⁸⁶ Firstly, the rights to provision have the function to serve basic needs. Secondly, the rights to protection have to protect children from harmful acts and practices. Last, the rights to participation have to empower children and make sure that they are able to participate in all decisions affecting their lives.¹⁸⁷ In the opinion of Cantwell, the ‘3 P’s were chosen for various reasons. One of these is to avoid the traditional categorisation of the three generation rights. Another reason is to highlight the fact that children do not only have the right to receive services and to be protected but also to participate in decisions regarding their own lives and society as a whole.¹⁸⁸

5.4. Today’s challenge: finding the balance between protection and Participation

5.4.1. Protection and participation, complementary or conflicting?

Today, one of the main challenges within children’s rights is finding the balance between two of the ‘3 P’s, namely protection and participation rights.

The preamble of the CRC already highlights the vulnerable position of children by stating that “childhood is entitled to special care and assistance” and that “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth.” Protection rights are passive rights as they are exercised by adults. This category focuses on the innocence of the child and the need for protection against various potential dangers. On the contrary, participation rights are active rights as they focus on the child being an independent individual with its own status in legal matters and with a real influence in decision-making.¹⁸⁹

¹⁸⁶ This system was established by Defence for Children International (DCI), together with UNICEF; “Defence for Children International is an independent non-governmental organisation that has been promoting and protecting children’s rights on a global, regional, national and local level for more than 35 years.”, see www.defenceforchildren.org/ (last consultation on 25 June 2016).

¹⁸⁷ Lurie, 2003.

¹⁸⁸ Cantwell, 1993.

¹⁸⁹ NOU, 1995, p. 26.

Authors such as Cantwell, Verhellen, Flekkøy and Kaufman question whether these categories should be seen as complementary or conflicting with each other. All mentioned authors reach the same conclusion, namely that the three categories of rights should be seen as equally necessary and interdependent. According to them, the other option would go against the spirit of the Convention itself that had the purpose to highlight the indivisibility and interdependency of all articles, without establishing a hierarchy.¹⁹⁰

However, as justly stated by Lurie, reality shows that these categories may appear to be in tension when applied in practice. In his view, this tension is “related to the belief that too much responsibility or too much participation can be harmful to children.”¹⁹¹ Therefore, society feels the need to protect them “from participating in difficult decision-making or from feeling pressure to express their views on painful or controversial matters.”¹⁹²

5.4.2. How to find a balance?

The way in which both categories of rights can be exercised varies with the age and maturity of the child. In other words: they are placed in a developmental context, “where different rights have different importance at different ages.”¹⁹³ Flekkøy and Kaufman describe this relationship between protection and participation as more complex. Although they agree that age and maturity are both important elements in the assessment of finding a balance, they consider other factors regarding the individual context that must be taken into account. Examples are “the experience of the child, the situation, the consequences of the decisions to be made and the benefits of increasing experience and autonomy.”¹⁹⁴

¹⁹⁰ Cantwell, 1993; Verhellen, 1997, p. 77.

¹⁹¹ Lurie, 2003.

¹⁹² Ibidem.

¹⁹³ Lurie, 2003.

¹⁹⁴ Flekkøy and Kaufman, 1997, pp. 66-67.

In the next chapter, I discuss which parameters the CRC itself as well as its monitoring body, the Children's Rights Committee, provide in finding the balance. Thereafter, I apply these 'guidelines' to the case of euthanasia for minors.

5.4.3. *The competency debate*

In the view of Lansdown, there is too much emphasis on the vulnerability of the child "due to inaccurate perceptions of childhood at the expense of their right to participation",¹⁹⁵ which undermines their right to participation.¹⁹⁶ She states that the cause of this is largely socially and politically constructed, "based on social and historical attitudes about extended childhood in industrialised countries [...] which are neither universal nor inevitable."¹⁹⁷ Verhellen finds that children still have to rely on their parents or legal guardians in many cases due to the lack of recognition of their competence.¹⁹⁸

Flekkoy and Kaufman state that the competence argument could be legitimate when there is "a real need for protection or consideration of the child and what is in his or her best interest."¹⁹⁹ However, this is only the case when it is not 'misused' as "a rationalisation for unreasonably limiting children's participation rights."²⁰⁰ According to them, a double standard has been set for children and adults: whereas children are expected to demonstrate their competence before being allowed to participate, adults are assumed to be competent until proven otherwise.²⁰¹

Now that I have given a short overview of the debate on the balance between protection and participation within children's rights, the next chapter will examine whether and how a human right to euthanasia would apply to minors.

¹⁹⁵ Lansdown, 1995, pp. 22-24.

¹⁹⁶ Ibidem, pp. 22-24.

¹⁹⁷ Ibidem, 1995, pp.22-24.

¹⁹⁸ Verhellen, 1997, p. 27.

¹⁹⁹ Flekkøy and Kaufman, 1997, p.48.

²⁰⁰ Ibidem,1997, p.48.

²⁰¹ Flekkøy and Kaufman, as cited by Lurie, 2003.

6. A human right to euthanasia for minors?

6.1. Introduction

Children are human beings. For this reason, a human right to euthanasia would naturally apply to minors. However, some issues occur that may (or may not) justify a difference in treatment compared to adults regarding this right. In this chapter, I aim to address whether euthanasia could be in conformity with children's human rights and if so, how this practice should be organised. In other words, how to find the balance between protection and participation? As already mentioned in the first chapter, the answers to these questions do not have the mere purpose to discuss the option of a universal human right to euthanasia for minors. They could also form a basic framework for states that want to legalise, decriminalise or simply hold a debate on euthanasia for minors, regardless of whether it must be considered a human right or not.

For this analysis, I focus on three human rights documents. The first one is the CRC because this is the main treaty within international human rights law that focuses on children's rights. The Convention developed a specific way of interpreting each of its articles, namely in the light of the four so-called 'guiding principles'. These are (1) the best interests of the child,²⁰² (2) the right to life, survival and development,²⁰³ (3) the principle of non-discrimination,²⁰⁴ and (4) respect for the views of the child.²⁰⁵ Therefore, I discuss the relevant rights in the CRC together under one section.

The two other documents that I examine are the UN Declaration on Human Rights and Bioethics (on the level of the UN) and the Convention on Biomedicine and Human Rights (on the level of the CoE). The reason for selecting these is that they offer special protection to people not able to consent. As children are often considered incompetent to give their informed consent, these provisions are of great relevance.

²⁰² Art. 3 CRC.

²⁰³ Art. 6 CRC.

²⁰⁴ Art. 2 CRC.

²⁰⁵ Art. 12 CRC.

I will not discuss every relevant right or every relevant right in detail to prevent too much repetition with the previous chapters. Therefore, I will not discuss the right to life or the right to health in detail anymore. However, the right to health also has an important participatory characteristic, namely the involvement of the child in health care decisions. These elements will be discussed throughout the analysis below.

6.2. The UN Convention on the rights of the child

6.2.1. The principle of non-discrimination

With regard to euthanasia, children are often perceived a vulnerable group as some argue that they are not capable of giving their informed consent.²⁰⁶ Therefore, one could say that they should fall outside the scope of a human right to euthanasia. In my opinion however, a total exclusion of children would be a violation of the principle of non-discrimination as enshrined in Article 2 CRC. As already stated in section 4.5, discrimination entails that a difference in treatment between persons in an analogous or relevantly similar positions is discriminatory if there is no objective and reasonable justification. This last condition means that the difference in treatment must be proportionate to the aim pursued.

