

UPPSALA UNIVERSITY

European Master's Degree in Human Rights and Democratisation

Academic Year 2018/19

Right to Life, Duty to Live?

The Case of Euthanasia for Persons with Dementia

Author: Petra Komel Gentilini

Supervisor: Professor Anna–Sara Lind

Abstract

Every three seconds a person develops dementia and with the aging world population the number of people affected by it is only expected to grow in the following years. Therefore as it is important to address end-of-life decisions including that of euthanasia; this work centers around the case of euthanasia for persons with dementia. In the context of this research the term euthanasia applies to situations in which a physician ends or assists in ending a life of a patient who is continuously and unbearably suffering, mentally or physically, and has no prospect of recovery. It encompasses explicit requests of patients that are capable to confirm their consent and cases in which a third person decides on behalf of an incompetent patient. First, the focus of this research is dedicated to answering the question whether euthanasia itself could be considered as a possible future human right. Hereby, the prospects of its development are addressed through the provisions of the existing human rights framework as established at the level of the United Nations and the Council of Europe. I argue that the present position of the two analysed human right bodies reflects positive indications towards the right of passive euthanasia. However, the practice of physician-assisted suicide and active euthanasia is still regarded as controversial. Nonetheless, this does not necessarily mean that the door is closed for the future establishment of a human right to euthanasia. Furthermore, this work deals with addressing a potential human right to euthanasia concerning persons with dementia. I argue that completely excluding persons with dementia from the scope of a human right to euthanasia qualifies as discrimination. Nevertheless, as persons with dementia are a vulnerable group they should be granted special support and protection when exercising this right. Lastly, this work presents the unique challenge that the progression of dementia poses on the proposed human right to euthanasia. Here, I argue that if the purpose of advanced directives is to give voice to the voiceless, persons in the advanced stages of dementia remain unheard.

Key words: euthanasia, human rights, dementia, advance directive, decision-making capability, the Netherlands.

Acknowledgment

I would like to express my sincere gratitude to my supervisor Professor Anna-Sara Lind for her meaningful encouragement, support and guidance provided. It was a real privilege and honour for me to have such an inspiring person as my supervisor. Tack så mycket!

This thesis could not have been accomplished without the encouragement and support from my family. I would like to thank my parents and my grandfather for always believing in me and standing behind my decisions.

List of abbreviations

| | |
|--------|--|
| UDHR | Universal Declaration on Human Rights |
| UN | United Nations |
| ECHR | European Convention on Human Rights |
| HRC | Human Rights Committee |
| ICCPR | International Covenant on Civil and Political Rights |
| CoE | Council of Europe |
| ECtHR | European Court of Human Rights |
| UK | United Kingdom |
| CAT | Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment |
| NIHRC | Northern Ireland Human Rights Commission |
| CRPD | Convention on the Rights of Persons with Disabilities |
| ICESCR | International Covenant on Economic, Social and Cultural Rights |
| ESC | European Social Charter |
| WHO | World Health Organization |
| OEWGA | Open-Ended Working Group on Ageing |
| RTE | Regional Euthanasia Review Committee (<i>Regionale Toetsingscommissie Euthanasie</i>) |

Table of Contents

| | |
|---|----|
| Abstract | 4 |
| Acknowledgment..... | 5 |
| List of abbreviations | 6 |
| Table of Contents | 7 |
| Prologue | 10 |
| The Power of Language | 11 |
| Introduction | 12 |
| Introduction to the thesis topic | 12 |
| Research questions | 13 |
| Methodological considerations..... | 14 |
| Delimitations | 16 |
| Chapter Progression | 16 |
| 1. Definitions..... | 18 |
| 1.1. Defining Euthanasia | 18 |
| 1.2. Forms of Euthanasia..... | 18 |
| 1.2.1. Active and Passive Euthanasia | 18 |
| 1.2.2. Voluntary and Non-Voluntary Euthanasia | 19 |
| 1.2.3. Physician Assisted Suicide and Euthanasia..... | 20 |
| 1.2.4. Euthanasia as Interpreted in this Research | 20 |
| 1.3. Defining Dementia | 20 |
| 1.4. Stages of Dementia..... | 21 |
| 1.4.1. Mild Dementia..... | 22 |
| 1.4.2. Moderate Dementia | 22 |
| 1.4.3. Advanced Dementia | 22 |
| 1.4.4. Dementia as Interpreted in This Research..... | 23 |
| 2. The Notion of Human Dignity | 24 |
| 2.1. Introduction | 24 |
| 2.2. Human Dignity in Human Rights Documents..... | 24 |
| 2.3. Human Dignity and Euthanasia..... | 25 |
| 2.4. Concept of Dignity and Personal Autonomy..... | 26 |
| 2.5. Conclusion..... | 27 |
| 3. Euthanasia as a Human Right..... | 28 |

| | | |
|--------|--|----|
| 3.1. | Introduction | 28 |
| 3.2. | Right to Life | 28 |
| 3.2.1. | The Right to Life at the United Nations | 29 |
| 3.2.2. | The Right to Life in ECtHR Case Law..... | 30 |
| 3.3. | Right to Privacy..... | 33 |
| 3.3.1. | The Right to Privacy at the United Nations..... | 34 |
| 3.3.2. | The Right to Privacy in ECtHR Case Law | 34 |
| 3.3.3. | Margin of Appreciation | 38 |
| 3.3.4. | Slippery Slope | 40 |
| 3.4. | Prohibition of Torture, Inhuman and Degrading Treatment..... | 42 |
| 3.4.1. | Torture | 43 |
| 3.4.2. | Inhuman and Degrading Treatment..... | 46 |
| 3.4.3. | Inhuman and Degrading Treatment in ECtHR Case Law | 47 |
| 3.4.4. | Northern Ireland Abortion Case | 49 |
| 3.5. | Principle of Non-Discrimination | 51 |
| 3.5.1. | Principle of Non-Discrimination at the United Nations | 51 |
| 3.5.2. | Principle of Non-Discrimination in the ECtHR Case Law..... | 52 |
| 3.6. | Right to Health | 53 |
| 3.6.1. | Right to Health at the United Nations | 53 |
| 3.6.2. | Right to Health at the CoE Level | 55 |
| 3.7. | National Legal Developments - Current Examples..... | 57 |
| 3.8. | Conclusion..... | 59 |
| 4. | Legal Capacity of Persons with Dementia within International Law..... | 63 |
| 4.1. | UN Convention on the Rights of Persons with Disabilities (CRPD) | 63 |
| 4.1.1. | From Substitute Decision-Making Paradigm Towards Supported Decision-Making ... | 65 |
| 5. | A Human Right to Euthanasia for Persons with Dementia | 69 |
| 5.1. | Introduction | 69 |
| 5.2. | UN Convention on the Rights of Persons with Disabilities | 70 |
| 5.2.1. | Equality and Non-Discrimination..... | 70 |
| 5.2.2. | Right to Life | 71 |
| 5.2.3. | Equal Recognition Before the Law | 72 |
| 5.2.4. | Right to Health | 74 |
| 5.3. | Protection of Persons Without the Capacity to Consent..... | 75 |
| 5.4. | Conclusion..... | 76 |

| | |
|--|----|
| 6. The Dilemma Surrounding Dementia and Euthanasia | 78 |
| 6.1. Introduction | 78 |
| 6.2. Validity and Effectiveness of Advanced Directives in Dementia | 78 |
| 6.3. Evidence from the Dutch practice | 81 |
| 6.3.1. Euthanasia Code 2018 | 81 |
| 6.3.2. Early Death as a Guarantee | 83 |
| 6.4. Conclusion..... | 83 |
| 7. End Conclusion | 85 |
| References | 87 |

Prologue

On 31 December 2013, 93 year-old Irena, a fully independent grandmother with an impeccable memory, suffered an ischemic attack, interrupting the blood flow to her brain. Upon waking up in the hospital, she no longer recognized her family and had been diagnosed with vascular dementia. At first Irena was able to move independently but quickly she was confined to bed. After spending the next three months of her life at the hospital and at the rehabilitation centre, she had been moved to the retirement home where she required 24 hour care. This disease transformed Irena, stealing her memories and her words, leaving behind a weak body with an empty stare. Three years later, on the 27th of January 2017, Irena lost her physical life.

As Irena's granddaughter I directly experienced how dementia robbed her of her independence as well as how it robbed me of my grandmother. Doctors at the retirement home made it clear that there was no possibility of improvement and that it was only a matter of when her body would *give up*. While driving back home from one of my visits, a question hit me - would I rather decide to lose my life or lose myself the way she did?

The Power of Language

Language and the words used when discussing dementia and persons living with it can have a great impact on how they are viewed and treated within the society as well as how they see themselves.

Knowing the amount of fear, stigma and negativity often attached to ‘dementia’, this work, in-line with the guidelines issued by DEEP¹, avoids using terms such as: *suffering; demented patient; victim; burden; or living death*. Instead it consistently talks about persons with dementia. The reason behind this decision is to highlight that behind dementia there are humans with life stories and memories who each experience and perceive dementia in a unique, subjective way. Hence we should not allow dementia diagnosis to define their entire existence.

¹ DEEP 2014, pp. 2-3.

Introduction

*If you don't want to die too late, you will have to die too early. Simply because dying on time is too difficult.*²

Henk Blanken, *My Death Is Not My Own*

Introduction to the thesis topic

Centring around euthanasia for persons with dementia, this work will deal with cases similar to the one presented in the prologue. Deriving from the Greek words *eu* and *thanatos* which together stand for good death,³ euthanasia is a more controversial issue than its etymological origins belie. Due to its ethical, medical, legal and religious dimensions, euthanasia represents one of the most complicated issues relating to several human rights. With the improved life expectancy globally⁴, developments made in medical technology and religious organizations losing their influence, the debate over legalising euthanasia is gaining its momentum worldwide.⁵

The issue of euthanasia becomes even more controversial when it comes to persons diagnosed with dementia. Unfortunately there is already a great deal of stigma attached to dementia, making the possibility of providing euthanasia for these cases an uncommon topic of public debate. Every three seconds a person develops dementia⁶ and the number of people affected by this disease will continue to rise as our population ages. In light of these concerning forecasts for the future and my own personal experience, this work will shed light on this issue and aims to contribute to this discussion by offering a perspective grounded in a human rights framework.

Despite some countries, such as Belgium and the Netherlands, having an established euthanasia law, dementia poses unique problems as to the exercising of this legal procedure. Euthanasia may be legal in those countries but it is not expressed as a right. This leaves those seeking euthanasia in the event of a dementia diagnosis without a guarantee that their wishes expressed in an advance euthanasia directive written while still mentally competent will

² Blanken 2018a (emphasis added).

³ For a more elaborate definition of euthanasia see chapter 2.

⁴ World Health Organization 2017a, p. 2.

⁵ Kilda and Gusha 2016, pp. 73–4.

⁶ Alzheimer's Disease International 2018, p. 32.

indeed be honoured.⁷ Doctors are allowed to euthanize individuals but are not *obliged* to do so. A central argument in favour of establishing the euthanasia law is one's right to self-determination. The paradox in cases of dementia is that the last word in the advanced dementia is not owned by the individual or his family but by the acting doctor whomever that may be.⁸ In reality, few doctors are willing to perform euthanasia on individuals that are no longer mentally capable of making a well-founded request for a dignified death.⁹

Research questions

This work will use a human rights framework to address several research questions in connection with euthanasia for people with dementia.

Euthanasia being one of the most complex human rights issues, the first and primary research question will be if euthanasia *itself* could be considered as a possible future human right; *what are the prospects of developing a Right to Euthanasia?*

This question will be addressed through the following sub-questions:

- 1) Do any of the provisions within the existing human rights framework lend themselves to the creation of a human right to euthanasia?
- 2) Have there been any developments in the European Court of Human Rights case law or jurisprudential developments elsewhere that could indicate a trajectory towards considering euthanasia as a human right?

The second guiding research question addresses a potential human right to euthanasia concerning people diagnosed with dementia in all stages of the disease. This question will be divided into the following two sub-questions:

- 1) How should this human right be practiced in compliance with the human rights of persons with dementia?
- 2) What are the unique conditions posed by dementia on the proposed human right to euthanasia?

⁷ Blanken 2018a.

⁸ Blanken 2018b.

⁹ Dresser 2018, p. 117.

Methodological considerations

As euthanasia can be deconstructed in multiple scientific strata, it is important to point out that its density *inter alia* combines law and ethics. These are the two main components, and this thesis aims at showing the nexuses in which they intertwine, touching upon the end-of-life decisions when relevant as well.

For the first part of the research, an analysis of numerous human rights treaties, and documents on international inter-governmental decisions will be examined; also relevant case law of the competent international tribunals and bodies will be scrutinized and taken into consideration. In order for the analysis to be as precise and pertinent as possible, the focus will be given to both international human rights protection system, as recognized within the United Nations, and the most prominent component of the European regional human rights protection system, i.e. Council of Europe and the role of its respective documents. While the motivation for scrutinizing the United Nations system stems from the idea of framing the answers concerning a universal human right to euthanasia, which could potentially also be founded upon the decisions of the international community, and later transmitted to national legislations, the focus on the European system evolved from the fact that European Court of Human Rights still remains the only human rights court, which had established a significant collection of the case law on end-of-life decisions. Moreover, another reason for focusing on the European system stems from the fact that I present the limits of legal euthanasia in practice, through evidence from the Dutch practice.

Within the scope of the above mentioned systems, the thesis primarily examines the Convention on the Rights of Persons with Disabilities for the latter includes the rights of persons with dementia and the European Convention on Human Rights for the purpose of analysing the prospect of establishing a human right to euthanasia based on its principles. Moreover, several other international human rights treaties, such as: the International Covenant on Civil and Political Rights; the International Covenant on Civil and Political Rights; the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment; the Universal Declaration on Bioethics and Human Rights; the Oviedo Convention on Human Rights and Biomedicine and the European Social Charter were taken under examination in cases in which their content could present significant added value to the subject of the thesis.

Lastly the unique challenge accompanying the progression of the dementia is presented through the analysis of theoretical and philosophical discussions. In order to show how this problematic is reflected in practice the evidence from the Dutch practice is analysed. This is done through the examination of Euthanasia Code 2018 and annual Regional Euthanasia Review Committee's reports.

Delimitations

Largely governing the existing legislation related to euthanasia requests is the issue of unbearable suffering without prospect of improvement.¹⁰ In cases of mental diseases this unbearable suffering remains insufficiently understood, especially when individuals are not perceived mentally competent to voice it.¹¹ However this research only focuses on persons diagnosed with dementia, both in early and advanced stages without being limited to individuals who expressed their wishes in an advanced directive while still mentally competent. This flexibility allows for an exploration of the impact that euthanasia as a human right would have on persons in both early and advanced stages of dementia. However this work does recognize that advance stage dementia presents its own difficulties.

The thesis addresses the research questions from a human rights, legal, philosophical and ethical perspectives but does not include any religious or medical dimensions. I decided to exclude religious dimensions as I believe euthanasia should be an individual's personal choice and does not infringe upon anyone's right to religion.¹² Other than defining dementia and providing a topical explanation of its effects on mental capacity and decision-making, this work does not go into more medical details as the medical science is not the focus of this work.

The definition of euthanasia and of dementia as discussed in the first chapter further determine which aspects are excluded or included in the scope of the research.

Chapter Progression

In order to prevent any uncertainties which may occur due to the breadth of the term 'euthanasia', this work starts with a chapter clarifying the definition of euthanasia and dementia which was used in the context of the research. At the same time this chapter also clarifies which aspects of both euthanasia and dementia are included in or excluded from the research.

The second chapter turns to euthanasia as a possible human right. To analyse this research question, the notion of human dignity is first discussed, as it is the foundation of all human

¹⁰ Verhofstadt et al. 2017, p. 238; Government of the Netherlands 2019.

¹¹ Verhofstadt et al. 2017, p. 238.