As it is clear that protecting the vulnerable is a legitimate aim, the more complex question is whether a total exclusion of minors from the scope of a human right to euthanasia (or of national law in case an individual state decides to decriminalise or legalise it) can be labelled proportionate. Throughout the years, more research has been conducted on the competence of minors in relation to health care decisions. These studies show that, in general, “the cognitive capabilities of a minor with an age of 15 years or older can be compared to those of an adult patient.”²⁰⁷ Therefore, excluding all minors is disproportionate in my view. An argument that is often invoked against this reasoning is that it would be contradictory to not give them the legal capacity to e.g. buy a car, but do give them the option to decide about their end of life.²⁰⁸ On this point, I

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²⁰⁷ Citation of Delbeke, 2014/2015, p. 167. She refers to T. Grisso en L. VierlinG, “Minor’s consent to treatment: a developmental perspective”, pp. 412-427 in *Professional Psychology*, vol. , pp. 422-423.

²⁰⁸ Jochemsen, 2001, pp. 7-12.

support the reasoning of the Belgian Constitutional Court regarding this issue. When examining the conformity of the Act that decriminalised active euthanasia for minors with the Belgian Constitution, the Court argued that “the fact that the minor is in principle incompetent to conduct legal actions regarding his person or goods does not prevent the legislature to partially deviate from this incompetency in the context of euthanasia to take into account the voluntary and deliberate choice of a minor who is capable to judge and who suffers persistent and unbearable.”²⁰⁹ What I derive from this reasoning is that the specific and exceptional elements belonging to the situation of a child that wishes to commit euthanasia justify a deviation from the general rule.

Even though I concluded that a total ban on euthanasia for minors if organised for adults would be disproportionate, I nevertheless argue that treating these two groups in exactly the same way would just as well amount to discrimination. As there are aspects that make children a more vulnerable group than adults, they should have additional protection regarding euthanasia.

6.2.2. The best interests of the child as the central notion

On the ground of Article 3 CRC, the best interests of the child shall be the primary consideration of states in all action concerning children, both in the public and private sphere.²¹⁰ Nonetheless, the way in which this obligation should be fulfilled in case of euthanasia is again subject of a very complex ethical and legal discussion. Therefore, this section will look into relevant aspects of the meaning of the best interests of the child as enshrined in Article 3 CRC to assess and determine its content with regard to euthanasia.

In its General Comment No. 14, the UN Committee on the Rights of the Child states that the best interests of the child “is a dynamic concept that encompasses various issues which are continuously evolving.”²¹¹ If any possible conflicts arise among rights enshrined in the Convention or other human right treaties, the best interests of the child

²⁰⁹ Belgian Constitutional Court, Judgment no. 153/2015, 29 October 2015, B.28.2.

²¹⁰ UN Committee on the Rights of the Child, *General Comment No. 14 on the Best Interests of the Child*, § 1.

²¹¹ *Ibidem*, § 11.

shall be taken into account to resolve this conflict.²¹² As the case of euthanasia is often represented as a matter of balancing the right to life against other rights, this notion offers the main guideline to find a balance and solve the conflict.

However, indicating this principle as the ultimate guideline is not sufficient. A next step is to examine what the content of this notion is in the context of euthanasia. The Committee tried to establish a framework for the assessment of the best interests of the child. However, it emphasises that “[this framework] does not attempt to prescribe what is best for the child in any given situation at any point in time.”²¹³ On the contrary, it should be determined on a case-by-case-basis because of its flexible and adaptable nature: “it should be adjusted and defined on an individual basis according to the specific situation of the child or children concerned, taking into consideration their personal context, situation and needs.”²¹⁴ The Committee regards this flexibility as positive because “it allows to be responsive to the situation of individual children and to evolve knowledge about child development.”²¹⁵ On the contrary however, it is also easier to manipulate.²¹⁶ As discussed in the previous chapter, children are seen more and more as autonomous subjects, also in health care settings. Because of the dynamic and evolving character of the best interests of the child, this evolution could have an influence on the way we think about children and their right to autonomy regarding euthanasia. Another conclusion that can be derived from the information above is that, when one accepts that euthanasia is not necessarily a violation of children’s human rights, there is not one ‘best interest of the child’. For each child, there should be an individual assessment on the ground of his specific context, also regarding euthanasia.

As children are often highly dependent on their parents (or other legal guardians), both legally and socially, it is necessary to consider their role in determining the best interests of the child, especially in situations where a conflict arises between the interests or rights of the parents and those of the child. First, the Committee found that “an adult’s judgement of a child’s best interests cannot override the obligation to respect

²¹² Ibidem, § 33.

²¹³ Ibidem § 11.

²¹⁴ Ibidem, § 32.

²¹⁵ Ibidem, § 34.

²¹⁶ Ibidem, § 34.

all the child's rights under the Convention."²¹⁷ These conflicts should be resolved on a case-by-case basis, "carefully balancing the interests of all parties and finding a suitable compromise."²¹⁸ However, a harmonisation is not always possible. Here, "authorities and decision-makers will have to analyse and weigh the rights of all those concerned, bearing in mind that the rights of the child to have his or her best interests taken as a primary consideration means that the child's interests have high priority and not just one of several considerations. Therefore, a larger weight must be attached to what serves the child best."²¹⁹ Of particular interest to the case of euthanasia is that the Committee mentions that "there might be situations where protection factors affecting a child [...] need to be assessed in relation to measures of empowerment [...]."²²⁰ In this type of situation, such as euthanasia for minors, "the age and maturity of the child should guide the balancing of the elements."²²¹ If a child expresses his or her wish to commit euthanasia, against the will of the parents, the first option seems to be to find a compromise. However, if the child keeps expressing that it wants to die, a case-by-case assessment must take place by authorities and decision-makers in which the best interests of the child must be taken as the primary consideration.

6.2.3. *The right to life*

Article 6 CRC states that "(1) States Parties recognise that every child has the inherent right to life, (2) States Parties shall ensure to the maximum extent possible the survival and development of the child." The UN Committee on the Rights of the Child found itself "concerned that euthanasia can be applied to patients under 18 years of age."²²² It did so in the concluding observations on the report of the Netherlands in 2015, one of the only two countries that decriminalised active euthanasia for minors. The Committee criticised the Netherlands for insufficient transparency and oversight of the practice. Therefore, it formulated a few recommendations, namely "(a) to ensure strong control

²¹⁷ UN Committee on the Rights of the Child, General Comment No. 13 on the Right to Protection from All Forms of Violence, § 61.

²¹⁸

²¹⁹ Ibidem, § 39.

²²⁰ Ibidem, § 83

²²¹ Ibidem, § 83.