¹² Taylor 2007, pp. 505-509.

rights, especially in the context of euthanasia. Euthanasia is sometimes referred to as a dignified death.¹³ Accordingly, the notion of ‘dignity’ seems essential for analysing the possibility of euthanasia as a human right.

In the third chapter euthanasia as a human right is addressed from different aspects, with the help of two sub-questions. The sub-questions discussed are:

- 1) Do any of the provisions within the existing human rights framework lend themselves to the creation of a human right to euthanasia?;
- 2) Have there been any developments in the European Court of Human Rights case law or jurisprudential developments elsewhere that could indicate a trajectory towards considering euthanasia as a human right?

In the following chapters the focus is devoted to applying a human rights framework to euthanasia in the cases of persons with dementia. As a point of departure the legal capacity that they enjoy under the Convention on the Rights of Persons with Disabilities is studied in chapter four. After outlining the legal capacities, chapter five examines whether a human right to euthanasia could be compliant with the rights of persons with dementia and how this practice should be properly conducted.

This is followed by chapter six which presents the unique challenge posed by progression of dementia on euthanasia practice. In order to present the limits of legal euthanasia in practice, it is explained through evidence from Dutch practice.

The work ends with an overall conclusion in which findings to my research questions are being discussed.

¹³Allmark 2002, p. 255.

1. Definitions

1.1. Defining Euthanasia

In the 17th century, the term *euthanasia* was first used in a medical context by sir Francis Bacon. He referred to a simple, happy and painless death, which prevented the physical suffering of the body and for which the doctor was indirectly responsible.¹⁴ Since euthanasia is a broad concept, presently there are many different interpretations of its meaning.¹⁵ This is reflected (and complicated) by the fact that the majority of states do not provide a formal definition in their legislation.¹⁶ Generally, euthanasia is any action or omission that causes or intends to cause the death of a patient, in order to prevent said patient's suffering.¹⁷ Though euthanasia may be definitionally broad, it is important to delineate and clarify its different forms.

1.2. Forms of Euthanasia

Euthanasia can be categorized as either *active* or *passive* depending on the actions of the third party.¹⁸ A further division into voluntary and involuntary euthanasia determines whether or not the person in consideration had expressed their wish or not, and whether their will is respected or not. There may be various combinations among the above-mentioned forms of euthanasia.

1.2.1. Active and Passive Euthanasia

Active euthanasia is interpreted in terms of causing death in an active way, that is, the way in which a third person *ensures* that a given person receives a deadly active substance in a certain way.¹⁹ In this sense, the euthanizer acts *upon* the euthanised. Usually, this is performed by a lethal injection or an overdose of tablets.²⁰

¹⁴ Sarafis et al. 2013, p. 22.

¹⁵ Dimmock and Fisher 2017, p. 123.

¹⁶ Groenhuijsen 2007, p. 4.

¹⁷ Sanchini et al. 2014, p. 1.

¹⁸ In this chapter of thesis, third person refers to a physician.

¹⁹ Sarafis et al. 2013, p. 22.

²⁰ Dimmock and Fisher 2017, p. 124.

Unlike active euthanasia, passive euthanasia refers to cases in which medical treatment is withdrawn or withheld in order to hasten death.²¹ Examples include switching off a life support machine, not resuscitating a person, abolishment of the existing treatment or not opting out for a medical procedure or intervention that could result in a prolongation of patient's life.²² It is important to keep in mind that not all withdrawals or withholdings of life prolonging medical treatment are considered passive euthanasia.²³ For any medical action to be defined as euthanasia there must be something done or not done with the purpose of causing death²⁴ which must be in the patient's best interest.²⁵

Many people perceive passive euthanasia as morally more palatable than active euthanasia. Many find it harder to see a third party kill a patient by a deliberate act than allowing a patient to die by withdrawing the treatment.²⁶ However, scholars such as James Rachels are correct in that there is no ethical difference between passive and active euthanasia. Switching off a life support machine is just as much of an action as administering a lethal injection is²⁷, and in both cases the third party's objective is to end the patient's life.²⁸

For the purposes of this work, the focus is solely on active euthanasia. This decision is motivated by the fact that dementia is a mental disorder which primarily attacks the brain and when the individuals make request for euthanasia they often want it to be performed before it is too late, and their body is giving in.²⁹

1.2.2. Voluntary and Non-Voluntary Euthanasia

Voluntary euthanasia implies that a competent patient made an explicit and voluntary request whereas in the case of non-voluntary euthanasia a guardian or a physician decides on behalf on an incompetent patient.³⁰ Both voluntary and non-voluntary euthanasia will be discussed as the issues of voluntariness, competence and consent are of major importance when it comes to persons with dementia.

²¹ Murray 2017, p. 67.

²² Australian Human Rights Commission 2016, p. 4.

²³ Garrard and Wilkinson 2005, p. 65.

²⁴ Euthanasia.com 2019.

²⁵ Garrard and Wilkinson 2005, p. 65.

²⁶ BBC 2014.

²⁷ Ibidem.

²⁸ Garrard and Wilkinson 2005, p. 65.

²⁹ Bomford 2019.

³⁰ Polaris and Lehmann 2016, p. 176.

1.2.3. Physician Assisted Suicide and Euthanasia

Euthanasia is generally defined as a physician intentionally, directly and knowingly acting with aim of causing death of another person (e.g. administering a lethal injection). In the case of physician assisted suicide the physician intentionally, directly and knowingly provides the means of death to another person for self-administration (e.g. providing a prescription for a lethal injection or dose of drugs).³¹

Both euthanasia and physician assisted suicide are included in this interpretation of forms of euthanasia as they share the same purpose, which is putting an end to a patient's unbearable suffering and helping them die when they explicitly request it. The only difference is in the person who makes the last step. If I were to accept the distinction between the two, assisted suicide is simply not applicable in the advanced stages of dementia.

1.2.4. Euthanasia as Interpreted in this Research

In the context of this work, the term of 'euthanasia' applies to situations in which a physician ends or assists in ending a life of a patient who is continuously and unbearably suffering, mentally or physically, and has no prospect of recovery. It encompasses explicit requests of patients that are capable to confirm their consent and cases in which a third person decides on behalf of an incompetent patient.

1.3. Defining Dementia

The syndrome of dementia is a progressive neurodegenerative process which, by affecting one or more cognitive domains, causes disability, dependency and decline in a person's ability to function and perform everyday activities.³² Dementia is a general term for several diseases which are mostly progressive, can affect behaviour, personality, perception, cognitive abilities or memory³³, but all types of dementia can impair decision-making capability³⁴. However no diagnosis of dementia automatically equates to incapability³⁵ as capability may change over time and as the individual might have the capability to decide on some less complex decisions

³¹ Strinic 2015, pp. 2–3.

³² Taylor and Close 2018, p. 303.

³³ Ibidem.

³⁴ Darby and Dickerson 2017, p. 270.

³⁵ Rodgers and Kass 2018, p. 924; Pennington et al. 2018, p. 778.

but has none when it comes to more complex ones.³⁶ In essence, capability, like decision-making can be measured in degrees.

While age is the strongest known risk factor, it is a common misconception that dementia is a natural and inevitable consequence of aging.³⁷ The most common cause of dementia is Alzheimer's disease which represents 60–70% of all dementia cases. However there are numerous other causes of dementia, namely dementia with Lewy bodies, vascular dementia, and frontotemporal dementia.³⁸ The boundaries between different causes are blurred while numerous causes often coexist.³⁹ Being a major cause of disability and dependence it impacts the psychological, physical and social well-being of not only the individuals afflicted by dementia but also their families, care-givers, communities and societies.⁴⁰

A lack of understanding and awareness of dementia often results in stigmatisation and barriers to diagnosis and care.⁴¹ Persons with dementia are often victims of discrimination and denied their human rights both in care homes and more generally in their community. They are also less likely to be diagnosed and receive proper care and support for any concurrent health problems that might cause a faster decline if left untreated.⁴²

Currently approximately 50 million people worldwide are affected by dementia, a figure that is predicted to grow to 82 million by 2030 and 152 million by 2050. It ranks as the second largest cause of disability for individuals aged 70 and older, and the seventh leading cause of death.⁴³

1.4. Stages of Dementia

Dementia usually progresses in three stages but each individual experiences the progression differently. It all depends on the impact of the disease and individual's personality and physical well-being before becoming ill.⁴⁴ In addition, it is also common that individuals have more than one type of dementia. There are three stages of the natural course of dementia

³⁶ Rodgers and Kass 2018, p. 922.

³⁷ World Health Organization 2018, p. 6.

³⁸ The University of Queensland Australia 2017; Darby and Dickerson 2017, p. 270.

³⁹ World Health Organization 2017a, p. 2.

⁴⁰ Taylor and Close 2018, p. 303.

⁴¹ World Health Organization 2017b.

⁴² World Health Organization 2017a, pp. 14, 22.

⁴³ World Health Organization 2018, p. 6.

⁴⁴ World Health Organization 2017b.

through which the capabilities of individuals worsen and eventually the ability to function comes to an end.⁴⁵

1.4.1. Mild Dementia

In this very early stage of dementia, which usually lasts the first year or two⁴⁶, an individual can still maintain a social life and largely function independently. This stage is often overlooked and its symptoms are often attributed to the aging process.⁴⁷ Main symptoms at this stage are forgetfulness, issues with organizing, planning, concentrating on tasks and becoming lost in familiar places.⁴⁸

1.4.2. Moderate Dementia

As dementia progresses to the middle stage, brain damage is already extensive enough to cause difficulties in performing daily activities, expressing thoughts and more serious memory issues than in the earlier stage.⁴⁹ An individual in this stage might forget recent events, might be unable to remember their personal history, may not remember their address and become lost in their home.⁵⁰

At this stage individuals start needing help with personal care. Those suffering from this stage of dementia often experience increasing difficulty with communication and organizing their thoughts. They may have trouble understanding what people around them are saying and trying to communicate. Social isolation often ensues as they may be unable to follow conversations. Individuals experience mood changes such as depression, aggression, repeated questioning, wandering and frustration.⁵¹

1.4.3. Advanced Dementia

In this last stage of dementia individuals become completely dependent and inactive. Their communication is limited to using only words or expressions. Memory disturbances increase and they may not remember their family members and may think that they are in another time

⁴⁵ Dementia Care Central 2018.

⁴⁶ World Health Organization 2012, p. 7.

⁴⁷ World Health Organization 2017b.

⁴⁸ Dementia Care Central 2018.

⁴⁹ Ibidem.

⁵⁰ Alzheimer's Association 2019.

⁵¹ Dementia Care Central 2018.

period. At the very end of this stage they may be incapable of any verbal communication and they are most likely to be confined to a bed.⁵²

1.4.4. Dementia as Interpreted in This Research

In the context of this work, the term of ‘dementia’ applies to a neurodegenerative process which can deprive individuals of their capacity to make autonomous end-of-life decisions. However there is no certainty as the process of the disease is different with each individual. It encompasses persons in all three stages of the disease progress, namely the mild, moderate, and advanced dementia.

Now that the interpretation of both euthanasia and dementia has been clarified, the following chapters examine the possibility of euthanasia as a human right. As human rights are deemed to be founded on the notion of human dignity this will be the point of departure.

⁵² Ibidem.

2. The Notion of Human Dignity

2.1. Introduction

In order to analyse the possibility of euthanasia as a human right this chapter touches upon the notion of human dignity, which is perceived as the foundation for human rights⁵³ as well as a justification for imposing limitations on governmental power.⁵⁴ The term ‘dignity’ is etymologically connected to value and worth but today there are many different interpretations of it.⁵⁵ The notion is invoked on both sides of the arguments, or as Smith better said ‘[s]ometimes, it appears to be a sword; other times it is used as a shield’.⁵⁶

2.2. Human Dignity in Human Rights Documents

Human dignity has a fundamental moral and legal value which has been declared throughout the last 100 years or so by communities of faith, international bodies and sovereign countries.⁵⁷ Dignity appears in many national constitutions⁵⁸, international conventions and declarations.⁵⁹

Following the decision to open the Preamble of the Universal Declaration of Human Rights (UDHR) in 1948 by stating that the ‘recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world ...’ many documents, declarations, legislations and policy papers have been based on the notion of human dignity across the globe.⁶⁰

In 1986, the General Assembly of United Nations (UN) set international standards in the field of human rights and one of those standards requires that all human rights instruments ‘derive from the inherent dignity and worth of the human person’ (Resolution 120/41).⁶¹ Another key

⁵³ Kateb 2011, p. 4.

⁵⁴ O'Mahony 2012, p. 559.

⁵⁵ Kaczor and George 2017, p. 69.

⁵⁶ Smith 2012, p. 128.

⁵⁷ Barilan 2012, p. 2.

⁵⁸ By the end of 2012 the notion of human dignity appeared in the constitutions of 162 countries which accounts for 84% of sovereign member states of the UN. (see Barilan 2012, p. 2).

⁵⁹ Foster 2011, p. 85.

⁶⁰ Barilan 2012, p. 2; Universal Declaration of Human Rights 1948, Preamble.

⁶¹ Barilan 2012, p. 2.

document guiding both international law and the global order, the Geneva Conventions, also place importance on dignity in its Common Article 3 and in its Additional Protocol 1.⁶²

All the above mentioned international human rights documents refer to human dignity in connection with term ‘inherent’ which stipulates that it is something basic to any human being and that this inborn value cannot be legitimately taken away by the authorities.⁶³ Furthermore, the provision under Article 1 of the UDHR stating that, ‘all human beings are born free and equal in dignity and rights’ applies to everyone ‘without distinction of any kind’.⁶⁴ Nonetheless the notion of dignity remains vague. Its interpretation is therefore, ‘left to intuitive understanding, conditioned in large measure by cultural factors’.⁶⁵

There are also a few human rights charters which do not mention dignity explicitly such as the European Convention on Human Rights (ECHR or ‘Convention’).⁶⁶ Despite no mention of dignity itself in the Convention, there is a general agreement which says that dignity is both the ultimate aim and the foundation of human rights systems.⁶⁷ This agreement is reflected in the statement of the Strasbourg Court in *Pretty v United Kingdom* stating that: ‘the very essence of the Convention is respect for human dignity and human freedom’.⁶⁸ Another important statement is that of the Council of Europe (CoE) which 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’.⁶⁹

2.3. Human Dignity and Euthanasia

The UNESCO Universal Declaration on Bioethics and Human Rights states that, ‘ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms’.⁷⁰ However, in spite of the

⁶² Foster 2011, p. 86.

⁶³ Schachter 1983, p. 853; Sulmasy 2008, p. 476.

⁶⁴ Universal Declaration of Human Rights 1948, Art. 1,2.

⁶⁵ Schachter 1983, p. 849; Andorno 2009, p. 229.

⁶⁶ Foster 2011, p. 86.

⁶⁷ Dupre 2009, p. 198.

⁶⁸ ECtHR, *Pretty v. United Kingdom* 2002, para. 65.

⁶⁹ Council of Europe 2014, p. 6.

⁷⁰ Foster 2011, p. 88; Universal Declaration on Bioethics and Human Rights 2005.

established international agreement on the importance of the notion, there is no universal understanding of what dignity actually entails⁷¹.

In debates over euthanasia the notion is applied in diametrically opposite ways, both by advocates and opponents.⁷² The conflict stems from the confusion of perceiving dignity as something inherent to a human-being. All too often this disregards any possible external characteristics and the more every-day interpretation of terms such as ‘dignified’ and ‘dignity’ carrying the connotation of self-respect, status, poise and stateliness.⁷³ Scholars defending the role of dignity in bioethics often refer to two dimensions of dignity. First dimension is subjective, reflecting individual's perception of dignified death whereas the second dimension is general and applies to all human beings.⁷⁴ So if dignity can be achieved through the enjoyment of human rights but at the same time it is also an inherent and permanent constant for all humans can we really talk about life *without* dignity?⁷⁵

I believe that human dignity means much more than simply the respect of an individual's human rights or it being an inherent characteristic which is inviolable. Dignity understood in a more personal, subjective dimension is of utmost importance for all of us and each individual should have the right to determine their idea of a dignified death.