²²² UN Committee on the Rights of the Child, Concluding observations on the fourth periodic report of the Netherlands, 8 June 2015, CRC/C/NDL/CO/4, § 28.

of the practice of euthanasia towards underage patients, (b) ensure that the psychological status of the child and parents or guardians requesting termination of life are seriously taken into consideration when determining whether to grant the request, (c) ensure that all cases of euthanasia towards underage patients are reported, and particularly included into annual reports of the regional assessment committees, and given the fullest possible overview; and (d) consider the possibility of abolishing the use of euthanasia towards patients under 18 years of age.”²²³ What can be concluded from this, is that the UN Committee on the Rights of the Child has not stated that euthanasia for minors would be a violation of the right to life as enshrined in the Convention. However, it is undeniable that it expressed itself very critical about this practice. This becomes particularly clear through the last recommendation to consider the possibility of abolishing the use of euthanasia towards patients under 18 years of age. What strikes me is that the Committee does not make a distinction between younger and older children in stating that the Netherlands should consider abolishing this practice. This actually goes against their own policy which states that the age and maturity of the child should be taken into account in giving due weight to the child’s view. This is especially the case because the Committee makes this distinction and mentions this fact when it comes to decision-making in health care setting (this will be discussed more in depth later).

6.2.4. *The right of the child to be heard*

Article 12 CRC is unique within the human rights system as it is the only provision that directly addresses the right to be heard from children.²²⁴ It states the following: “(1) States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (2) For this purpose, the child shall in particular be provided the opportunity to be heard in

²²³ UN Committee on the Rights of the Child, Concluding observations on the fourth periodic report of the Netherlands, 8 June 2015, CRC/C/NDL/CO/4, §§ 28-29, available at tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NLD/INT_CRC_COC_NLD_20805_E.pdf (last consultation on 26 May 2016).

²²⁴

any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.”

The UN Committee on the Rights of the Child found that the child’s right to express his or her views has to be respected to realise the provisions of the Convention, both in the context of individual health-care decisions and through the development of health policy and services.²²⁵ Furthermore, it emphasises that children, also those with a young age, “should be included in decision-making processes in a manner consistent with their evolving capacities.”²²⁶ Therefore, States Parties should provide children with information about treatments, effects and outcomes, “including in formats appropriate and accessible to children with disabilities.”²²⁷ Where the child’s safety or well-being requires this, States Parties need to ensure “that children have access to confidential medical counselling and advice without parental consent, irrespective of the child’s age.”²²⁸ One of the examples that the Committee gives is the situation in which there is a conflict between parents and the child over access to health services.²²⁹

Some countries introduced a fixed age in their legislation at which the right to consent transfers to the child without an assessment of capacity, which is applauded by the Committee. However, if a younger child can demonstrate capacity to express an informed view on her or his treatment, the Committee strongly recommends that States Parties ensure that this view is given due weight.²³⁰

6.2.3. *Evolving capacities of the child*

A concept that appears several times during the examination of the rights hereafter is that of the evolving capacities of the child. This principle is central to the balance

²²⁵ Ibidem, § 98.

²²⁶ Ibidem, § 100.

²²⁷ Ibidem, § 100.

²²⁸ Ibidem, § 101.

²²⁹ Ibidem, §101.

²³⁰ Ibidem, § 102.

between protection and participation.²³¹ It is enshrined in Article 5 CRC, which states: “States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.” Also in this case, the CRC takes a pioneer position as it is the first human rights document to include this principle.²³² The UNICEF Innocenti Research Centre recognised this in one of its reports by stating that “it establishes a direct relationship between the child and the State that challenges the presumption that parents have rights of ownership over the child”,²³³ which is the first time in international law.

The evolving capacities of the child aim to refer to “processes of maturation and learning whereby children progressively acquire knowledge, competencies and understanding, including acquiring understand about their right and about how they can best be realised.”²³⁴ Article 5 CRC lays a duty on parents to protect children by giving them guidance. However, they have to “continually adjust the levels of support and guidance they offer to a child”²³⁵, in accordance with the child’s evolving capacities. The UN Committee on Children’s Rights stated that “these adjustments take account of a child’s interests and wishes as well as the child’s capacities for autonomous decision-making and comprehension of his or her best interests.”²³⁶ Thereby, it is of importance that the Committee asks attention for the individual variations in capacities of children and the way in which they react to situations. This process should be considered positive and enabling, “not an excuse for authoritarian practices that restrict children’s autonomy and self-expression and which have traditionally been justified by pointing to

²³¹ UNICEF Innocenti Research Centre, *The evolving capacities of the child*, 2005, available at www.unicef-irc.org/publications/pdf/evolving-eng.pdf (last consultation on 11 July 2016), p. ix.

²³² *Ibidem*, p. ix.

²³³ Holmberg and Himes, 2000.

²³⁴ UN Committee on the Rights of the Child, *General Comment No. 7 on Implementing Child Rights in Early Childhood*, § 17.

²³⁵ *Ibidem*.

²³⁶ *Ibidem*.

children's relative immaturity and their need for socialisation.”²³⁷ To support this principle, parents “should be encouraged to offer ‘direction and guidance’ in a child-centred way, through dialogue and example, in ways that enhance young children’s capacities to exercise their rights, including their right to participation.”²³⁸

6.3. The protection of people not able to consent

The UN Declaration on Human Rights and Bioethics includes Article 7 on persons without the capacity to consent. This provision states that special protection must be given to persons who do not have the capacity to consent. When one wants to authorise medical practice, this “should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law.” However, “the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent.” Article 6 of the Convention on Biomedicine and Human Rights provides a similar protection. With regard to minors, the Article mentions that “[w]here, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.” Furthermore, “the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.”

6.4. Conclusion

A first conclusion that I derive from my analysis is that totally excluding children from the scope of a human right to euthanasia (or from the scope of the national law in case an individual state decriminalises or legalises euthanasia) would be a violation of the non-discrimination principle. However, treating adults and children in exactly the same way in relation to euthanasia would just as well amount to discrimination as children do have to be perceived a vulnerable group, in need of additional protection.

²³⁷ Ibidem.

²³⁸ Ibidem.

Although the Committee on the Rights of the Child did not state that this practice is a violation of the right to life, there are clear indications that it takes in a negative position towards euthanasia for children. As I mentioned, what strikes me is that the Court recommended considering the possibility of abolishing the use of euthanasia towards all patients under 18 years old, thereby not taking into account the age and maturity of each child in giving due weight to the child's view.

When organising euthanasia for minors, where a balancing of rights is very present, the best interests of the child should be seen as the central notion to be taken into consideration. Thereby, the Committee on the Rights of the Child emphasises that the content of this notion should be determined on a case-by-case basis. This indicates that an individual assessment should take place to determine the best interests of a child who wishes to commit euthanasia. As discussed in chapter 5, children are seen more and more as autonomous subjects of rights, rather than purely in need of protection. The fact that the Committee highlights the dynamic character of this provision could be interesting for the acknowledgment of children's autonomy when assessing the best interests of the child. In case of a conflict between the parents' rights or interests and those of the child, a first step is to try to find a compromise by carefully balancing their rights and interests against each other. If it is not possible to harmonise these, authorities will have to analyse and weigh these rights, with the best interests of the child as the highest priority. Therefore, if a child expresses his or her wish to commit euthanasia, against the will of the parents, the first option seems to be to find a compromise. However, if the child keeps expressing its wish to die, a case-by-case assessment must take place by authorities and decision-makers in which the best interests of the child must be taken as the primary consideration.

The UN Committee on the Rights of the Child found that the child's right to express his or her views has to be respected to realise the provisions of the Convention, both in the context of individual health-care decisions and through the development of health policy and services.²³⁹ Therefore, children have to be informed in an understandable

²³⁹ Ibidem, § 98.

way about their treatments, effects and outcomes. If there is a conflict between parents and children on euthanasia, the State should ensure that children can have access to confidential medical counselling. Even though the Committee is positive about the fact that some countries introduce a fixed age in their legislation at which the right to consent transfers to the child without an assessment of capacity, it does emphasise that also younger children can be capable. Therefore, also their view should be given due weight. The Committee finds that the amount in which a minor can decide for himself is dependent on his age and maturity, but also on other individual circumstances of the case. As euthanasia is a decision with very serious consequences, I would argue that a high level of competence is required.

Also the evolving capacities of the child have to be taken into account as they form another central element in finding the balance between protection and participation. This provision has an important similarity with the protection of people not able to consent, enshrined in the UN Declaration on Human Rights and Bioethics and the Convention on Biomedicine and Human Rights as it creates a duty on parents to protect children by giving them guidance. However, the more competent the child becomes, the lower the level of support and guidance required. Moreover, not every child reaches the same level of development at the same time. Therefore, the Committee asks to take these individual situations into consideration.

Now that a framework was constructed to facilitate the process of finding the balance between autonomy and protection, I will examine how the Netherlands and Belgium have implemented this into their legal systems regarding euthanasia for minors.

7. A comparative discussion on the implementation of children's human rights regarding euthanasia for minors: the cases of the Netherlands and Belgium

7.1. Introduction

In this chapter, I conduct a comparative law discussion on the implementation of children's human rights regarding euthanasia for minors in the Netherlands and Belgium.²⁴⁰ As mentioned in the first chapter, the choice for these two countries is rather logical in the sense that these are the only two countries in the world that decriminalised active euthanasia for minors under precise conditions. Therefore, the Netherlands and Belgium offer the most 'complete' analysis as this is the most controversial form of euthanasia in general.²⁴¹ This comparative law analysis will be performed through the functional method, which means that I focus on the function of the law to handle a specific issue. In this case, this means that I examine how both states find the balance between protection and participation with regard to euthanasia for minors. Hereby, I will mainly focus on the legal systems.²⁴² Other aspects such as history, public opinion and practice will only briefly be addressed.

7.2. The health care context

As discussed in chapter 4 and 5, euthanasia is often looked upon as a threat to the full implementation of the right to health. In general, it could be stated that both the Netherlands and Belgium provide a high level of health care.²⁴³ With regard to vulnerable groups, GRIFFITHS stated that Dutch health care is accessible to almost every inhabitant.²⁴⁴ According to the Belgian Health Care Knowledge Centre, Belgium takes

²⁴⁰ Belgium and the Netherlands signed all mentioned documents in this thesis, except for the Convention on Human Rights and Biomedicine. Whereas the Netherlands signed the treaty but did not ratify it, Belgium neither signed nor ratified it, see www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures?p_auth=46Ho8786 (last consultation on 12 July 2016).

²⁴¹ However, I am fully aware of the fact that both countries take in a *pro* euthanasia position.

²⁴² An aspect of the regulation on euthanasia that I will not discuss is the possibility to formulate a 'voorafgaande wilsbeschikking'. As this is part of a very complex legal matter, I decided to leave this out of the scope of this research.

²⁴³ Griffiths, 2008, p. 28; Belgian Health care Knowledge Centre, 2012.

²⁴⁴ Griffiths, 2008, p.28.

several measures to ensure access for more vulnerable population groups.²⁴⁵ Furthermore, both countries provide qualitative palliative care.²⁴⁶

7.3. The law

7.3.1. Passive euthanasia

Dutch law distinguishes three categories of minors regarding the refusal of treatment. The first category consists of minors under the age of 12. As they are not considered capable of making their own decisions regarding health care, parents and other caregivers have to consent in case of refusing treatment. However, children do have the right to be involved as much as possible in the process. Therefore, information has to be delivered to them in an ‘understandable’ way.²⁴⁷ The second category consists of minors from the age of 12 until 15. These have to give their consent for treatment, together with the parents. If the child refuses treatment, the principle is that no one can force him or her, even in case the parents disagree. Nevertheless, the caregiver does have to assure himself that the child is capable of understanding the consequences of his or her decision.²⁴⁸ When the refused treatment is medically necessary, the caregiver has to discuss this with the minor and try to find a compromise that is acceptable for the minor.²⁴⁹ The last category includes minors from the age of 16 and 17. They are considered capable to refuse treatment, without the consent of the parents. Even if the treatment is medically necessary, the caregiver has to respect the opinion of the child.²⁵⁰

Passive euthanasia is not explicitly mentioned in Belgian law as it does not fall under the scope of ‘euthanasia’. Therefore, children who want to refuse treatment fall under the scope of the general Act on Patients’ Rights of 22 August 2002. This regulation is

²⁴⁵ Belgian Health care Knowledge Centre, 2012, p. 239-240.

²⁴⁶ Griffiths, 2008, p. 18; Belgian Health Care Knowledge Centre, 2012, p. 39. However, a criticism that was formulated against Belgium regarding palliative care is that mainly terminal patients use this option whereas non-terminal people were still reluctant to consider this option. The Belgian Government was fully aware of this problem and adjusted the law on palliative care to make it more accessible to everyone.

²⁴⁷ Art. 448, para. 2 Dutch Medical Treatment Act.

²⁴⁸ Ibidem, Art. 450, para. 2.

²⁴⁹ Nederlandse Patiënten Consumenten Federatie, 2009, p. 9.

²⁵⁰ Art. 447 Dutch Medical Treatment Act; Nederlandse Patiënten Consumenten Federatie, 2009, p. 9.

based on the so-called ‘mature minor doctrine’.²⁵¹ In principle, minors will be legally represented by their parents and will not be able to exercise their rights independently. However, if he or she ‘can be regarded capable of assessing his or her interests in a reasonable way’ in the given context, he or she can exercise these rights independently.²⁵²

In essence, the difference between both systems is that the Netherlands chooses to grant the right to refuse treatment on the basis of age categories, whereas Belgium uses the criterion of ‘being capable of assessing his or her interests in a reasonable way. As mentioned in the previous chapter, the Committee on the Rights of the Child encourages States to install fixed age limits on the ground of which children are considered competent automatically. Dutch law introduces this mechanism as children are considered capable from the age of 16, without an assessment. However, the Committee further stated that children younger than this age can be capable too. Therefore, also their view should be given due weight. In this sense, the Belgian law is more inclusive as there is no mentioning of a minimum age. In my opinion, the latter system is preferable from a children’s rights point of view as it is stated many times that children’s competence to decide should not only be assessed on the ground of age but also on the ground of maturity. Therefore, introducing a minimum age to be able to refuse treatment seems to be arbitrary. Even though it might be possible to grant a child the right to refuse treatment if it is younger than 12 years old on some ‘emergency situation’ ground, the fact that there is a legal minimum limit may discourage physicians to use this option if necessary.