2.4. Concept of Dignity and Personal Autonomy

A core element of dignity is personal autonomy which plays a big role in euthanasia debates.⁷⁶ Autonomy in this context is understood to be reflected in any decision made by an individual that has provided their informed consent. Informed consent is made when the individual understands their medical condition, their range of treatment, care and palliative options, as well as the consequences of each choice, and after due consideration, still decides to execute the decision.⁷⁷

Accordingly, an individual's dignity is respected if, and to reiterate, only if, their autonomous requests and choices are fulfilled and respected.⁷⁸ In cases of euthanasia requests, when an

⁷¹ O'Mahony 2012, p. 557.

⁷² Azize 2007, p. 57.

⁷³ O'Mahony 2012, pp. 561–62.

⁷⁴ Dresser 2017, p. 109.

⁷⁵ Ibidem.

⁷⁶ Stoecker 2017, p. 41.

⁷⁷ Kaczor and George 2017, p. 78.

⁷⁸ Ibidem.

individual makes an autonomous end-of-life decision, attributed dignity leads to acceptance and respect of the choice made, as a way of reaffirming the individual's value and dignity.⁷⁹ Although the question of cases in which it is impossible to obtain informed consent remains. This is often the problematic in dementia cases and will be further discussed in chapter seven.

2.5. Conclusion

As mentioned in the introduction to this chapter, human dignity which all human is understood to be the basis for human rights and therefore a human right to euthanasia must rest on this notion. Hence, if there were to be a universal understanding of what exactly human dignity entails which would acknowledge also the subjective dimension this could establish the base for euthanasia as a human right. Especially as all human rights systems claim to (and should) be guided by unwavering commitment to protect dignity.

If euthanasia would be added to the catalogue of existing human rights this would mean that individuals could enforce their euthanasia claims with the help of international human rights law regardless the legal status of euthanasia in their country of origin.

Now that the point of departure, namely the notion of human dignity has been examined, the following chapter analyses the possibility of euthanasia as a human right.

⁷⁹ Kaczor and George 2017, p. 78.

3. Euthanasia as a Human Right

3.1. Introduction

As euthanasia is one of the most complex human rights issues, this chapter addresses the prospects of developing a human right to euthanasia through analysing the provisions within the existing human rights framework. In the context of this work, a right to euthanasia does not equal the absolute right to die. Instead it refers to right to dying with dignity in order to prevent further suffering. As defined in chapter one, this work applies the term ‘euthanasia’ to situations in which a physician ends or assists in ending the life of a patient that is continuously and unbearably suffering, mentally or physically, and is without prospect of recovery. It encompasses explicit requests of patients that are capable to confirm their consent and cases in which a third person decides on behalf of an incompetent patient.

Currently there is no human rights treaty or document which explicitly provides a human right to euthanasia. As all human rights are interdependent, indivisible and interrelated, a human right to euthanasia should be created in accordance with existing human rights. This includes not violating any other human right.

This chapter addresses the possible future human right to euthanasia through analysing five human rights often invoked both by critics and supporters in euthanasia discussions. These are: 1) right to life; 2) right to privacy; 3) prohibition of torture, inhuman and degrading treatment; 4) principle of non-discrimination and 5) right to health. Another aim of this chapter is to find any developments from the European Court of Human Rights case law or jurisprudential developments elsewhere which could indicate a trajectory towards considering euthanasia as a human right.

3.2. Right to Life

In today’s understanding of human rights, the individual is placed at the centre; its dignity and the protection and promotion as such is both the *raison d’être* and the ends of human rights. This analysis starts at the beginning, with the respect for the life of each individual, which is closely related and can be seen as an expression of human dignity.⁸⁰

⁸⁰ Ziebertz and Zaccaria 2019, p. 1.

Despite the right to life ranking as one of the most fundamental provisions of international human rights documents, there is no existing agreement on the definition of when life begins or ends.⁸¹ These definitions differ between countries, reflecting a diversity of values and worldviews. There are also key distinctions and conflicts on this issue within countries themselves arising when legislation and religious convictions clash.⁸² The right to life is often referred to as an *absolute* right but we should remember that this does not always apply (e.g. abortion, euthanasia, death penalty, use of lethal force in self-defence).⁸³ Therefore, the right to life requires a strict interpretation due to the limited circumstances in which it can be legitimately deprived.⁸⁴ Unsurprisingly, the right to life is used as one of the main arguments by both supporters and opponents of legal, regulated euthanasia.

3.2.1. The Right to Life at the United Nations

In 2018 the Human Rights Committee (HRC or ‘the Committee’) adopted General Comment No. 36 on Article 6 (right to life) of the International Covenant on Civil and Political Rights (ICCPR) which amended and replaced the two earlier general comments, namely No. 6⁸⁵ and 14⁸⁶ adopted in 1982 and 1984.

The opening paragraph of Article 6 states that ‘[e]very human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life’.⁸⁷ This statement makes it clear that the state parties have both positive and negative obligations towards the right to life.

In its general remarks given in the General Comment, the Committee, touches upon the relation between the right to life and end of life choices. They state that the right to life ‘concerns the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity’.⁸⁸ This statement implies that Article 6 does not include the right die on one’s own terms. Deprivation of life is defined as, ‘an intentional or otherwise foreseeable and

⁸¹ Ziebertz and Zaccaria, 2019, p. 2; Sartori 2018, p. 25.

⁸² Ziebertz and Zaccaria 2019, p. 2.

⁸³ Ibidem.

⁸⁴ Sartori, 2018, p. 25; UNHRC, *General comment No. 36* on Article 6 of the International Covenant on Civil and Political Rights, on the right to life, para. 10.

⁸⁵ UNHRC, *General comment No. 6* on Article 6 (Right to Life).

⁸⁶ UNHRC, *General comment No. 14* on Article 6 (Right to Life) Nuclear Weapons and the Right to Life.

⁸⁷ ICCPR 1976, Art. 6.

⁸⁸ UNHRC, *General comment No. 36* on Article 6 of the International Covenant on Civil and Political Rights, on the right to life, para. 3.

preventable life-terminating harm or injury, caused by an act or omission. It goes beyond injury to bodily or mental integrity or threat thereto.⁸⁹

Further in the document The Committee explicitly refers to euthanasia. The Committee has determined that the signatory states allowing the medical facilitation of the termination of life for adults experiencing physical or mental pain and suffering and wish to die with dignity,⁹⁰ ‘must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision of their patients, with a view to protecting patients from pressure and abuse’.⁹¹ This statement shows that when signatory states provide all necessary safeguards, the practice of euthanasia is *not* considered as a violation of Article 6 of the ICCPR. Nonetheless none of the three mentioned comments views the right to life as containing the right to die with dignity, which is often heralded by supporters of access to euthanasia. Interestingly, while the Committee acknowledges that some state parties to ICCPR legalized euthanasia, and included mental suffering as one of the reasons, the HRC remains reluctant to consider termination of life for minors despite it being legal in some states.

3.2.2. The Right to Life in ECtHR Case Law

There is no doubt as to the right to life as an obligation for the Member States of CoE; they have both a positive obligation to protect the individual and criminalize offences against them and in certain circumstances also a negative obligation to protect the individuals against themselves.⁹² Nonetheless there is no clear definition about what these obligations actually entail.⁹³

a) *Pretty v. UK*

The inaugural case examined by the European Court of Human Rights (ECtHR) in relation to the termination of life as being in a person’s best interest was *Pretty v. UK* in 2002.⁹⁴ Mrs. Pretty suffered from an incurable motor neurone disease affecting her muscles. The

⁸⁹ Ibidem, para. 6; UNHRC, *General comment No. 35* on Article 9 (Liberty and security of person), para. 9, 55.

⁹⁰ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* on the Right to the Highest Attainable Standard of Health (Art. 12), para. 25.

⁹¹ UNHRC, *General comment No. 36* on Article 6 of the International Covenant on Civil and Political Rights, on the right to life, para. 9; UNHRC, *Concluding Observations: the Netherlands*, para. 7.

⁹² Sartori 2018, p. 25; Wicks, 2012, pp. 201–202.

⁹³ Ziebertz and Zaccaria 2019, p. 3.

⁹⁴ Sartori 2018, p. 27.

applicant's condition deteriorated quickly, she was paralysed from neck down, her speech was undecipherable and she was being fed through a tube. However her decision-making capacity and intellect were intact. She wished to control how and when she dies as she wanted to be spared the further indignity and suffering which the natural course of the disease would bring.⁹⁵ As she was physically unable to commit suicide herself, her husband was willing to assist her but this type of assistance is illegal under the United Kingdom's (UK) law. Therefore her husband could have faced persecution.

Mrs. Pretty submitted that Article 2 of the ECHR contains both the right to life and the right to die. She argued that the Article protects, 'not life itself but the right to life' and that its purpose is to protect individuals from arbitrary deprivation of life by third parties, not individuals from themselves. Thus, the article recognises the individual's right to choose whether or not to live and protects their right to die to, 'avoid inevitable suffering and indignity as the corollary of the right to life'.⁹⁶ As discussed in the previous chapter, human dignity is ostensibly achieved through the enjoyment of human rights.

In its assessment, the ECtHR stated that Article 2 sets out the limited circumstances in which the deprivation of life may be justified.⁹⁷ Furthermore the Court held that besides the negative obligations, States also have a positive obligation to take all appropriate steps in order to safeguard the lives of those within their jurisdiction.⁹⁸ This obligation implies that state authorities ought to take preventive measures to protect the lives of individuals from criminal acts of another individual.⁹⁹ Moreover Article 2 was also found to apply in a case in which a mentally ill prisoner demonstrated signs of being suicidal.¹⁰⁰

The Court was not persuaded by the interpretation of Article 2 as involving a negative aspect as Mrs. Pretty had argued. Additionally the Court stated that the provision is not concerned with issues to do with quality of life nor personal end-of-life choices and that it cannot, 'without a distortion of language, be interpreted as conferring the diametrically opposite right,

⁹⁵ European Court of Human Rights 2015.

⁹⁶ ECtHR, *Pretty v. United Kingdom* 2002, para. 35.

⁹⁷ Hereby, the Court referred to ECtHR, *Mc Cann and Others v. the United Kingdom* 1995, para. 149–150.

⁹⁸ Hereby, the Court referred to ECtHR, *L.C.B. v. the United Kingdom* 1998, para. 36.

⁹⁹ Hereby the Court referred to: ECtHR, *Osman v. the United Kingdom* 1998, para. 115 and ECtHR, *Kiliç v. Turkey* 2000, para. 62, 76; ECtHR, *Pretty v. the United Kingdom* 2002, para. 38.

¹⁰⁰ ECtHR, *Keenan v. the United Kingdom* 2001.

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'.¹⁰¹

The applicant also argued that if the Convention does not recognize the right to die, those countries that permit assisted suicide would be breaching it. The ECtHR rebutted that in this case it is not up to the Court to assess whether a state of law in any other country breaches the right to life. Furthermore, the ECtHR took a stand that the, 'infliction of harm on individuals at liberty, by their own or another's hand, 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'.¹⁰² This statement can be seen as an indication that end-of-life cases should be assessed on a case by case basis, and an acknowledgement that in some cases the blanket ban on euthanasia might constitute a breach of the right to privacy.

b) The case of Lambert and Others v. France

In the case of *Lambert* a number of applicants disagreed with a judgement made by the French Conseil d'État to legitimise the decision made by the doctor treating their tetraplegic relative Vincent Lambert in which the doctor decided to discontinue Mr. Lambert's artificial nutrition and hydration.¹⁰³ The applicants submitted that said withdrawal would breach State obligations under Article 2 of the Convention.¹⁰⁴

The Grand Chamber of the Court held that implementing the Conseil d'État's judgement would not cause any violation of Article 2. In the absence of consensus concerning positive obligations among Member States, the Court recognised that the latter have a certain margin of appreciation.¹⁰⁵ While there is no consensus among CoE States in favour of withdrawal of artificial life-sustaining treatment, there is an existing consensus regarding the 'paramount importance of the patient's wishes in the decision-making process, however those wishes are expressed'.¹⁰⁶ The Court also found both the legislative framework as provided by the

¹⁰¹ ECtHR, *Pretty v. the United Kingdom* 2002, para. 39.

¹⁰² *Ibidem*, para. 41.

¹⁰³ ECtHR, *Lambert and Others v. France* 2015, para. 11, 45–51.

¹⁰⁴ *Ibidem*, para. 113.

¹⁰⁵ *Ibidem*, para. 144.

¹⁰⁶ *Ibidem*, para. 146.

domestic law as well as the decision-making process to be compatible with the provision of Article 2.¹⁰⁷

The ruling in this case may seem quite permissive concerning the right to die,¹⁰⁸ but the Court also stressed, ‘that the issue before it in the present case is not that of euthanasia, but rather the withdrawal of life-sustaining treatment’.¹⁰⁹ This statement implies that this permissive attitude is likely limited to the less controversial practice of passive euthanasia. Overall, the *Lambert* case can be seen as a cautious but still ‘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’.¹¹⁰

3.3. Right to Privacy

Evidently, one of the strongest arguments for euthanasia is the desire for self-determination, the individuals urge to decide how and when to terminate their life in accordance with their personal values and without having any constraints imposed on their decision by others.¹¹¹ The notion of self-determination right until the end of life is certainly compelling.

End-of-life decision-making is without a doubt one of the most intimate and private events an individual can encounter during their lifetime. End-of-life planning is no less private or deserving of less moral protection than marital matters, sexual intimacy, family planning or reproductive decision-making, all of which fall within the scope of pragmatic instances of the importance of privacy.¹¹²

A key issue for this line of argumentation is the question of whom, if anyone, has to right to decide in the name of those that are unable to make autonomous choices?¹¹³ This dilemma is discussed in chapter five.

¹⁰⁷ Ibidem, para. 181.

¹⁰⁸ Tretyakov, 2015.

¹⁰⁹ ECtHR, *Lambert and Others v. France 2015*, para. 141.

¹¹⁰ Tretyakov, 2015.

¹¹¹ Dowbiggin 2003, p. 176.

¹¹² Beauchamp 2000, p. 289.

¹¹³ Klein 1994, p. 137.

3.3.1. The Right to Privacy at the United Nations

Article 17 of the ICCPR states that, ‘no one shall be subjected to arbitrary or unlawful interference with his privacy, family...’¹¹⁴ This vague provision leaves us with two questions regarding euthanasia: first, whether ‘privacy’ entails end-of-life decisions; and second, if the prohibition of euthanasia qualifies as arbitrary or unlawful interference.

Until today, HRC only adopted one General Comment on Article 17, namely General Comment No. 16, adopted in 1988.¹¹⁵ Its interpretation of the Article does not offer any concrete answers as to the what constitutes ‘privacy’ and what can be understood to be arbitrary or unlawful interference. However later on, through the reports of Special Rapporteurs, the HRC offers an interpretation of privacy stating that, ‘[p]rivacy is a fundamental human right that has been defined as a presumption that individuals should have an area of autonomous development, interaction and liberty, a ‘private sphere’ with or without interaction with others and free from State intervention and free from excessive unsolicited intervention by other uninvited individuals.’¹¹⁶ Therefore if end-of-life decisions would be seen as a part of the private sphere, the State's prohibition would qualify as arbitrary and unlawful interference.

3.3.2. The Right to Privacy in ECtHR Case Law

While the right to life in ECtHR case law is perceived as a provision which ‘enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction’¹¹⁷, the right to private and family life is increasingly understood as an entitlement to personal autonomy.¹¹⁸

a) *The Case of Pretty v. UK*

In regards to Article 8, Mrs. Pretty submitted that as the right to self-determination, encompasses the right to make decisions about one’s body as well as what happens to it, euthanasia is explicitly guaranteed in this Article's provision. According to Mrs. Pretty, this

¹¹⁴ ICCPR 1976, Art. 17.

¹¹⁵ UNHRC, *CCPR General Comment No. 16: Article 17 (Right to Privacy) The Right to Respect of Privacy, Family, Home and Correspondence, and protection of Honour and Reputation.*

¹¹⁶ UNHRC, *Report of the Special Rapporteur on the promotion and protection of human rights and fundamental freedoms while countering terrorism, Martin Scheinin 2009*, para. 11.

¹¹⁷ ECtHR, *L.C.B. v. the United Kingdom 1998*, para. 36.

¹¹⁸ Hendriks 2018, p. 546.

entails, ‘the right to choose when and how to die and that nothing could be more intimately connected to the manner in which a person conducted her life than the manner and timing of her death’.¹¹⁹ Further, she argued that any reasons for interfering with such an intimate event must be particularly serious and that the government failed to show that the interference was justified; in the context of the ICCPR, this can be understood as ‘arbitrary’. The Government claimed that Article 8 was not engaged as ‘the right to private life did not include a right to die’ and even if it did, the state is entitled to interfere with rights under Article 8 within the margin of appreciation.

In its assessment, the ECtHR stated that the concept of *private life* ‘is a broad term not susceptible to exhaustive definition’. Furthermore the Court acknowledged that personal autonomy constitutes an important principle underlying the interpretation of the guarantees made in Article 8.¹²⁰ They 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’.¹²¹ In contrast with its arguments concerning the right to life, the Court now considered quality of life as taking on significance under Article 8.¹²² Hereby the ECtHR was not prepared to exclude that the UK law preventing Mrs. Pretty to exercise her choice, thus constitutes an undue interference with applicant’s right to respect for private life.¹²³

The second part of the Court’s judgement in *Pretty vs. UK* focused on how the state’s interference conformed with the requirements imposed by Article 8; like any other interference, this one had to be exercised in accordance with the law. As the UK law prohibits assisted suicide this requirement was fulfilled.

Furthermore interference by the state must have a legitimate aim and be deemed necessary in a democratic society which implies a proportionality of the interference with the aim pursued. The Court found that the interference pursued a legitimate aim in safeguarding life, thereby protecting the rights of others. Regarding the notion of *necessity*, the ECtHR applied the

¹¹⁹ ECtHR, *Pretty v United Kingdom* 2002, para. 58.

¹²⁰ *Ibidem*, para. 59–61

¹²¹ *Ibidem*, para. 62

¹²² *Ibidem*, para. 65

¹²³ *Ibidem*, para. 67

margin of appreciation doctrine.¹²⁴ In the absence of consensus between the CoE states as well as the delicate relationship between euthanasia and ethics, which varies from state to state, the Court decided that the margin of appreciation ought to be broad. The ECtHR also found that the interference was proportional to the aim pursued therefore it did not find a violation of Article 8.¹²⁵

b) *Haas v. Switzerland*

Although the Court decided that the right to life does not contain a right to die in the *Pretty* case,¹²⁶ this does not mean that the ECtHR necessarily denies Member States the authority to allow individuals to decide how and when to die.¹²⁷ This follows from the case against Switzerland in which the applicant, Mr. Haas, had been suffering from an acute bipolar affective disorder for roughly two decades and had attempted to commit suicide on two occasions in addition to several stays in psychiatric hospitals. On several occasions, the applicant attempted to obtain a prescription, from a psychiatrist, for the necessary lethal substance, namely 15 grams of sodium pentobarbital. This substance is only available in Switzerland upon prescription by a medical physician. Suffice it to say, all of the applicant's attempts were unsuccessful.¹²⁸

After the applicant failed to obtain the necessary prescription he invoked Article 8, complaining that as the prescription would not be met in his case, his right to choose the time and manner of his death was not respected.¹²⁹ The court cited the *Pretty* case but instead of stating a 'choice', it considered 'an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention'.¹³⁰

Nonetheless, despite granting States a wide margin of appreciation, allowing them to give a big say to individuals in their end of life decisions, the Court agrees with the Swiss Federal

¹²⁴ Margin of appreciation doctrine broadly refers to room for manoeuvre the Strasbourg institutions accord to national authorities in fulfilling their obligations under ECHR (see Greer 2000, p. 5); ECtHR, *Pretty v United Kingdom*, para. 68–70.

¹²⁵ ECtHR, *Pretty v United Kingdom* 2002, para. 70–78.

¹²⁶ *Ibidem*, para. 39.

¹²⁷ Hendriks 2018, p. 566.

¹²⁸ ECtHR, *Haas v. Switzerland* 2011, para. 7.

¹²⁹ *Ibidem*, para. 32.

¹³⁰ *Ibidem*, para. 50–51.

Court that under the positive obligations under Article 2, States should ‘establish a procedure capable of ensuring that a decision to end one’s life does correspond to the free will of the individual concerned’.¹³¹ Having regard to the margin of appreciation enjoyed by the State and to the foregoing the State concluded that there has been no violation of Article 8.¹³²

c) *Gross v. Switzerland*

Like *Haas v. Switzerland*, *Gross v. Switzerland* also refers to a refusal to prescribe a lethal dose of sodium pentobarbital. However, unlike the case of *Haas*, the applicant, Mrs. Gross was an elderly woman who wished to end her suffering which resulted from a progressive decline of her physical and mental faculties. Her requests for the prescription were denied by many medical practitioners as she was not suffering from any medically classified terminal illness.¹³³

Following this denial, the applicant lodged an application with the Court concerning Article 8. The majority of Chamber held that there had been a violation of Article 8.¹³⁴ After the Government informed the Court that the applicant had obtained the prescription and ended her life during the course of application, the case was declared inadmissible.¹³⁵ Despite losing all its legal value in the strictest sense, this case demonstrates a willingness by the ECtHR to adopt a procedural perspective on end-of-life issues.¹³⁶

d) *Koch v. Germany*

Koch also concerns a request for a lethal drug and like *Gross*, deals with it from a procedural approach. Mr. Koch’s wife, having been completely paralysed and in need of artificial ventilation following an accident, wished to end her life but was unable to obtain a prescription for the lethal drug.¹³⁷ Following the denial of her request, Mr. Koch and his wife travelled to Switzerland where she committed suicide with assistance from an organisation

¹³¹ Ibidem, para. 58.

¹³² Ibidem, para. 61.

¹³³ ECtHR, *Gross v. Switzerland* 2013, para. 10–15.

¹³⁴ Ibidem, para. 29.

¹³⁵ Ibidem, para. 30.

¹³⁶ Sartori 2018, p. 31.

¹³⁷ ECtHR, *Koch v. Germany* 2012, para. 8–10.

called *Dignitas*.¹³⁸ After returning to Germany, Mr. Koch lodged an action for a declaration that the Federal Institute's decision to deny access to a lethal drug had been unlawful.¹³⁹

After the competent domestic court declared his efforts inadmissible,¹⁴⁰ Mr. Koch lodged a complaint to the ECtHR. Accordingly, Mr. Koch claimed the domestic courts had infringed upon his procedural rights protected by Article 8 in their refusal to examine the merits of his complaint.¹⁴¹ Due to his intimate relationship with his wife and his immediate involvement in the realisation of her end-of-life wish, the ECtHR acknowledged his legal standing¹⁴² and that the domestic court's refusal to examine his complaint's merits violated Mr. Koch's rights in respect to Article 8¹⁴³. Nonetheless, the Court remained reluctant to define what the right to private life exactly entails. Perhaps a right to assist a loved one in fulfilling their end-of-life wish? Finally the Court considered that Article 8 of the ECHR 'may entail a right to judicial review even in a case in which the substantive right in question had yet to be established'.¹⁴⁴

The aforementioned ECtHR judgements share a concern for end-of-life-choices in relation to Article 8 of the ECHR in that all of them discuss the doctrine of margin of appreciation¹⁴⁵ while recognizing that all concerned States expressed fear of abuse of euthanasia practice¹⁴⁶ which is encompassed in the popular aphorism of a *slippery slope* or mythologically as a Pandora's Box of sorts. That is why these two aspects are further discussed here.

3.3.3. Margin of Appreciation

The term margin of appreciation refers to the space for manoeuvre that the Strasbourg organs are willing to grant to national authorities, in fulfilling their obligations under ECHR.¹⁴⁷ It was judicially developed by the ECtHR and has now become the main conceptual doctrine in the jurisprudential and institutional architecture of the ECHR. Originally the margin of appreciation was applied in the context of derogations but has since spread to the interpretation of obligations under all substantive articles, including obligations under non-

¹³⁸ Ibidem, para. 12.

¹³⁹ Ibidem, para. 15.

¹⁴⁰ ECtHR, *Koch v. Germany* 2012, para. 16–20.

¹⁴¹ Ibidem, para. 60.

¹⁴² Ibidem, para. 50.

¹⁴³ Ibidem, para. 65–72.

¹⁴⁴ Ibidem, para. 53.

¹⁴⁵ See: *Pretty v. UK* 2002, para. 60; *Haas v. Switzerland* 2011, para. 55; *Koch v. Germany*, 2012 para. 18, 70.

¹⁴⁶ See: *Pretty v. UK* 2002, para. 74; *Haas v. Switzerland* 2011, para. 56; *Koch v. Germany* 2012, para. 42.

¹⁴⁷ Council of Europe 2019.

derogative articles. With the ECtHR case law expanding the scope of ECHR rights so did the significance of margin of appreciation.¹⁴⁸

Regarding positive obligations, Member States typically enjoy a wide margin of appreciation in determining the actions necessary to ensure compliance of needs and resources of the community and individuals with the ECHR. A wide margin of appreciation is also applied when the State is required to strike a balance between the competing rights and interests protected under the ECHR on one hand and the protection of public and private interests on the other.¹⁴⁹

When determining the width of the margin of appreciation, the ECtHR often considers consensus and common values understood as emerging from Member State's practices.¹⁵⁰ The application of the margin of appreciation means that restrictions may vary from one Member State to the another or even between regions within one State.¹⁵¹ With the help of comparative methodology, the ECtHR discovers the degree of European consensus on a certain issue and the stronger the consensus is, the narrower the margin of appreciation is while the reverse is true too; the weaker the consensus, the wider the margin of appreciation may be.¹⁵²

An instructive example of this relativity is the case of *Schalk and Kopf v. Austria*¹⁵³ in which the Court denied the existence of a right to same sex marriage, formed in reliance of the margin of appreciation as well as the absence of consensus.¹⁵⁴ As former ECtHR President Sir Nicolas Bratza explained, the Court must seek consensus *prior* to narrowing the margin in order 'to prevent any rapid and arbitrary development of the Convention rights' while ensuring 'legal developments keep pace with, but do not leap ahead of, societal changes within Europe'.¹⁵⁵

Nonetheless consensus does not necessarily narrow the margin of appreciation. This is the case when there consensus on the broader context of the issue is lacking or when 'special historical or political considerations exist which render a more restrictive practice necessary'.¹⁵⁶ In cases raising moral, social or ethical questions the margin of appreciation

¹⁴⁸ Mcgoldrick 2016, pp. 21–23.

¹⁴⁹ Ibidem, pp. 23–24.

¹⁵⁰ Dzehtsiarou 2015, p. 106.

¹⁵¹ ECtHR, *Case of Mouvement Raëlien Suisse v. Switzerland* 2012, para. 64–65.

¹⁵² Mcgoldrick 2016, p. 28.

¹⁵³ ECtHR, *Schalk and Kopf v. Austria* 2010.

¹⁵⁴ Ibidem, para. 61–62.

¹⁵⁵ Mcgoldrick 2016, p. 28.

¹⁵⁶ Ibidem.

tends to remain wider. When searching for consensus in controversial issues it is important to bear in mind that it might take significant time for the attendant jurisprudence to be established. This permits States time to analyse the comparative social, scientific and economic developments within and across other States.¹⁵⁷

Kindly recall that over 16 years were required for the ECtHR's jurisprudence on transsexuals to change significantly although during that same period of time European consensus changed very little.¹⁵⁸ Instead what influenced the change in ECtHR's jurisprudence was a continuing international trend of increased social acceptance of transsexuals and legal recognition of an increased number of sexual and gender identities.¹⁵⁹

From the aforementioned case of changing consensus on transsexuals it can be concluded that the margin of appreciation in cases concerning end-of-life-issues could conceivably narrow with time too. Amid an improved life expectancy globally there are evermore discussions concerning the legalisation of euthanasia both in Europe and elsewhere. As the international trends of social acceptance and legal recognition have already proved to have significant impact the ECtHR's jurisprudence, the national legal developments concerning euthanasia will be further discussed in section 3.7.

3.3.4. Slippery Slope

The *slippery slope* line of argumentation is often invoked when morally contested social change is proposed¹⁶⁰ therefore its presence in euthanasia discussions is unsurprising. The fear, additionally fuelled by the Holocaust experience of racially motivated euthanasia, is that accepting voluntary euthanasia or physician assisted suicide for certain individuals would inevitably lead to abuse and overuse particularly for the already marginalized.¹⁶¹

Accordingly, the *slippery slope* is based on the claim that acceptance of a particular course of action will eventually lead to some undesirable and unintended outcome. Even if the original action is in itself moral, rejecting it might be the ethical thing to do in order to avoid sliding down the slope of misuse and abuse.¹⁶² If we apply this argument to euthanasia that would mean that accepting the practice of voluntary euthanasia would lead to non-voluntary

¹⁵⁷ Ibidem, p. 29.

¹⁵⁸ Ibidem.

¹⁵⁹ Sandland 2003, p. 191.

¹⁶⁰ Lewis 2007, p. 197.

¹⁶¹ Lerner and Caplan 2015, p. 1640.

¹⁶² Ibidem.

euthanasia. Therefore in order to prevent such a violation, maintaining the criminalization of voluntary euthanasia is seen as a solution to prevent non-voluntary euthanasia, or murder.

What opened a slippery slope argument in discussions of voluntary euthanasia is the natural way of understanding the physician–patient interaction as the patient making an autonomous request for euthanasia and the physician complies with it just in cases where he or she concludes that it is in the patient’s best interest to die.¹⁶³

There are many different conceptualisations of the slippery slope argument but for brevity’s sake, this work focuses on the two most invoked in discussions surrounding euthanasia.

The first form, known as the empirical slippery slope, enjoys the most credibility and is most often used by opponents to the legalisation of euthanasia.¹⁶⁴ This argument claims that the establishment of practice A (voluntary euthanasia) will, as time passes, and as social and psychological processes change, change a given society’s values and moral perception of the less desirable practice B (non-voluntary euthanasia).¹⁶⁵ In other words, the legitimization of practice A brings practice B closer to the mainstream.

There are two leading formulations of empirical slippery slope arguments against voluntary euthanasia. The first one charges that the acceptance of a voluntary euthanasia practice would, with time, lead to its overutilization and routinization, and consequently facilitate the rise of non-voluntary euthanasia cases. The second formulation argues that the acceptance of voluntary euthanasia will eventually slide down the slope into an exploitative practice targeting vulnerable groups.¹⁶⁶ However, both formulations lack supporting empirical data. Instead, research shows that since the enactment of the euthanasia law in the Netherlands, the rates of non-voluntary euthanasia have decreased¹⁶⁷ while there is no evidence of a heightened risk imposed upon vulnerable groups.¹⁶⁸

The second kind of slippery slope argumentation takes a logical form.¹⁶⁹ The idea of this argument is that due to their conceptual similarities, the acceptance of a practice A (voluntary

¹⁶³ Daskal 2018, p. 24.

¹⁶⁴ Lewis 2007, p. 197.

¹⁶⁵ Potter 2018, p. 241.

¹⁶⁶ Ibidem.

¹⁶⁷ Onwuteaka-Philipsen et al., 2012, p. 910.

¹⁶⁸ Battin et al. 2007, p. 591.