7.3.2. *Physician-assisted suicide*

In the Netherlands, physician-assisted suicide and active euthanasia fall under the same legal regulation.²⁵³ Under Belgian law, there is no explicit regulation for physician-

²⁵¹ Veny, 2014, p. 169.

²⁵² Art. 12 Belgian Act on Patients’ Rights of 22 August 2002.

²⁵³ Preamble, Wet van 12 april 2001, houdende toetsing van levensbeëindiging op verzoek en hulp bij zelfdoding en wijziging van het Wetboek van Strafrecht en van de Wet op de lijkbezorging (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding) (hereafter: ‘Dutch Law on Euthanasia’)

assisted suicide. Some tried to bring this practice under the scope of the Belgian Act on Euthanasia of 2002, but without success. In the meantime, both the National Council of the Order of Physicians and the Federal Control and Evaluation Commission for Euthanasia have stated that the Belgian Act on Euthanasia can be invoked as a ground of justification for physician-assisted suicide, on the condition that all criteria in this act are fulfilled.²⁵⁴ In practice, this means that the analysis on active euthanasia in the next section will equally apply to physician-assisted suicide.

7.3.3. *Active euthanasia*

7.3.3.1. The legalisation of active euthanasia for minors

In April 2001, the Netherlands became the first country in the world to decriminalise euthanasia for minors. This practice falls under the scope of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 (hereafter: Dutch Euthanasia Act of 2002).²⁵⁵

In Belgium, the Belgian federal government adopted the Act on Euthanasia of 28 May 2002 (hereafter: Belgian Euthanasia Act of 2002). However, a significant difference was that it only decriminalised euthanasia for adults and ‘emancipated’ minors.²⁵⁶ In 2014 however, this was changed and active euthanasia became possible for non-emancipated minors too. This did not come as a surprise, knowing that even during the initial debates, the question of including minors was raised. Nonetheless, several reasons occurred to exclude this group at that time. Some thought that euthanasia regarding minors was not enough discussed to be able to decriminalise this practice.²⁵⁷ Another reason was that proponents of euthanasia did not want to sabotage the

²⁵⁴ MELC CONSORTIUM, 2011, pp. 39-40.

²⁵⁵ The Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 1 April 2002 (hereafter: the ‘Dutch Law on Euthanasia of 2002’)

²⁵⁶ This is a legal mechanism that makes minors legally competent before the age of 18. See Art. 476 and 477 of the Belgian Civil Code. As a consequence, the parents lose their parental authority. A logical question that was raised is whether minors could become emancipated with the ultimate aim of being able to request euthanasia. There was no clear opinion on this matter.

²⁵⁷ Report Laloy and Van Riet, *Parl.St.* Senate 2000-01, 2-244/22, 37 en 59.

possibility of a legal framework for adults by bringing in the even more controversial theme of euthanasia for minors.²⁵⁸ The fact that non-emancipated minors were excluded was highly criticised by a few academics²⁵⁹ as well as in the parliament. As a result, several proposals were submitted to extend the scope of the law.²⁶⁰ In the end, the Act of 26 February 2014 was adopted to expand the scope of the Belgian Act on Euthanasia of 2002 to non-emancipated minors.²⁶¹ In the previous chapter, I defended the fact that excluding minors completely from the possibility of euthanasia when decriminalised for adults is a form of discrimination. Therefore, the inclusion of minors is a very positive evolution in my view. Furthermore, as euthanasia for minors already took place in practice, bringing it under the scope of the law brings it under strict supervision, which can only be encouraged due to the vulnerable position of children.²⁶²

7.3.3.2. Fixed age limits v. the competence to judge

Similar to the system for passive euthanasia, the Dutch Law on Euthanasia of 2002 distinguishes three age categories. First, children who are under the age of 12 are not able to request euthanasia. However, some argue that doctors could invoke the legal concept of the ‘emergency situation’.²⁶³ Second, children with an age between 12 and 16 who can be regarded capable of assessing their interests in a reasonable way can request euthanasia on the condition that the child’s parents give their consent.²⁶⁴ Last, a child of 16 or 17 years old can request euthanasia if he or she can be regarded capable of assessing their interests in a reasonable way. However, although the physician who

²⁵⁸ Veny, 2014, p. 164.

²⁵⁹ T. Vansweevelt, ‘De euthanasiewet. Toepassingsgebied en krachtlijnen’, *NjW* 2002, 456; E. Delbeke, ‘Juridische aspecten van zorgverlening aan het levenseinde’, *T.Gez.* 2011-12, p. 349, nr. 10.

²⁶⁰ See e.g. Wetsvoorstel van 28 oktober 2010 tot aanvulling van de wet van 28 mei 2002 betreffende de euthanasie, wat minderjarigen betreft, *Parl.St.* Kamer 2010-11, 0496/1; Wetsvoorstel van 19 december 2007 tot wijziging van de wet van 28 mei 2002 betreffende de euthanasie voor wat betreft minderjarigen, *Parl.St.* Kamer 2007-08, 0611/1 (heringediende versie van het wetsvoorstel van 15 juni 2006, *Parl.St.* Kamer 2005-06, 2553/1; Wetsvoorstel van 16 september 2008 tot wijziging van art. 3 van de wet van 28 mei 2002 betreffende de euthanasie, inzake euthanasie bij minderjarigen, *Parl.St.* Senaat 2007-08, 4-920/1.

²⁶¹ Act of 28 February 2014 amending the Act of 28 May 2002 concerning euthanasia, in order to allow euthanasia for minors.

²⁶² Pousset, Bilsen, Cohen, Chambaere, Deliens, and Mortier, 2010, pp. 547-553.

²⁶³ Legemaate, J., 2006, p. 32.

²⁶⁴ Art. 2, para. 4 Dutch Law on Euthanasia of 2002; The condition of the consent of the parent will be examined further in this chapter.

treats the patients has the obligation to involve the parents in the decision-making process, the latter do not have to give their consent.²⁶⁵ The parent's consent is a condition that will be addressed later in this chapter.

On the ground of Article 3 of the Belgian Act on Euthanasia of 2002, the minor patient has to be 'oordeelsbekwaam'. Even though it is quite difficult to find an equivalent of this term in the English language, it could be translated as having 'the competence to judge'. This entails that someone is capable of following a decision-making process in the broad sense, such as e.g. being able to understand information, process this information and to take a voluntary and autonomous decision.²⁶⁶ This is the only condition, which means that there are no age restrictions. Belgium did not follow the Netherlands on this point, mainly because the majority found that an age limit always has an arbitrary character.²⁶⁷ Furthermore, reaching the capability to judge is part of a larger process in which other individual circumstances and context could play a significant role.²⁶⁸ Specific factors that are scrutinised when assessing the competence to judge are age, maturity and the seriousness of the consequences of the decision.²⁶⁹

The reasoning I applied on the regulation of passive euthanasia in both countries can be equally applied to active euthanasia and physician-assisted suicide. In this light, it is positive that a debate has been started in the Netherlands to follow Belgium on this point and remove the age limits.²⁷⁰

²⁶⁵ Art. 2, para. 3. Dutch Law on Euthanasia of 2002.

²⁶⁶ Delbeke, 2012.

²⁶⁷ Leenen, Gevers and Legemaate, 2007, p. 171; Lantos and Miles, 1989, p. 461; Rosato, 1996, p. 49; Verslag Khattabi en Van Hoof, *Parl.St.* Senaat 2013-14, 5-2170/4, 8, 13, 14, 21, 22, 24, 27, 30 en 69.

²⁶⁸ Mannaerts and Mortier, 2006, p. 260.

²⁶⁹ Vansweevelt, 1997, p. 328.

²⁷⁰ This was e.g. requested by the Dutch Association for Paediatrics. See Dutch Association for Paediatrics, 2016.

7.3.3.3. Terminal v. non-terminal

In the Netherlands, adults as well as minors do not have to be in a terminal state to be able to request euthanasia.²⁷¹ In Belgium however, we see again a difference in treatment. Whereas minors have to be in a terminal state, adults and emancipated minors do not.²⁷² During the parliamentary debates, several definitions were given to the term ‘terminal’.²⁷³ In the end, the legislator decided to leave this assessment up to the physician, who has to judge the situation as a ‘normal, careful physician who is placed under the same circumstances’.²⁷⁴ The only guideline offered by the law is that non-terminal patients are not expected to die within one month. This can be derived from the condition that there has to be a waiting period of at least a month in case of a euthanasia request of a non-terminal adult or emancipated minor. If the death the patient can be foreseen within some days, weeks or months, it should be considered foreseeable within a reasonable time frame.²⁷⁵ I agree with E. DELBEKE who criticises this material condition. According to her, also non-terminal minor patients can suffer hopelessly and unbearably. This suffering can even be enforced by the fact that people know that they will not die within a short period of time.²⁷⁶ Therefore, this difference in treatment must have an objective and reasonable justification to not be discriminatory. In my opinion, this condition is lacking. To me, it seems as if the idea that “children shouldn’t die” is enshrined in this provision.

7.3.3.4. The type and amount of suffering

Under Dutch law, adults as well as minors can request euthanasia in case of hopeless and unbearable suffering. Although the law does not specify the type of suffering, the

²⁷¹ This is not explicitly mentioned in the law. However, due to the fact that the law does not mention that euthanasia is only a possibility for people who are in a terminal state, together with the practice shows that this is no condition under Dutch law.

²⁷² However, there are stricter conditions for non-terminal adults and emancipated minors than for terminal ones. See Art. 3, para. 3 Belgian Act on Euthanasia of 2002.

²⁷³ For more information, see Vansweevelt, 2003.

²⁷⁴ Verslag Laloy en Van Riet, *Parl.St.* Senaat 2000-01, 2-244/22, 683, 849 en 853; Vansweevelt, 2003, p. 251.

²⁷⁵ FCEC, Tweede verslag aan de wetgevende kamers (2004-05), *Parl. St.* Kamer 2006, 2733/001, 61.

²⁷⁶ Delbeke, 2014/2015, p. 168, para. 18.

Aanwijzing vervolgingsbeslissing inzake levensbeëindiging op verzoek (euthanasie en hulp bij zelfdoding) has made clear that the suffering can be the consequence of a physical as well as a psychiatric illness. However, these illnesses must be medically classifiable. ‘Hopeless’ entails that the illness or condition must be incurable. Furthermore, it must not be possible to alleviate the suffering. The use of the word ‘unbearable’ indicates that the suffering has to reach a certain minimum level.²⁷⁷

The Belgian Act on Euthanasia of 2002 imposes almost the same conditions as the Dutch legislation. Minors have to find themselves in a medically hopeless situation of continuous and unbearable suffering due to an accident or a disease that cannot be alleviated. However, again, the Belgian legislator treats adults differently from minors on this point. Whereas adults and emancipated minors can request euthanasia for physical as well as mental suffering, only have this possibility in case of physical suffering.²⁷⁸ During the parliamentary debates, many expressed their significant preference to exclude mental suffering for minors. One concern of the legislator was that he did not want to encourage depressive teenagers to request euthanasia, contrary to the strong anti-suicide policy of the Belgian Government.²⁷⁹ Others disagreed, arguing that giving young people the ability to commit euthanasia for mental suffering could form an opportunity to open a dialogue between the medical personnel and the patient.²⁸⁰ The main reason however was based on statistics showing that there are almost exclusively cases of physical suffering.²⁸¹ Furthermore, it is very difficult to diagnose a minor with a psychiatric disease and even more challenging to determine the

²⁷⁷ Aanwijzing vervolgingsbeslissing inzake levensbeëindiging op verzoek (euthanasie en hulp bij zelfdoding) of 1 January 2013, para. 5.3.

²⁷⁸ Art. 3, para. 1 Belgian Act on Euthanasia of 2002; Interestingly, the original law proposal did not limit euthanasia for minors to physical suffering. However, during the parliamentary debates, many expressed their preference to exclude mental suffering.

²⁷⁹ See Hand. United Commissions for the Justice and for the Social Matters 2013-14, 4 December 2013, No. 5-2170/4, 45, 47; Hand. United Commissions for the Justice and for the Social Matters 2012-13, 56; Hand. United Commissions for the justice and for the Social Matters 2013-14, 4 December 2013, No. 5-2170/4, 41, 47, 56.

²⁸⁰ Thuyt, 2013, pp. 8-13.

²⁸¹ Report Khattabi and Van Hoof, *Parl. St.* Senate 2013-14, 5-2170/4, 61, 62.

incurability.²⁸² Others declared that it is possible to distinguish a depression related to adolescence and an incurable psychiatric disease.²⁸³

According to E. DELBEKE, this very strict condition for minors might be formulated stricter than the legislator wanted: “The condition of physical suffering implies that the patient has to have physical pain before euthanasia can be committed. Combined with the condition that the suffering may not be alleviated, this means that euthanasia cannot be applied when the physical pain and other symptoms of the minor patient can be controlled.”²⁸⁴ Therefore, she asks herself whether this was the result that the legislator aimed for, “when a minor cancer patient, who is suffering physically because of his severe and incurable disease, but of whom the symptoms could be controlled with the help of pain treatment, [...] strictly speaking cannot commit euthanasia.”²⁸⁵ Although the legislator probably wanted to exclude the possibility for minors that they would be able to commit euthanasia for a psychiatric disease, this is already prevented by the fact that the patient should die within a reasonable time due to this disease.²⁸⁶ In my opinion, the reasoning of the Government is not sufficient enough to justify the difference in treatment between adults and minors on this aspect.

7.3.3.5. The consent of the parents

According to Dutch law, the parents or legal guardians have to give their consent to be able to commit euthanasia for minors who are 12 until 15 years old. From the age of 16, the physician who treats the patient still has the obligation to consult the parents. However, their advice is non-binding. In Belgium however, the parents have to give their consent regardless of the age of the minor. First of all, one could say that this condition is the externalisation of the duty for parents to protect their children and provide them with the necessary guidance. However, the fact that parents have to give

²⁸² Ibidem, 64.

²⁸³ Ibidem, 68.

²⁸⁴ Delbeke, p. 168, para. 17.