¹⁶⁹ Daskal 2018, p. 26.

euthanasia) logically entails the acceptance of a less desirable practice B (non-voluntary euthanasia).¹⁷⁰

Instead of understanding voluntary euthanasia as being a requirement that the physician makes an independent judgement as to if a patient is better-off dead, we should see the physician as respecting the patient's autonomy, independent from well-being, and focusing on the idea that the patient's request for aid in dying provides significant evidence about what is best for them.¹⁷¹ Even though the physician is not required to make an independent judgement if the patient is better-off dead, they must still judge on if the patient is within the boundaries of appropriate deference.

The amount of well-being, quality and length of life that the patient is sacrificing all come into account when trying to trace out the relevant boundaries.¹⁷² This reveals an important difference between deliberation and decision-making in cases of voluntary and non-voluntary euthanasia. In voluntary euthanasia the main role of the physician is to facilitate and support the patient's deliberation while they do not need to decide on whether death is in best interest of the patient. On the other hand, in cases of non-voluntary euthanasia this type of decision is the physician's sole requirement.¹⁷³

3.4. Prohibition of Torture, Inhuman and Degrading Treatment

The third examined right which could entail an argument in favour of euthanasia is the prohibition of torture, inhumane and degrading treatment. This provision has an absolute, non-derogable character and as such been accepted as a matter of customary international law.¹⁷⁴

Torture cases clearly present the gravest form of violation but this provision entails many different types of assaults on physical integrity and human dignity.¹⁷⁵ Having already discussed the notion of human dignity in connection with euthanasia, perhaps the prohibition of euthanasia practice constitutes torture or inhuman and degrading treatment. This possibility is examined in the passages below.

¹⁷⁰ Potter 2018, p. 240.

¹⁷¹ Daskal 2018, pp. 30, 34.

¹⁷² Ibidem, p. 32.

¹⁷³ Ibidem, p. 33.

¹⁷⁴ UN Committee against Torture, *General Comment No. 2 on the Implementation of Article 2.*

¹⁷⁵ Council of Europe 2003a, p. 9.

3.4.1. Torture

As the definition of torture is ‘subject to ongoing reassessment in light of present-day conditions and the changing values of democratic societies’ it is really hard to conceptualize what it concretely entails.¹⁷⁶ Nonetheless, Article 1 of the UN Convention against Torture (CAT)¹⁷⁷ provides a definition of torture which reflects four essential elements of torture: a) an act inflicting severe pain or suffering, whether physical or mental; b) the element of intent; c) the specific purpose; and d) the involvement of a State official, at least by acquiescence.¹⁷⁸

In order for the prohibition of euthanasia to qualify as torture it would have to fulfil all the aforementioned elements hence the following section discusses the presence of these elements.

a) An act inflicting severe pain or suffering, whether physical or mental:

It is impossible to hold the concerned State responsible for the suffering which leads individuals to end-of-life-choices, but it can be argued that by failing to legalise and/or decriminalise euthanasia, the State is causing additional mental suffering while allowing the existing suffering to persist. As such, States are neglecting their positive obligation to protect citizens from torture.

b) The element of intent:

According to the ECtHR statement in *Peers v. Greece* as well as *Groni v. Albania*, ‘a violation of Article 3 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’.¹⁷⁹ It is implausible to argue that in prohibiting euthanasia States intend to degrade, humiliate or punish the victims. However, after considering the ECtHR’s position on the element of intent this requirement could be fulfilled as the prohibition of euthanasia might leave the individual

¹⁷⁶ UNHRC, 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. 14. In the General Comment no. 20 on Art 7 ICCPR the UNHCR stated that: “The Covenant does not contain any definition of the concepts covered by article 7, not does the Committee consider it 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: Article 7 (Prohibition of Torture, or Other Cruel, Inhuman or Degrading Treatment or Punishment*, para 4).

¹⁷⁷ CAT 1987, Art. 1. Para. 1; ECtHR never tried to exactly define what the term means but has however adopted in part the definition provided by the UN CAT (see Council of Europe 2003, p. 11).

¹⁷⁸ UNHRC, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Manfred Nowak 2010, para. 43.

¹⁷⁹ ECtHR, *Peers v. Greece 2001*, para. 68, 74; ECtHR, *Groni v. Albania 2009*, para. 125.

feeling degraded, humiliated and punished by virtue of *not* having the right to make end-of-life decisions. Furthermore by prohibiting euthanasia, States are unnecessarily prolonging the suffering which is tantamount to a failure to stop or prevent torture.

c) The specific purpose:

Article 1 of CAT specifies several purposes for which intentional torture is inflicted, namely: obtaining information from a victim or a third person; extraction of a confession; punishment; intimidation; coercion; and most pertinently, *discrimination*.¹⁸⁰ According to the former Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Manfred Nowak there is a general acceptance that this list of purposes is only of an indicative nature, that it is not exhaustive. However only purposes which have ‘something in common with the purposes expressly listed’ are sufficient.¹⁸¹

The chief argument from concerned States in existing case law on end-of-life-issues is usually to lean on their positive obligation to safeguard the life, health and safety of all its citizens.¹⁸² It is very difficult to find the purposes of the Governments as sufficient; the only purpose on which we could argue is that of discrimination. Persons with certain disabilities can be seen to be discriminated against in their inability to commit suicide themselves, which itself not a criminal offence while others are permitted this legal alternative under euthanasia prohibition. Another argument for discrimination is based on economic marginalization as the wealthy can afford to travel and end their lives in countries with legalised euthanasia such as Switzerland. Despite the two aforementioned arguments demonstrating discrimination¹⁸³ resulting from the prohibition of euthanasia practice, this cannot be seen as the intent of the Government.

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

This element does not only involve public officials in the strictest sense, but doctors and health-care professionals, including those working in private hospitals, other institutions and detention centres.¹⁸⁴ Therefore this requirement is relevant to discourse surrounding euthanasia.

¹⁸⁰ CAT 1987, Art. 1.

¹⁸¹ UNHRC, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak 2010*, para.35.

¹⁸² Example: ECtHR, *Haas v. Switzerland 2011*, para. 46–49.

¹⁸³ Further discussed in the 4.5. section.

¹⁸⁴ UN General Assembly, *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak 2008*, para. 51.

From the above analysis it can be concluded that not all four obligations which are required for a conduct to be considered as torture are met in euthanasia case. Lacking is the specific purpose and the argumentation for the element of intent rests on largely subjective grounds. As neither of these two elements needs to be fulfilled for conduct to be considered as inhumane or degrading treatment, this option is examined in section 4.4.2.

3.4.1.1. Abusive Practices in Health-Care Settings

The 2013 Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Juan E. Méndez sheds light on certain forms of abuse in health-care settings which ‘may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment’.¹⁸⁵ It should be noted that the focus on abuse in these settings is a relatively recent development.

Despite its typical enshrinement in legal frameworks at the national level, informed consent is still frequently compromised in health-care settings as a result of power imbalances between patients and doctors, heightened by stigma and discrimination.¹⁸⁶ According to the Report ‘The mandate has recognized 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 concerned’.¹⁸⁷ This statement can be seen as a step towards passive euthanasia including the stopping of life-prolonging medical treatments which cannot achieve any therapeutic purpose (*Lambert and others v. France*). Of course this requires considering the informed consent of the concerned person as previously expressed through an advanced directive.

Intrusive and irreversible procedures performed on patients without their full, free and informed consent are often justified on the grounds of medical necessity.¹⁸⁸ At this point, the Report refers to the case of *Herczegfaly v. Austria* in which the Court found that ‘continuously sedating and administering forcible feeding to a patient who was physically

¹⁸⁵ UNHRC, 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*, p.1 and para.15.

¹⁸⁶ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover 2009*, para. 92.

¹⁸⁷ UN General Assembly, *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak 2008*, para. 40, 47.

¹⁸⁸ UNHRC, 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.

restrained by being tied to a bed for a period of two weeks' was consistent with the provision of Article 3 because the treatment was viewed as a medical necessity and aligned with contemporaneous psychiatric practices.¹⁸⁹

As such, the doctrine of medical necessity continues to present an obstacle to prevention from arbitrary abuse in health-care systems. Accordingly, Méndez clarified that "treatment provided in violation of the terms of the Convention on the Rights of Persons with Disabilities – either through coercion or discrimination – cannot be legitimate or justified under the medical necessity doctrine".¹⁹⁰

3.4.2. Inhuman and Degrading Treatment

Article 16 of CAT acknowledges 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 acquiescence of a public official or other person acting in an official capacity'.¹⁹¹ For a treatment to be defined as inhuman it must reach a minimum threshold of severity and 'cause either actual bodily harm or intense mental suffering'. The difference between torture and inhumane treatment is the severity of suffering but also that the latter does not need to be deliberate nor inflicted for a purpose.¹⁹² True for both torture and inhuman treatment is that the thresholds for both are jointly evolving with social changes.¹⁹³

Degrading treatment involves humiliation and debasement as opposed to physical and mental suffering. As is the case with inhuman treatment, degrading treatment does not require the element of intent.¹⁹⁴

¹⁸⁹ ECtHR, *Herczegfalvy v. Austria* 1992, para. 27, 83.

¹⁹⁰ UNHRC, 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. 35.

¹⁹¹ CAT 1987, Art. 16.

¹⁹² ECtHR, *Ireland v. the United Kingdom* 1978, para. 167.

¹⁹³ Council of Europe 2017.

¹⁹⁴ ECtHR, *Price v. the United Kingdom* 2001, para. 24, 30.

3.4.3. Inhuman and Degrading Treatment in ECtHR Case Law

a) *Pretty v. United Kingdom*

Mrs. Pretty focused her complaint before the Court on Article 3 of the ECHR. She submitted that the suffering which she faced qualified as degrading treatment under Article 3. While acknowledging that the Government is not directly responsible for the suffering which her disease was causing, she highlighted that the Court's case law previously established that States have both negative and positive obligations under this provision. In this case this would mean that the Government's obligation was to take the necessary steps to protect her from suffering which she would have to endure.¹⁹⁵

The applicant also argued that as the right under Article 3 has an absolute character there is no room for 'striking a balance between her right to be protected by degrading treatment and any competing interest of the community'.¹⁹⁶ Mrs. Pretty saw this delicate balance as being disproportionate as the English law imposed a ban on assisted suicide *without* considering the individual circumstances of each case.¹⁹⁷

Another point of dispute in her submission was that margin of appreciation should not be allowed under Article 3. Even if it was the case, the Government should still take into consideration each individual's circumstances while refraining from asserting that all terminally ill or disabled individuals that are contemplating suicide are, definitionally, vulnerable, and that the blanket ban is needed for their protection.¹⁹⁸ The Government submitted that Article 3 was not engaged in this case as this provision primarily imposes a negative obligation with the exception of three situations which are not applicable in this case. To further support their claim the Government mentioned that the Court's case law, 'indicated that where positive obligations arose they were not absolute but must be interpreted in such a way as not to impose an impossible or disproportionate burden on the authorities'.¹⁹⁹ Even if Article were engaged, it did not confer a legally enforceable right to die as States are afforded a certain margin of appreciation for any positive obligation.²⁰⁰

¹⁹⁵ ECtHR, *Pretty v. the United Kingdom* 2002, para. 44.

¹⁹⁶ *Ibidem*, para. 45.

¹⁹⁷ *Ibidem*.

¹⁹⁸ *Ibidem*, para. 46.

¹⁹⁹ *Ibidem*, para. 47.

²⁰⁰ *Ibidem*, para. 48.

In its assessment, the Court confirmed that Article 3 primarily imposes negative obligations on States. However taken in conjunction with Article 1 of the Convention, it creates a positive obligation on States, ‘to take measures designated to ensure that individuals within their jurisdictions are not subjected to torture or inhuman and degrading treatment or punishment, including such treatment administered by private individuals’.²⁰¹ As Mrs. Pretty focused her application on degrading treatment, the Court referred to its previous case law stating 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’.²⁰² What may also be covered by Article 3 is suffering which naturally occurs from illness, whether physical or mental, where it is, or risks being exacerbated by treatment for which the authorities can be held responsible.²⁰³

The Court concluded that as the concerned State has not inflicted any ill-treatment on the applicant, and there was no complaint about the applicant not receiving the adequate medical care from the State medical authorities, there is no comparable act or treatment on the part of the State.²⁰⁴ Furthermore the Court found the applicant’s claim that ‘the criminal-law prohibition on assisted suicide disclose inhuman and degrading treatment for which State is responsible as they will thereby be failing to protect her from the suffering which awaits her’ as placing a new, extended construction on the concept of treatment.²⁰⁵

Despite the ECHR being a living instrument any interpretation must also align with the fundamental objectives of the Convention, meaning that Article 3 must be construed in harmony with Article 2 of the ECHR.²⁰⁶ As Article 2 does not entail any right on an individual to require a State to permit or facilitate his or her death, the Court concluded that there is no positive obligation as requested by the applicant granted under Article 3.²⁰⁷

With this decision the Court redesigned the limits of Article 3 and excluded from it the obligation to protect and ensure human dignity. Although, perhaps the Court erred, as this

²⁰¹ ECtHR, *A. v. the United Kingdom* 1998, para. 22; ECtHR, *Pretty v. the United Kingdom* 2002, para. 51.

²⁰² ECtHR, *Price v. the United Kingdom* 2001, para. 24-30.

²⁰³ ECtHR, *Pretty v. the United Kingdom* 2002, para. 52.

²⁰⁴ *Ibidem*, para. 53.

²⁰⁵ *Ibidem*, para. 54.

²⁰⁶ *Ibidem*.

²⁰⁷ *Ibidem*, para. 54–56.

very notion, dignity, is one of the Convention's fundamental guarantee, surely is the most appropriate one to be ensured under this provision. Nonetheless this case did not prevent any subsequent claims that the blanket ban of euthanasia violates Article 3 as the arguments before the Court did not contemplate any possibility of the State itself inflicting ill-treatment, contrary to Article 3, on Mrs. Pretty. Hence the following section presents important points made in the recent UK Supreme Court decision in the *Northern Ireland Abortion Case* which discusses this possibility.

3.4.4. Northern Ireland Abortion Case

In this case, the Northern Ireland Human Rights Commission (NIHRC) challenged the compatibility Northern Ireland criminalisation of abortion with Article 3. A majority considered the appellant to be lacking in standing and dismissed the appeal on a procedural basis. Nonetheless, several members of the Supreme Court, including some in the majority, proceeded to consider whether the ban on abortion in cases of rape, incest or fatal foetal abnormality was compatible with, inter alia, Article 3.²⁰⁸

The UK Supreme Court's president Hale did not consider it necessary to examine the Article 3 claim given her finding that the ban violated Article 8, however she did hold that, 'the risk of persecution of the woman, and of those who help her, thus, forcing her to take that risk if she procures an illegal abortion in Northern Ireland, or to travel to Great Britain if she is able to arrange that, constitutes 'treatment' by the state for this purpose. It is the State which is subjecting her to the agonising dilemma'.²⁰⁹ She further added that it cannot be said that all women will reach the threshold of suffering required for the treatment to violate Article 3. Focus should be given on the facts of the individual case.²¹⁰

While Lord Mance rejected the general claim, he did not foreclose the possibility that Northern Irish authority's treatment of a pregnant woman, concerning abortion, might in particular cases violate Article 3.²¹¹

Implicit within these two statements is the acknowledgement that the blanket ban may constitute 'treatment' for the purposes of Article 3.

²⁰⁸ The Supreme Court of the United Kingdom, *In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)*, para. 1–3.

²⁰⁹ *Ibidem*, para. 33.

²¹⁰ *Ibidem*, para. 34.

²¹¹ *Ibidem*, para. 103.