²⁸⁵ Ibidem, p. 168, para. 17

²⁸⁶ Ibidem, p. 168, para. 17.

their consent is partially against the spirit of the Act itself, namely giving more autonomy to children to decide on the end of their life. Moreover, the fact that a minor is considered ‘competent to judge’ entails that he should be able to make an independent and well-considered decision. Furthermore, the Belgian law does not make a distinction between younger and older children, such as the Netherlands. This be considered a lack of recognition of children’s evolving capacities and their right to be heard. Therefore, I would criticise this point in Belgian law. However, the little research that has been conducted in Flanders on the attitude of minors towards euthanasia for children learns us that children, both these who have suffered from a serious illness as those who do not, wish that their parents play a very decisive role in the procedure.

HOWEVER, the little research that we have on the attitudes of Flemish children on euthanasia for minors learns us that children, both children that have suffered from a serious illness as those who don’t, wish that their parents play a very decisive role in the procedure.

7.3.3.6. Other procedural requirements

On the ground of Article 2 of the Dutch Act on Euthanasia, a physician has to fulfil a list of requirements of due care. These are that the physician has to ensure himself that (1) the patient’s request was voluntary and carefully considered, (2) the patient’s suffering was unbearable and there was no prospect of improvement, (3) he informed the patient concerning ‘his situation and his prospects, (4) he and the patient were convinced that there was ‘no reasonable alternative in light of the patient’s situation, (5) he consulted at least one other, independent physician who must have seen the patient and given a written opinion on the requirements of due care, (6) he terminated the patient’s life or provided assisted suicide with due medical care and attention and (7) he reported the case to the municipal pathologist. The Human Rights Committee found itself concerned that these are exactly the same requirements as for an adult who request suicide.²⁸⁷

²⁸⁷ Committee on the Rights of the Child, *Concluding observations on the fourth periodic report of the Netherlands*, 8 June 2015, CRC/C/NDL/CO/4, § 28.

Also Article 3 of the Belgian Act on Euthanasia of 2002 formulates very similar requirements of due care that have to be fulfilled by the physician who treats the patient. Firstly, he has to inform the patient about his health situation and life expectation. Moreover, he has to discuss the patient's euthanasia request with the patient himself and discuss any remaining options, whether therapeutic or palliative, and their implications. Also, the physician has to ensure himself, together with the patient, (1) that the situation in which the patient finds himself is no reasonable alternative to euthanasia and that the request of the patient is entirely voluntary, (2) of the continuous physical and mental suffering of the patient and the sustainable character of his request, (3) he has to have multiple conversations with the patient that will be spread over a reasonable period of time, taking into account the development of the health condition of the patient, (4) he has to consult another independent physician to assess the seriousness and the incurable nature of the condition. Furthermore, he must be qualified to judge the condition. This is however a non-binding advice, (5) the request must not only be discussed with the physician who treats the patient but also with medical personnel in case there is a regular contact with the patient, (6) also, the patient has to get the chance to discuss his request with his family and friends that he appoints himself. However, this only happens on the request of the patient and, (7) in general, the physician must ensure himself that the patient has had the opportunity to talk about his request with the persons he wishes to meet.

Besides these general obligations, some additional preconditions were formulated for euthanasia requested by a minor. The most significant one is that the physician who treats the minor patient must consult a child or youth psychiatrist or psychologist to give advice on the previously discussed competence to judge. The Belgian Constitutional Court judged that this advice must be considered binding.²⁸⁸ Furthermore, the physician has to consult the legal representatives of the minor and give them all information. Furthermore, he has to ensure himself of the consent of the parents.²⁸⁹ The request of the

²⁸⁸ Belgian Constitutional Court, Judgment no. 153/2015, 29 October 2015, B.28.2

²⁸⁹ Art. 3, para. 2, °7 Law on Euthanasia.

minor patient, and the consent of the parents in the case of a minor, has to be written down. If the patient is not able to sign anymore himself, this can be done by an adult that is assigned by the patient himself and that has no material interest in the death of this patient. The request of the patient is reversible at any time. After the patient has committed euthanasia, psychological help is offered to all people involved.²⁹⁰

7.3.3.7. Controlling mechanisms

Controlling mechanisms are very similar in both countries. However, they do differ on some points.

Under Dutch law, the physician has the obligation to write a report in which he has to motivate why he respected the requirements of due care as formulated by law. Thereafter, an independent pathologist examines the body on the way and with which means euthanasia took place. He also has to write a report on his findings. Both the reports of the physician and the pathologist are sent to the Regional Review Commission. If the commission has further questions, it can still contact the physician. If the Review Commission finds that the euthanasia took place in accordance with the law, the procedure ends. However, if the Commission is in doubt, the report will be send to the Public Prosecutor, as well as to the ‘regional inspector’. Whereas the Public Prosecutor can decide to prosecute the physician, the inspector has the competence to impose disciplinary punishments.²⁹¹

Under Belgian law, the physician has to fill in an anonymous registration document on all the conditions described by law. This document is sent to the Federal Evaluation Commission on Euthanasia that conducts an *a posteriori* check. Similar to the Dutch system, if the Commission decides that all the conditions are met, the procedure ends. If the body however decides with a two third majority that the conditions do not seem to be met, the report will be send to the public prosecutor, similar to the Netherlands.

²⁹⁰ Art. 3, para. 4, °1. Belgian Act on Euthanasia of 2002.

²⁹¹ Chapter 3 Duth Act on Euthanasia of 2002.

Moreover, if its members are in doubt, the anonymity of the registration document can be lifted with a normal majority vote to ask some further information to the physician.²⁹²

From this information, it seems clear that the Netherlands has a stronger controlling system on several points. An important one however that has not been mentioned yet is the fact that both Dutch and Belgian physicians have the obligation to report on every administered euthanasia request. However, Belgian law does not provide an explicit sanction whereas Dutch law is very strict.²⁹³ According to a survey, only 53 percent of Belgian physicians reported on all euthanasia cases.²⁹⁴ Although this percentage has increased through time, it has not yet reached the 92 percent of the Dutch physicians in 2010.²⁹⁵

Another debate that is sometimes raised, both in the Netherlands and Belgium, is whether there should be an *a priori* controlling mechanism. However, this option has been rejected, e.g. to make the already stressful situation not even more stressful for the patient and his parents. Furthermore, as only terminal children can request euthanasia, there is often not much time for long procedures.²⁹⁶

7.4. Conclusion

To me, it is very difficult to identify or select the system that found the best balance between protection and participation as they both possess very clear advantages and disadvantages. In my view, both systems seem to struggle with finding the exact balance between protection and participation. However, I would argue that they struggle on different points in their regulation.

²⁹² Chapter 5 Belgian Act on Euthanasia of 2002.

²⁹³ Brochier, De Loze, Diesbach, Montero, 2012.

²⁹⁴ MELC CONSORTIUM, 2011, pp. 275-291.

²⁹⁵ Van Der Heide (eds.), 2012, p. 232.

²⁹⁶ Delbeke, 2012, pp. 173-174.

Belgian law provides a much more inclusive approach as there are no age limits for minors to request euthanasia. In my view, this was a very positive and deliberate choice from the legislator. This system responds the most to one of the 'red threats' throughout the Convention, namely that competence to make one's own decisions should not only be assessed on the ground of age but also on the ground of maturity. Moreover, the assessment of the child's competence to judge on the basis of a consult with a child and youth psychiatrist or psychologist seems to be a great and necessary protection mechanism. In my opinion, this is where the law is balanced out perfectly. However, there are aspects in which minors are treated different than adults under the guise of protection, such as the fact that they have to die within a reasonable time and the fact that they can only request euthanasia for physical suffering. As I stated in my analysis, many of the provided reasons do not seem sufficient enough to me to justify this difference in treatment. Also the fact that the Belgian law requires the consent of the parents, regardless the age of the child could be considered a lack of recognition of children's evolving capacities and their right to be heard. A last important point of attention is the controlling mechanism. The fact that not reporting euthanasia is not punished in practice seems to be a legitimate point of concern. The Children's Rights Committee did not yet draft a report on Belgium since the adoption of the law that made euthanasia for minors possible. In my view, the Committee would still highly criticise this practice as there is a clear general reluctance towards the possibility of euthanasia for minors. However, as I believe that the focus lays more on protection within the Belgian system compared to the Netherlands, it might be a bit more nuanced.

The Netherlands however seem to fail to balance the rights of the minor because of the invocation of a minimum age. Therefore, it is very positive that this limitation might disappear in the future. The strength of this system however is the fact that consent of the parents is not required for every age category and its transparent way of controlling.

8. End conclusion

This master's thesis focused on several aspects of euthanasia for minors. For a more detailed examination of the proposed research questions, I refer to the conclusions at the end of chapters 4, 5 and 7.

The first research question focused on the possible existence of a universal human right to euthanasia. Thereby, I examined whether this right could be derived from other already existing human rights or whether there are any developments towards a future human right to euthanasia. With regard to passive euthanasia, many indications can be observed, both on the basis of the right to privacy as on the basis of the prohibition of torture, inhuman and degrading treatments, towards the recognition of a human right to passive euthanasia. Nonetheless, with regard to active euthanasia and physician-assisted suicide however, human rights bodies still remain very reluctant. This does not mean however that no developments are taking place at the national level or regarding other highly ethical issues, such as abortion. These might put the door on hold for the practice of active euthanasia and physician-assisted suicide. When asking whether the establishment of a human right to euthanasia would be desirable at the moment, my answer is rather negative as I would argue that the right to health forms an important burden. As long as access to health care does not improve, a universal human right to euthanasia could form a realistic danger for vulnerable groups.

The second research question focused on the way in which a human right to euthanasia would be applicable to minors. A first conclusion that I derive from my analysis is that totally excluding children from the scope of a human right to euthanasia (or from the scope of the national law in case an individual state decriminalises or legalises euthanasia) would be a violation of the non-discrimination principle. However, treating adults and children in exactly the same way in relation to euthanasia would just as well amount to discrimination as children do have to be perceived a vulnerable group, in need of additional protection. When comparing my own view to the one of the

Committee on Children's Rights, it is clear that the Committee is way more reluctant towards the practice of euthanasia for minors.

On the ground of children's rights and rights aiming to protect the ones that are not able to consent, I aimed to create a kind of guiding line to find the balance between protection and participation when organising euthanasia. Besides the central notion of the best interests of the child, another conception that often occurred throughout the examination of the relevant rights was that it is of great importance to assess each child's best interests, competence, need for protection on a case-by-case basis, not only taking into consideration his or her age but also elements such as maturity and the specific context. The cases of the Netherlands and Belgium show that finding the balance between protection and participation on euthanasia for minors is a complex matter. As both systems possess clearly positive and clearly negative aspects in my opinion, I find it very difficult to indicate which system responds the most to the demands of children's human rights.

Last, I would like to reiterate my words that I used in the beginning. To me, the primary motivation for writing my thesis on euthanasia for minors is to break the silence and to initiate further discussion on this issue. Even if one does not agree on the possibility of euthanasia for children, the most important thing is that this group is given a voice. Because children also suffer. Children also die.

Epilogue

In the prologue of this master's thesis, I presented the story of Kina, a 13-year old Belgian girl who suffered from the so-called locked-in syndrome.²⁹⁷ One day, she formed the words 'I want to die'.

In the documentary, her father says: "You are shocked as a parent because you do not expect that your child is thinking about death. I asked her to repeat what she just told me. And again, she formed the words 'I want to die' and smiled. I asked her if she was joking. 'No', she said and smiled again. We thought she was just having a bad day." After three years, these moments where she expressed her unwillingness to live became longer and more intense. "Every day, she repeated that she was sad, wanted to die, wanted to go to her grandpa and wanted to go to the white light. During this period, we talked a lot with her about life and death", her father explains. Kina wanted to talk to the physician who treated her for her illness. This physician testifies in the documentary: "I asked her some very explicit questions, such as 'Kina, do you really want to die?', 'Do you know what this means?', 'Do you know what dying means?', 'Do you know that you will not be able to come back, that this would be forever?'" She continues: "I immediately had the impression that this girl was much more mature in her way of thinking than I could have ever presumed. She had been thinking in a deeper way than I have ever thought about life and death for myself so to speak." After this conversation, her physician, together with paediatricians of the revalidation centre where Kina stayed during the week, first tried to detect elements that made her want to die, such as pain, sleeping badly and so on. A temporary treatment with anti-depressants was started but Kina kept expressing that she wanted to die. Her father tells: "You do not want to give up your child but you also know that Kina does not want to live any longer, and who are we to decide about someone else's life? Kina made this decision herself. She did not decide this in one night but over a period of half a year to one year. It became more and more clear and we accepted it. If we had not given our consent as parents, it would not

²⁹⁷ This is a translation of the story of Kina as told in the Belgian documentary 'Ook kinderen sterven' ('Also children die') of 12 January 2015 in which different cases of euthanasia for minors are discussed. This documentary is available (only in Dutch, without subtitles) on the following link: dredactie.be/cm/vrtnieuws/videozone/programmas/koppen/2.37172 (last consultation on 5 May 2016).

have happened... but that, I think, would have been inhumane.” Her mother completes: “Loving someone is also about letting go.” At the moment of Kina’s death, active euthanasia²⁹⁸ for minors was not yet legalised in Belgium. Therefore, she only had the right to refuse treatment as she reached the age of 16. In her case, this was the cessation of the artificial respiration. Her father tells about the last night Kina lived: “We were awake the whole night. We laughed a lot, ate crisps, gave each other cuddles. It was difficult... but also beautiful in a way.” On Monday 22 April 2013, at the age of 17, Kina died. Her physician describes: “First, we gave her something that made her calm and told her that this was the moment where she would really fall into a very deep sleep. After administering the medicine, she slowly fell into a coma. It all happened in a very peaceful way. When we were sure that she was in a deep sleep, we stopped her artificial respiration and removed her cannula, as this was also one of her wishes. Some time passed and at one point, her heart stopped beating.” Her father concludes with the following words: “Kina laughed until the last second. She was so happy that she was freed from this world. Afterwards, this strengthens us a bit. It makes it a bit more bearable... but the chair remains empty, the room remains empty.”

²⁹⁸ For a definition of active euthanasia and an explanation of the difference between active and passive euthanasia, see *infra* ‘II. A definition of euthanasia’.

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