Lord Kerr, with whom Lord Wilson agrees, rejected the Government's claim that those forbidden to have an abortion 'had not been 'treated' at all by the state'. He further supported this rejection by stating that, '[a]t present, a girl or woman who obtains an abortion in circumstances other than those narrowly prescribed [by the relevant legislation] commits a criminal offence and is liable to prosecution. That constitutes ill-treatment in so far as imposing that sanction on women amounts to a breach of Article 3. Likewise, requiring a woman to carry to term a foetus who is doomed to die, or a foetus who is the consequence of rape or incest, when the impact on the mother is inhuman or degrading is, in every sense, treatment which because of its inhumanity or degrading effect, is in violation of Article 3'.²¹²

In cases of both abortion and euthanasia, the suffering is first caused by a condition, which in the majority of cases is not caused by the State. However, the continued suffering experienced by pregnant women that cannot access abortion as well as that of people that cannot access assisted suicide is caused by the criminalisation of said practices constituting inhuman treatment by a State. In other words, in the context of dignified deaths, blanket bans on euthanasia preclude many individuals from lawfully accessing assistance in dying.

Consequently they are exposed to agonising dilemma of whether they should risk exposing their loved ones to the risk of persecution by seeking assistance in dying. Should they travel without their loved ones by their side, to avoid this risk, and confront death alone in a foreign country? Those suffering from degenerative illnesses might decide to travel and access assisted suicide in the early stages as they fear that they would lose their ability to do so later on. What is left for those who cannot afford to travel or are unable to, those that find themselves living in a State with a blanket ban on euthanasia is to face the spectre of a death in which they have no control and which may be painful, undignified and distressing.

As the ban may constitute 'treatment' it must meet the minimum level of severity. The ECtHR explained that, '[i]n order for ill-treatment to fall within the scope of Article 3, it must attain a minimum level of severity. The assessment of this minimum depends on all the circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim'.²¹³ From this it can be concluded that if blanket bans constitute treatment for the purposes of Article 3, they will meet minimum standards in certain cases, such as the one of Mrs. Pretty.

²¹² Ibidem, para. 231.

²¹³ ECtHR, *Gäfgen v Germany* 2010, para 88.

3.5. Principle of Non-Discrimination

The principle of non-discrimination is a fundamental tenet of human rights law which provides for equal enjoyment of human rights by all human beings without distinction.

In end-of-life discussions the principle of non-discrimination is most often brought up by persons with disabilities. Though suicide is decriminalised in most Member States this choice is not available to everyone. Persons with certain disabilities that wish to end their life are often unable to do it without any assistance. By asking a third person for help they expose the third part to potential persecution. Hence they often argue that this presents a breach of their right to personal autonomy in conjunction with the principle of non-discrimination and equality before the law.

3.5.1. Principle of Non-Discrimination at the United Nations

Article 2, Paragraph 1 of the ICCPR states, "[e]ach State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status".²¹⁴ Vitaly, 'or other status' implies that the mentioned list of distinctions is not exhaustive and as such also applies to disabilities etc.

The Convention on the Rights of Persons with Disabilities (CRPD) defines discrimination on the basis of disability as, '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'.²¹⁵ Furthermore in the Preamble to the CRPD, State Parties recognized discrimination on the basis of disability as a violation of the inherent dignity and worth of a human being.²¹⁶

Persons with disabilities are often deprived of their personal autonomy and subsequently their human dignity on the basis of their disability. CRPD reflects this reality when setting out its general principles. The first general Principle ensures, '[r]espect for inherent dignity,

²¹⁴ ICCPR 1976, Art.2, para 1.

²¹⁵ CRPD 2008, Art. 2.

²¹⁶ Ibidem, Preamble (h).

individual autonomy including the freedom to make one's own choices, and independence of persons', followed by non-discrimination.²¹⁷ Moreover Article 5 of the CRPD binds State Parties to prohibit all discrimination based on disability and 'guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds'.²¹⁸

Although the CRPD does not explicitly mention end-of-life-choices, it does highlight the importance of the respect for the inherent dignity of all human beings and one of its core elements, chiefly personal autonomy. Foundational to personal autonomy is the freedom to make one's own choices which can provide an underpinning for justifying euthanasia requests.

3.5.2. Principle of Non-Discrimination in the ECtHR Case Law

a) *Pretty v. UK*

Amongst other claims, Mrs. Pretty also submitted that she suffered from discrimination as an effect of the equal application of the blanket ban on assisted suicide; which due to her disability had a different effect on her as she could not end her life without assistance. She argued that she was treated differently and less favourably than those without a disability preventing them from lawfully committing suicide. The Government based its justification for the blanket ban on the need to protect the vulnerable but the applicant refused to be *marked* as vulnerable and needing of protection.²¹⁹

In its assessment, the ECtHR found that as the applicant's rights under Article 8 were engaged it must also consider the alleged violation of Article 14.²²⁰ The Court continued with stating that State Parties 'enjoy a margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a different treatment'.²²¹ Moreover discrimination can also arise when States *fail* to treat differently persons whose situations are significantly different without any objective and reasonable justification.²²² However in this case the Court found that there was an objective and reasonable justification for not distinguishing between those who are capable and not physically capable of committing suicide unaided. Building this exemption into the law would, according to the ECtHR,

²¹⁷ CRPD 2008, Art. 3.

²¹⁸ Ibidem, Art. 5.

²¹⁹ ECtHR, *Pretty v. the United Kingdom* 2002, para. 85.

²²⁰ Ibidem, para. 86.

²²¹ Ibidem, para. 88; the Court referred to ECtHR, *Camp and Bourimi v. the Netherlands* 2000, para. 37.

²²² ECtHR, *Thlimmenos v. Greece* 2000, para. 44.

seriously undermine the protection of life and increase the risk of abuse therefore they concluded that there was no violation of Article 14.²²³

This decision highlights two principles already discussed under the right to privacy section 3.3., namely the margin of appreciation and the argument of a slippery slope. Therefore, as is the case with Article 6, it is only a matter of time and the direction of Europe and, indeed, the world's, winds of social change before the Court's jurisprudence begins to change on this matter.

3.6. Right to Health

The right to health is closely dependent upon and related to the realization of other human rights enshrined in the International Bill of Rights including the already analysed rights to human dignity, life, non-discrimination, the prohibition against torture and to privacy.²²⁴

A prominent argument against the legalisation of euthanasia claims that the solution to pain relief and suffering lays in States investing more towards genuine medical care for dying individuals, specifically palliative care.²²⁵ As euthanasia practice is easier, quicker and cheaper than palliative care, there is a fear that euthanasia will become the norm and that States will respond with decreasing their investments into palliative care; in effect that euthanasia will replace rather than supplement palliative care.²²⁶ But can it authoritatively be said that legalising euthanasia would cause a decrease of States' investment into palliative care and that one practice necessarily excludes the other?

3.6.1. Right to Health at the United Nations

The right to health is recognized in many international human rights instruments but the most comprehensive article regarding it can be found in the International Covenant on Economic, Social and Cultural rights (ICESCR or 'the Covenant').²²⁷ In accordance with the provisions under Article 12 of the Covenant, States Parties, 'recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' and the steps

²²³ ECtHR, *Pretty v. the United Kingdom* 2002, para. 88–89.

²²⁴ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* on the Right to the Highest Attainable Standard of Health, para. 3–4.

²²⁵ Ten Have and Welie 2005, p. 7.

²²⁶ The Irish Council for Bioethics 2018, p. 4.

²²⁷ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* on the Right to the Highest Attainable Standard of Health, para. 2.

required in order to achieve a full realization of this right using the maximum of its available resources.²²⁸ Clearly, the Article contains both freedoms and entitlements. The freedoms include the right to be free from interference and the right to control one's body and health whereas the entitlements include the right to a health-care system that, 'provides equality of opportunities for people to enjoy the highest attainable level of health'.²²⁹ Furthermore, other than providing for progressive realization, the Covenant also imposes immediate obligations on States such as the principle of non-discrimination and the obligation to take the necessary steps to ensure the full realization of the right to health.²³⁰

The right to health contains four interrelated elements. First is that of availability which indicates that States must provide a functioning and qualitatively sufficient public health system of which, '[t]he precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level'.²³¹ The second element, accessibility, consists of four overlapping dimensions such as non-discrimination, physical accessibility, economic accessibility or affordability and access to information. The third element is acceptability which provides that '[a]ll health facilities, goods and services must be respectful of medical ethics and culturally appropriate'. The final element is quality and it specifies that the health-care system must be medically and scientifically appropriate and of good quality.²³²

When talking about which actions or omissions amount to a violation of the right to health, the Committee states that it is important to make a distinction between a State's *unwillingness* and its *inability* to comply with its obligations under Article 12 of the ICESCR. Therefore what amounts to a violation is when a State, 'is unwilling to use the maximum of its available resources for the realization of the right to health'. However this ethic does not apply when it comes to the core obligations which are non-derogable.²³³

Under specific legal obligations of the General Comment the Committee highlights that inter alia palliative health services fall under the obligation to respect the right to health.²³⁴ Consistently the Special Rapporteur on Torture Méndez stated that the denial of pain relief

²²⁸ ICESCR 1976, Art. 12, para 1, 2.

²²⁹ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14 on the Right to the Highest Attainable Standard of Health*, para. 8.

²³⁰ *Ibidem*, para. 30.

²³¹ *Ibidem*, para. 12a.

²³² *Ibidem*, para. 12.

²³³ *Ibidem*, para.47.

²³⁴ *Ibidem*, para. 34.

could constitute inhuman and degrading treatment. He highlighted that, ‘[w]hen 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’.²³⁵ In his report from 2013, Méndez called upon signatory States to ensure full access to palliative care as well as for its integration into the public health system.²³⁶ Therefore States that are unreasonably decreasing investment into palliative care, despite having available resources, would be violating both Article 12 ICESCR and Article 7 ICCPR. This indicates the strong interdependence and interrelatedness of the two rights.

3.6.2. Right to Health at the CoE Level

The right to health can be found in Article 11 of the Revised European Social Charter (ESC) stating, ‘the Contracting 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’.²³⁷ Like the ICESCR, State Parties to the ESC undertake to pursue the highest possible standard of health attainable with all of their available means and to refrain from any type of discrimination in this sphere.²³⁸

In the framework of the CoE, palliative care is included in several Recommendations of the Committee of Ministers to Member States. A Recommendation on the organisation of palliative care from 2003 provided guidelines for implementing palliative care in Europe. The Recommendation’s preamble considered palliative care as constituting an integral part of the health-care system and an inalienable element of the right to health, therefore it should be available to all that need it.²³⁹

²³⁵ UNHRC, 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. 54.

²³⁶ *Ibidem*, para. 86.

²³⁷ ESC 1996, Art. 11.

²³⁸ Council of Europe 2015, pp. 9–11.

²³⁹ Council of Europe 2003b, *Recommendation of the Committee of Ministers to member states on the organisation of palliative care*, Preamble.

The rationale behind the legal inclusion of palliative care in the Recommendation on the Promotion of Human Rights of Older Persons is that, ‘human dignity should be respected throughout all stages in every individual’s life, including the terminally-ill and dying, and that palliative care helps to preserve this dignity by providing an appropriate environment for such patients and helping them to cope with the pain and other distressing symptoms’.²⁴⁰ As Europe ages, there is a heightened need for the establishment of functional palliative and end-of-life-care services which is also one of the points of the Parliamentary Assembly’s Recommendation on the situation of elderly persons in Europe.²⁴¹

The World Health Organization (WHO) defines palliative care as, ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.²⁴² In contrast, the philosophy behind euthanasia decisions is that individuals wish to end their life and unbearable suffering on their own terms; when they feel that the time is right and in a way that maintains their dignity.

Certainly, this is not the case of one practice, either euthanasia or palliative care, necessarily excluding the other, but rather one of cooperation and complementarity between the two. Individuals should be informed about both euthanasia and palliative care while having the possibility to request the practice that satisfies them most. For instance, they may choose to start with palliative care and in the case of dissatisfaction, request euthanasia.

In the discussion above it has been established that palliative care forms an inalienable core of the right to health and that it is the duty of States to fulfil their obligations and use all available resources for its realization. As the practices of euthanasia and palliative care do not inherently exclude one another, and if the States would fulfil their obligations, to which they have committed with ratification of human rights treaties, the decriminalisation of euthanasia would not result in any decrease in palliative care investments. However as also acknowledged by the Committee, today the full achievement of the right to health still

²⁴⁰ Council of Europe 2014, *Explanatory Memorandum of Recommendation of the Committee of Ministers to member States on the promotion of human rights of older persons*, para. 72.

²⁴¹ CoE Parliamentary Assembly 2007, *Recommendation 1796: The situation of elderly persons in Europe*, para. 11.4.

²⁴² World Health Organization 2019.

remains a distant goal across the world, including many State Parties.²⁴³ In those cases, States may abuse, even exploit, the cheaper and quicker practice of euthanasia.

3.7. National Legal Developments - Current Examples

In recent years there have been many developments made at the national level towards the legal recognition of the right to die with dignity as well as the legalisation of certain forms of euthanasia. As shown in the above 3.3.3. section the ECtHR jurisprudence might take quite some time to change, taking into consideration societal changes and legal developments in Europe as well as on a global scale. Therefore this section highlights some of the national developments recently made which might not only have a transnational effect of causing debates and initiatives in other states but could also contribute to a future recognition of euthanasia as a human right on the supranational level.

In February 2015 the Supreme Court of Canada released its ruling in *Carter v. Canada* concerning physician-assisted death.²⁴⁴ The Court concluded, ‘the prohibition on physician-assisted dying infringes the right to life, liberty and security ... and that it does so in a manner that is overbroad and thus is not in accordance with the principles of fundamental justice’.²⁴⁵ Furthermore the Court disagreed that the right to life requires an absolute ban on assisted dying or that individuals cannot give up their right to life as this would create a ‘duty to live’ and not a ‘right to life’.²⁴⁶

With the Supreme Court acknowledging the importance of the object of the prohibition, which was to protect vulnerable persons ‘from being induced to commit suicide at a time of weakness’, the law did not have an arbitrary character.²⁴⁷ However the prohibition has been declared as being overboard as the limitation of individual’s rights is not necessarily connected to its objective.²⁴⁸ As a result of this ruling, in a year’s time Canada successfully legalised assisted suicide.²⁴⁹

²⁴³ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* on the Right to the Highest Attainable Standard of Health (Art. 12), para. 5.

²⁴⁴ Supreme Court of Canada, *Carter v. Canada (Attorney General)* 2015.

²⁴⁵ *Ibidem*, para. 56.

²⁴⁶ *Ibidem*, para. 63.

²⁴⁷ *Ibidem*, para. 90, 86.

²⁴⁸ *Ibidem*, p. 336.

²⁴⁹ Fine 2018.

The most recent case is that of *Common Cause v. Union of India*²⁵⁰ from March 2018, in which the Supreme Court of India made history by granting legal recognition to advanced medical directives or living wills²⁵¹ stating that ‘[t]o be autonomous, the patient should be competent to make decision and choices. In the event that he is incompetent to make choices, his wishes expressed in advance in the form of a living will, OR the wishes of surrogates acting on his behalf are to be respected’.²⁵² The Supreme Court also renewed legal recognition of passive euthanasia and robustly interpreted Article 21 of India’s Constitution, the right to life, as including the right to die with dignity.²⁵³

There have also been some positive developments in the Oceania region, more specifically in June 2019, Victoria became the first Australian state to legalise voluntary assisted dying by passing the Voluntary Assisted Dying Bill which was first introduced in 2017.²⁵⁴ There is also an ongoing inquiry in Queensland²⁵⁵ as well as in New Zealand where the Euthanasia bill passed its second reading.²⁵⁶

Assisted suicide legislation is also gaining increasing acceptance in the United States of America. Recently both Maine and New Jersey signed bills which made them the eighth and ninth states to successfully legalise assisted suicide.²⁵⁷

This examples of current national developments indicate that there are indeed some societal changes and legal developments going on which could in future contribute to the development of a human right to euthanasia or at least narrowing of the margin of appreciation. At this point it is important to recall that it took 16 years for the ECtHR’s jurisprudence on transsexuals to change and that what mostly instigated this change was the international trend of acceptance and legal recognition. From the above analysed developments and the example of transsexual jurisprudence we can conclude that changes concerning jurisprudence on euthanasia on both international and national level of other states are on its way.

²⁵⁰ The Supreme Court of India, *Common Cause v. Union of India* 2018, p. 1.

²⁵¹ Bandewar et al. 2018, p. 91.

²⁵² The Supreme Court of India, *Common Cause v. Union of India* 2018, p. 111.

²⁵³ The Supreme Court of India, *Common Cause v. Union of India* 2018, p. 69; Bandewar et al. 2018, p. 91.

²⁵⁴ Martin 2019.

²⁵⁵ Ibidem.

²⁵⁶ NZ Herald 2019.

²⁵⁷ Hefler 2019; Villeneuve 2019.

3.8. Conclusion

The aim of this chapter was to assess the prospects of developing a human right to euthanasia through examining the provisions of the existing human rights framework and any developments - both in the European Court of Human Rights case law and national developments - which could indicate a trajectory towards considering euthanasia as a human right.

The present position of the analysed human rights bodies clearly reflects the traditional distinction between the less controversial practice of passive euthanasia on one hand and physician-assisted suicide and active euthanasia as less favourable on the other.

First right that this work examined was the right to life. The language used, both at the level of the UN and the CoE, strictly denies any attempt to interpret the right to life as conferring the right to die. The ECtHR goes even further by saying that the provision under Article 2 of the ECHR does not create a right to self determination, which would confer on an individual the entitlement to choose death rather than life. However in the case of *Lambert and Others v. France*, the ECtHR recognizes the importance of patient's personal autonomy in the decision-making processes regarding the withdrawal of a treatment. This ruling may be seen as quite permissive regarding the right to die but taking into consideration the Court's emphasis that this case was not about euthanasia, it is likely that this permissive attitude is limited to the practice of passive euthanasia solely. As established in the introduction to this chapter, a human right to euthanasia should not violate any other right. In this context, the UN HRC has determined that when signatory states provide all necessary safeguards, the practice of euthanasia is not necessarily considered as a violation of the right to life. However, as the Committee included mental suffering as one of the reasons it remains reluctant to consider termination of life for minors despite it being legal in some states.

This work mainly discussed the right to privacy through the case law of the ECtHR, due to the fact that at the level of the UN there is no discussion revolving the right to privacy in connection with end of life decisions. It can however be concluded, from their interpretation of the right to privacy, that if the end-of-life decisions fall within an individual's 'private sphere' this would mean that euthanasia prohibition could constitute an arbitrary and unlawful interference. In the case of *Pretty v. UK*, the Court acknowledges that personal autonomy may also include activities of a physically dangerous nature for the individual. Furthermore, the

Court was not prepared to exclude that law prohibiting euthanasia could constitute an interference with the applicant's right to private life. In the case of *Haas v. Switzerland*, the Court even considered that it is not only a choice but an individual's right to decide how and when his or her life will end, provided the individual has the decision-making capacity. This can be seen as a large step towards the right to euthanasia. Despite the fact the case of *Gross v. Switzerland* lost its legal value, it shows the willingness of the ECtHR to adopt a procedural perspective on end-of-life issues. Common to all the analysed ECtHR's judgements concerning end-of-life-choices in relation to right to privacy, is that the Court grants the States a wide margin of appreciation, based on the argument that there is no established European consensus on the issue. Nonetheless, even if this consensus would become stronger in future it is difficult to determine when and if this would narrow down the margin. Furthermore, the ECtHR maintained that interference with the aim of protecting vulnerable groups is proportionate. A subsection on the slippery slope argument highlights, based that there is no heightened risk necessarily imposed upon vulnerable groups. However, it is important to point out that the used research was only focused on the situation in the Netherlands.

Third analysed right is the prohibition of torture, inhuman and degrading treatment. Due to its absolute character this right could form the strongest foundation for the human right to euthanasia. After discussing the four essential elements of torture, this work came to the conclusion that the prohibition of euthanasia does not amount to torture as it lacks specific purpose and the element of intent stands on mostly subjective grounds. As none of the two elements need to be fulfilled for conduct to be considered as inhumane or degrading treatment, this option is examined. The case of *Pretty v. UK* in which the applicant focused her application on degrading treatment can be seen as important for two reasons. Firstly because the Court established that suffering flowing from illness, including mental, which is or risks to be exacerbated by treatment for which the authorities can be held responsible may be covered by Article 3. Therefore, a prohibition of euthanasia could constitute as 'treatment'. The second reason is that it shows how the Court balances the provision of this absolute right with other rights, although the implementation of this right should be only a matter of scope. As the Court did not contemplate the possibility of the State itself inflicting ill-treatment, a parallel with the Northern Ireland Abortion Case has been drawn. The developments from this judgement could be of a great importance for the justification of blanket ban on euthanasia constituting as ill-treatment. Furthermore, the statement of the Special Rapporteur on Torture,

Manfred Nowak, that forced medical treatments may constitute torture or ill-treatment can be seen as an important step towards a right to passive euthanasia.

The principle of non-discrimination in context of euthanasia prohibition is most often brought up by persons with disabilities as the choice of committing suicide, a decriminalised act, is not available to everyone. CRPD does not explicitly mention the end-of-life-choices but it does highlight the importance of the respect for the inherent dignity and personal autonomy. Foundational to personal autonomy is the freedom to make one's own choices, which could be seen as solid ground for justifying euthanasia requests. In its case law, the ECtHR again refers to the margin of appreciation and proportionality to conclude that this difference of treatment in a similar situation does not constitute as discrimination. Therefore, it is a question of time and winds of social change before the Court's jurisprudence begins to change.

The last examined right was the right to health, which might present the biggest barrier to the establishment of the human right to euthanasia. This is due to the fact that a human right to euthanasia might be largely abused since a full achievement of the right to health still remains a distant goal across the world.

What is evident throughout the discussion revolving the right to euthanasia is the interrelatedness, interdependence and indivisibility of the existing human rights. For euthanasia to become a human right it would have to be built in conformity with all of the discussed provisions, in order to avoid the practice to become an overused norm.

As an answer to the first research question this work argues that each of the analysed provisions could lend themselves to the creation of a human right to euthanasia. However, this could only be made a reality with time and winds of social changes in perceiving death and end-of-life related issues as part of human life and not taboo. Another requirement would have to be the Member States full compliance with their obligations under international law in order to ensure a safe environment for all of their citizen by offering qualitative alternatives for dying individuals. Throughout the analysed ECtHR's case law and presented national developments we can with certainty conclude that they indicate a trajectory towards considering euthanasia as a human right. Therefore, the answer to the second research question is affirmative. However, it is important to highlight that passive euthanasia receives more support than active euthanasia and assisted-suicide, which are still perceived as controversial.

The following two chapters analyse the application of a potential human right to euthanasia concerning persons with dementia in all stages of the disease.

4. Legal Capacity of Persons with Dementia within International Law

This chapter, which serves as a point of departure for applying the human right to euthanasia, discusses persons with dementia as subjects within international law. Like any other individual, persons with dementia have legal rights and obligations although they face unique challenges and issues.²⁵⁸ In human rights' debates concerning the position of marginalised and vulnerable groups in society, persons with dementia are not given as much attention as other oppressed groups.²⁵⁹

Nonetheless dementia presents a human rights issue as diagnosis can lead to discrimination, marginalisation, social exclusion, inequality and other injustices.²⁶⁰ Although, dementia is also often understood as a disability, therefore the human rights of persons with dementia are protected by the UN CRPD which is 'diagnosis neutral' and its language of 'disability' includes psychological, physical and cognitive impairments caused by health conditions.²⁶¹

As the prevalence of dementia increases with age, this presents a unique concern with a rapidly aging global population.²⁶² In response, in 2010 the UN established an Open-Ended Working Group on Ageing (OEWGA). The Working Group strives to develop a convention that would promote and protect the rights and dignity of older people and that would be relevant to persons with dementia.²⁶³ Conceivably, some may view this inclusion as discriminatory as dementia is not a normal part of aging, and that although its prevalence does increase with age, young people can also be diagnosed with it.²⁶⁴

4.1. UN Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD is the most up-to-date international legal instrument specifically designed to designate the rights of persons with disabilities.²⁶⁵ Coming into force in 2008, the Convention does not create any new rights *per se*; all the rights enshrined in it already exist in the international human rights treaties. The aim behind the decision of not establishing any new

²⁵⁸ Doron et al. 2017, p. 1.

²⁵⁹ Mental Health Foundation 2015, p. 6.

²⁶⁰ Cahill 2018, p. 27.

²⁶¹ Mental Health Foundation 2015, p. 7, 9.

²⁶² The world population is aging due to declining fertility, increasing life longevity, international migration and advanced medical technology (see United Nations 2019).

²⁶³ UNDESA 2019; Mental Health Foundation 2015, p. 11.

²⁶⁴ Cahill 2018, p. 173.

²⁶⁵ Szmukler 2019, p. 34.

rights and obligations was to explicitly state that persons with disabilities are not an exception from human rights and that they have the same rights as every other human being.²⁶⁶ However the Convention specifies how the principles of human dignity, non-discrimination, equality, personal autonomy as well as full social inclusion and participation can be fully realised for persons with disabilities.²⁶⁷ Another reason that urged the CRPD drafting process was the perceived need to adjust the international human rights framework to the need of persons with disabilities.²⁶⁸ As a consequence, the rights enshrined in the CRPD were seen as a reestablishment of the already existing rights that other UN treaties recognised and stated, but not as providing new rights to persons with special needs.²⁶⁹

The Convention's main aim is to, 'promote, protect and ensure the full and equal enjoyment of human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity'.²⁷⁰ The mantra behind the Convention is, 'nothing about us without us' which is a reminder of the central role that persons with disabilities played in the development procedure of this treaty.²⁷¹ This guiding principle is reaffirmed in Article 33 which states, 'persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process'.²⁷²

Unfortunately, persons with dementia, their family members or representative organisations were not involved in the negotiations leading to the development of the Convention. Membership on the UN CRPD Committee whose role is to monitor the implementation of the Convention has also lacked any representation from those affected by dementia. By the provision granted under Article 33 this can be rectified and in future they can become actively involved in the monitoring process.²⁷³

For the purpose of the Convention, 'disability' is recognized as, 'an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'.²⁷⁴ With this statement the CRPD highlights the change in the approach to

²⁶⁶ CRPD 2008, Preamble (a-d), (y).

²⁶⁷ Szmukler 2019, p. 35.

²⁶⁸ UN Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities 2001.

²⁶⁹ Litins'ka 2018, p. 117.

²⁷⁰ CRPD 2008, Art. 1.

²⁷¹ Cahill 2018, p. 51.

²⁷² CRPD 2008, Art. 33.

²⁷³ Cahill 2018, p. 48.

²⁷⁴ CRPD 2008, Preamble (e)

impairments which were previously viewed as a cause for limitations.²⁷⁵ More directly, Article 1 specifies that persons with disabilities, ‘include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.²⁷⁶ From these two excerpts it can be concluded that the CRPD offers a *description* rather than a *definition* of ‘disability’ and ‘persons with disabilities’.

In terms of the CRPD’s inclusion of persons with dementia, a reference to ‘cognitive’ impairment in Article 1 would make it more explicit even though it may be understood as comprised within mental or intellectual impairment stated in the article. Nonetheless persons with dementia are protected under the CRPD as their experiences align with both the Preamble’s emphasis on impairments, which dementia definitely causes, as well as with Article 1 as dementia causes physical and intellectual impairments.²⁷⁷

Apart from some modern legal capacity legislation, the legal rights of persons with dementia are still quite unexplored. Additionally the CRPD’s requirement for a fully supported decision-making legal regime represents significant challenges in terms of operationalising mental capacity for people with severe cognitive impairment and those with acute learning disabilities.²⁷⁸

4.1.1. From Substitute Decision-Making Paradigm Towards Supported Decision-Making

In 2014 the UN CRPD Committee released General Comment No. 1 that provided guidelines for State Parties in properly ensuring the right to legal capacity, as set out in Article 12 of the CRPD, for persons with disabilities including persons with dementia.²⁷⁹ Article 12 of the CRPD implemented some new implications to the already existing right.²⁸⁰ The duty of states, ‘to provide access by persons with disabilities to the support they may require in exercising their legal capacity’²⁸¹ is the most important one. This represents a departure from the Committee’s observation that State Parties failed to ‘understand that the human rights-based

²⁷⁵ Litins’ka 2018, p. 118.

²⁷⁶ CRPD 2008, Art. 1.

²⁷⁷ Cahill 2018, pp. 41–42.

²⁷⁸ Mental Health Foundation 2015, p. 11.

²⁷⁹ Cahill 2018, p. 157.

²⁸⁰ Ibidem, p. 159.

²⁸¹ CRPD 2008, Art. 12(3).

model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making' as Article 12 does not use any of these two terms.²⁸²

Some argue that the Committee's interpretation of the Article differs from the States interpretation at the time that the CRPD negotiations concluded but other scholars demonstrated that the approach used by the Committee reflects the drafters' intentions. Although the General Comment is not being binding in international law, it represents an authoritative standard to which States will be held when appearing before the UN Committee.²⁸³ Nonetheless no State examined to date is as yet fully compliant with Article 12.²⁸⁴

According to the Committee, persons with cognitive and other types of disabilities are often disproportionately affected by denial of legal capacity and substitute decision-making regimes. It reaffirms that, 'a person's status as a person with a disability or the existence of an impairment... must never be grounds for denying legal capacity or any of the rights provided for in article 12'.²⁸⁵ Substitute decision-makers are usually family members, friends or state appointed representatives.²⁸⁶

The Committee requires the abolishment of all substitute decision-making practices and to replace them with supported decision-making, 'which respects the person's autonomy, will and preferences'.²⁸⁷ At this point it is important to highlight that not all appointments of outside decision-makers would violate the obligation set in the General Comment. For example the use of the advance planning tools, such as the advance directives, in which the individual would choose to delegate decision-making of a particular issue to a trusted person which would make decision based on appointer's will and preferences.²⁸⁸

Unlike some other legal instruments²⁸⁹, the Committee, distinguishes between legal and mental capacity stating that the former is a legal concept whereas the latter is a psychological

²⁸² UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, p. 159.

²⁸³ Cahill 2018, pp. 159–160.

²⁸⁴ Ibidem, p. 160.

²⁸⁵ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 9.

²⁸⁶ Cahill 2018, p. 160.

²⁸⁷ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 26.

²⁸⁸ Cahill 2018, p. 161; Arstein- Kerslake and Flynn 2016, p. 137.

²⁸⁹ Legal instruments such as: UDHR (Art. 6), ICCPR (Art. 16) and the Convention on the Elimination of All Forms of Discrimination Against Women (Art. 15); see General Comment No. 1, para. 13.

one.²⁹⁰ The Committee established that, ‘perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity’ and that Article 12 does not permit a person’s disability and/or decision-making skills to be taken as legitimate grounds for denying one’s legal capacity. Rather, one’s disability and/or decision-making skills create the requirement for the provision of support for the exercise of legal capacity in accordance to individual’s will and preferences.²⁹¹ This change in perceiving of capacity is very meaningful for persons with dementia.

Functional assessment of mental capacity, which is often in practice, can be seen as discriminatory against persons with disabilities as they are more likely to be requested to undergo the assessment, and subsequently have their legal capacity denied or restricted, than those without diagnosis or any disability at all, but might still have trouble making the same decision.²⁹² Furthermore the procedure of the capacity assessment can be seen as a barrier that hinders participation of persons with disabilities in society, as mentioned in CRPD Article 1.2.²⁹³

To achieve the paradigm shift provided by Article 12, the Committee has asked States to abolish substituted decision-making regimes which use the ‘best interest’ standards to impose decisions on individuals with disabilities that are perceived to lack mental capacity. Instead, the Committee has proposed that States provide support for the exercise of supported decision-making based on individual’s rights, will and preferences.²⁹⁴ In cases when it is impossible to determine the will and preferences of an individual, the Committee states that the ‘best interpretation’ of will and preferences must be established, involving those that are close to the individual such as relatives or friends.²⁹⁵

The Committee also states that safeguards for the exercise of legal capacity must involve protection against ‘undue influence’ on supported persons but at the same time they must also

²⁹⁰ Szmukler 2019, p. 34.

²⁹¹ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 13.

²⁹² Cahill 2018, pp. 163–164.

²⁹³ CRPD 2008, Art. 1.2.

²⁹⁴ *Ibidem*, p. 164.

²⁹⁵ Szmukler 2019, p. 35; UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 21.

respect the rights, will and preferences of the individual which include the right to make mistakes and take risks.²⁹⁶

²⁹⁶ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 22.

5. A Human Right to Euthanasia for Persons with Dementia

5.1. Introduction

In the light of improved life expectancy across the globe, the emergence of non-communicable diseases such as dementia are expected to further increase in the following years. Due to the high prevalence of dementia and its role as a major cause of disability and dependency the WHO pin-pointed this global epidemic as a public health priority.²⁹⁷ As the universal human right to euthanasia would apply to all human beings this would also entail persons with disabilities regardless of diagnosis. Therefore can we really view treating persons with dementia differently, simply based on impairment affecting their capacity to consent as legitimate? This chapter aims to address whether a human right to euthanasia could be compliant with the rights of persons with dementia as enshrined in the CRPD and how this practice should be properly conducted.

Accordingly, this work analyses provisions of three human rights documents. First, the CRPD, which is the main international legal instrument designating rights of persons with disabilities including persons with dementia. The discussion will be based on four interrelated, relevant rights from the Convention, namely: a) equality and non-discrimination; b) right to life; c) equal recognition before the law; and d) health.²⁹⁸ At this point this work will not discuss any other previously analysed conventions as the CRPD only re-establishes the already existing rights.

Following this, two documents will be examined, which, in their provisions, offer special protection to persons unable to consent. This issue of (in)capacity to provide consent is the main dilemma in terms of discussing euthanasia for persons with dementia. The two documents are the UN's Universal Declaration on Bioethics and Human rights and CoE's Oviedo Convention also known as the Convention on Human Rights and Biomedicine.

Article 12 which concerns the equal recognition before the law, will not be discussed in detail again in order to avoid repetition from the previous chapter. Nonetheless there will be a focus on the rights, will and preferences paradigm introduced by the Committee, in its General Comment on Article 12, which are important for euthanasia debate.

²⁹⁷ World Health Organization 2014, p. 6.

²⁹⁸ CRPD 2008, Art. 5, 10, 12, 25.

5.2. UN Convention on the Rights of Persons with Disabilities

5.2.1. Equality and Non-Discrimination

Persons with dementia are often perceived as a vulnerable group which needs to be protected due to impairment affecting their ability to consent. Some may argue that the human right to euthanasia should not apply to them. In my opinion this differentiation would constitute a violation of Article 5 of the CRPD which states, ‘State Parties shall prohibit all discrimination on the basis of disability ...’²⁹⁹ Protection of the vulnerable is of course a legitimate aim but this is the function of safeguards and the full realization of rule of law.

In General Comment No. 6 on equality and non-discrimination, the Committee affirms that States should start acknowledging persons with disabilities as full subjects of rights and as rights holders.³⁰⁰ Furthermore they argued that any kind of medically driven incapacity approach to disability should neither be seen as legitimized nor a norm for different or discriminatory treatment of persons with disabilities.³⁰¹ Therefore any denial of decision-making based on disability through either functional, status-base or outcome-based systems, is discriminatory.³⁰²

Most interesting about the aforementioned Comment is that the Committee did not discuss any connection between Article 5 and the right to life and the language it uses when addressing euthanasia practice. The statement says, ‘[d]iscrimination has occurred and continues to occur, including in brutal forms such as ..., systematic murder labelled ‘euthanasia’’.³⁰³ This labelling of euthanasia practice as systematic murder is alarming and reminds me of extreme anti-abortion crusaders that claim that legalized abortion constitutes genocide. As there is no proof of actual systemized murder practice in the context of stable States under the rule of law which have legalised voluntary euthanasia, this association with the legacy of the holocaust and eugenics is fear-mongering.

Excluding persons with dementia with an impaired capacity to consent is disproportionate. If States would implement the support decision-making practice that give importance to the

²⁹⁹ CRPD 2008, Art. 5.

³⁰⁰ UN Committee on the Rights of Persons with Disabilities, *General comment No. 6 on equality and non-discrimination 2018*, para. 2.

³⁰¹ *Ibidem*, para. 8.

³⁰² *Ibidem*, para. 47.

³⁰³ *Ibidem*, para. 7.

individual's preference and will, as mentioned in section 5.1.1., as well as develop advanced decision-making systems and establish effective safeguards, impaired cognitive ability should not pose any barriers.

5.2.2. Right to Life

Article 10 of the CRPD states, 'States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others'.³⁰⁴

The Committee, so far, has not written any General Comment on the scope of the right to life nor has it discussed it in connection with any of the other analysed rights. Nonetheless it was mentioned in the recent End of Mission Statement by the UN Special Rapporteur on the Rights of Persons with Disabilities on her visit to Canada. In this statement she expressed her concern about the implementation of legislation on medical assistance in dying since there is no existing protocol to show that persons with disabilities have been offered viable alternatives when eligible for assisted dying procedure. She has also received complaints about institutionalised persons being pressured to opt for physician assisted dying and that physicians do not formally report cases involving persons with disabilities. She urged the government to investigate the complaints mentioned and to put adequate safeguards into place in order to, 'ensure that persons with disabilities do not request assistive dying simply because of the absence of community-based alternatives and palliative care'.³⁰⁵

This statement of the Special Rapporteur, Ms. Catalina Devandas-Aguilar, does not provide any indication that euthanasia practice violates Article 10 CRPD. What is more, it shows that with the State's engagement and fulfilment of positive obligations, such as the establishment of adequate safeguards and use of all of its available resources to guarantee adequate and qualitative health care (palliative care and other alternatives), euthanasia practice request based on will and preferences can be seen as an option for persons with dementia. Nonetheless, we cannot forget that the Committee labelled euthanasia practice very critically and negatively.

³⁰⁴ CRPD 2008, Art. 10.

³⁰⁵ UNHRC, *End of Mission Statement by the United Nations Special Rapporteur on the rights of persons with disabilities* 2019.

5.2.3. Equal Recognition Before the Law

This section focuses on the support of legal capacity which must, according to the Committee, reflect respect for the rights, will and preferences of persons with disabilities. Supported decision-making allows persons with disabilities to, ‘choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or call on other forms of support, ..., or assistance with communication’.³⁰⁶ The Committee acknowledges the importance of advance planning as an important form of support for many persons with disabilities, through which they can communicate their will and preferences at a time when they might no longer be able to communicate them to the others. Furthermore they state that ‘[t]he point at which an advanced directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity’.³⁰⁷ In the event when despite significant efforts it is not possible to determine the will and preferences of the individual, the ‘best interpretation of will and practices’ applies.³⁰⁸

Despite the expression ‘will and preferences’ frequently appearing in the states of various UN bodies, including those that do not explicitly prohibit substitute decision-making, so far there is no authoritative definition as none have been provided in these statements.³⁰⁹ The meaning of preference is defined by the Oxford English Dictionary as ‘a greater liking for one alternative over another’³¹⁰ whereas will is a bit more elusive. Nonetheless, popularly, more weight is given to will than preferences when it comes to resolving an act in a particular way.

The distinction between will and desire or currently held preference is usually drawn in philosophical literature. Kant’s concept of will has been particularly influential, it can be summarized as: ‘The will, then, as distinct from the ability to choose, is the capacity to transform felt urges or desires with causal force into motivating reasons for action with justifying validity. To possess a will is therefore also to be able to test desires to see whether or not they can be validated as reasons’.³¹¹ Kant’s concept of will is a part of a larger narrative

³⁰⁶ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 17.

³⁰⁷ *Ibidem*.

³⁰⁸ *Ibidem*, para. 21.

³⁰⁹ Szmukler 2019, p. 38.

³¹⁰ Oxford English Dictionary 2019.

³¹¹ Schneewind 2004, p. 156-160.

which among others includes the choice of ends³¹² which makes this definition even more relevant for our discussion. In accordance with Kant and some more contemporary philosophical perspectives on the concept of will³¹³ it can be concluded that will manifests deeply held and reasonably stable and coherent personal values, beliefs, commitments and perception of good. In other words will can be understood *as an expression of personal autonomy*. This definition of will distinguishes it from desire or currently held preference, even if it is strongly expressed.³¹⁴

In case of persons with dementia, the decision-making impairment can cause inconsistency between will and preferences. The model of advanced directives clearly illustrates this problem. Imagine an individual states at Time 1, when their cognitive ability is not significantly impaired yet, that they want to be euthanized at a certain stage of the disease but then at Time 2 when their decision-making capacity is impaired, their preferences -which the person in the advanced directive asks to be ignored- contradict the expressed will and they refuse euthanasia, what should be done?

Usually honouring the preference expressed at Time 2 would undermine the will and subsequently the personal autonomy of an individual which would be inconsistent with CRPD's first General Principle stating, '[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.³¹⁵ A similar situation would apply when the individual had not made a written advanced directive, the only difference being that their life statements, values, choices and commitments evidenced by people close to them would count heavily in the decision on whether or not to respect the present preference stated at Time 2.³¹⁶

However the situation is even more complicated when it comes to persons with dementia as it is often argued that the person changes and subsequently so does their will. Whether this latter will should be given more importance than the previous strongly held but divergent will should be assessed on a case-by-case basis and with close cooperation with persons who have a close interest in the well-being of the concerned individual.³¹⁷

³¹² Szmukler 2019, p. 38.

³¹³ Watson 2003, p. 180-186; Bratman 2000, p. 257.

³¹⁴ Szmukler 2019, p. 38.

³¹⁵ CRPD 2008, Art. 3 (a).

³¹⁶ Szmukler 2019, p. 39.

³¹⁷ Ibidem.

The predicament of protection versus autonomy poses a further question; whether the respect for rights could override that of a well formulated will?³¹⁸ Turning to the CRPD as a whole, there is no provision which would be made for overriding or substitute-decision-making an individual's will or preferences based on the substitute-decision-maker's view on what constitutes the person's rights.³¹⁹

5.2.4. Right to Health

Historically, the views of persons with disabilities, individuals that were perceived merely as 'patients' were held less valuable than those of medical professionals. Through the medical model of disability, they were 'reduced' to their impairments and not recognized as right-holders. The focus was on curing them rather than taking into consideration their will and preferences. Today they should be recognized through a human-rights based approach as equal members of our diverse humanity.³²⁰

Unfortunately, in some cases the view of the health practitioner is still held as more valuable than that of the concerned individual or their supporter. This is often the case in euthanasia practice for persons with advanced dementia. Even if a person expressed their will and preferences in an advanced directive, it is the physician that decides. This problematic is further discussed in the following chapter.

In its report on the right to health, the Special Rapporteur appointed particular attention to the part (d) of Article 25³²¹ calling on State Parties to, '[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent, by inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities ...'.³²² Aguilar states that the provision refers to the right to free and informed consent to medical treatment and experimentation, including the right to refuse treatment.³²³ This can be understood as an indication to the right to passive euthanasia.

Furthermore the Committee on Persons with Disabilities expressed that State parties have an obligation not to allow substitute decision-makers to provide consent on behalf of persons

³¹⁸ Ibidem.

³¹⁹ Cahill 2018, p. 165.

³²⁰ UN General Assembly, *Report of the Special Rapporteur on the rights of persons with disabilities 2018*, para. 7.

³²¹ Ibidem, para. 14.

³²² CRPD 2008, Art. 25(d).

³²³ UN General Assembly, *Report of the Special Rapporteur on the rights of persons with disabilities 2018*, para. 14.

with disabilities. Instead they should implement supported decision-making regimes and medical personnel should take measures to ensure that supporters respect the individual's will and preferences and that they do not have undue influence over the decisions of individual in question.³²⁴ In cases where, despite significant efforts, it is not possible to obtain an individual's free and informed consent or to ascertain their will and preferences, the standard of best interpretation of the will and preference should apply as last resort.³²⁵

States should ensure and support advance planning as well as to actively involve the views of persons with disabilities in implementation of health-care services. These views might often contradict those of health-care professionals which are trained to act in best interest of the patient, as many still hold paternalistic views on disability.³²⁶ This could be useful for embedding euthanasia into palliative care as is the practice in Belgium.

5.3. Protection of Persons Without the Capacity to Consent

Article 7 of the Universal Declaration on Bioethics and Human Rights offers special protection to persons unable to consent. Any authorisation for medical practice, '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.'³²⁷

On the CoE level, the Oviedo Convention on Human Rights and Biomedicine similarly states, '[w]here, according to the law, an adult does not have the capacity to consent to an intervention because of a mentally disability, a disease or for similar reasons, 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, '[t]he individual concerned shall as far as possible take part in the authorisation procedure'.³²⁸ This provision of the Oviedo Convention reflects the substitute decision-making regime which conflicts with the human rights of persons with disabilities protected under the CRPD.

³²⁴ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law 2014*, para. 41.

³²⁵ *Ibidem*, para. 21.

³²⁶ UN General Assembly, *Report of the Special Rapporteur on the rights of persons with disabilities 2018*, para. 50, 61, 62.

³²⁷ Universal Declaration on Bioethics and Human Rights 2005, Art. 7 (a).

³²⁸ Convention on Human Rights and Biomedicine 1997, Art. 6 (3).

As the Oviedo Convention has been opened for signature in 1997, 9 years before the adoption of the CRPD this conflict does not come as a surprise. However the Draft Additional Protocol to the Oviedo Convention, of the Committee on Bioethics, proposed in June 2018³²⁹ again is at odds with the positive aspects of personal autonomy while violating the rights of persons with disabilities as enshrined in the CRPD. This brought the Committee on the Rights of Persons with Disabilities to call State parties to oppose the draft to the Oviedo Convention.³³⁰

5.4. Conclusion

This chapter dealt with the application of a possible human right to euthanasia concerning persons with dementia. This work agrees that persons with dementia should be treated as a vulnerable group and therefore granted special protection and support when it comes to exercising the right to euthanasia. At the same time, excluding them from the scope of applicability to a human right to euthanasia would constitute as discrimination. With the support of the well implemented supported decision-making regime, the impaired cognitive ability should not pose any barriers to the enjoyment of this right.

When it comes to the right to life, the statement of the Special Rapporteur on the Rights of Persons with disabilities does not provide any indication that euthanasia practice could present a violation of this right. What is more it shows that with State's engagement and fulfilment of positive obligations this practice can be seen as an option for persons with disabilities - including persons with dementia. Nonetheless, we cannot forget that the Committee on the Rights of Persons with Disabilities stated its negative position towards euthanasia by labelling it as systematic murder.

When it comes to organising the human right to euthanasia for persons with dementia there is a highlighted importance of advanced planning as a form of support for the individuals to communicate their will and preferences even when they are no longer able to communicate them to others. The advance directive must include the exact moment in which the directive comes into force. When a person did not complete an advanced directive and for some reason it is not possible to establish the will and preferences - their best interpretation would apply. As the nature of the disease is said to change the will and personality of the concerned person, this poses a problem to the effectiveness of the advanced directives. However, CRPD does not

³²⁹ Council of Europe 2018.

³³⁰ UN Committee on the Rights of Persons with Disabilities, *Statement by the Committee 2018*.

provide any provision which would allow overriding or substitute decision making an individual's will and preferences at any time.

Persons with dementia should according to the Special Rapporteur be provided the same quality of health care as others, based on an informed and free consent, including the right to refuse treatment. As a human right to euthanasia would present a part of health care the health practitioners should not be able to decide on behalf of persons with dementia. Instead they would have to ensure that supporters respect the individual's will and preferences and that there is no undue influence or pressure over the decisions of the individual. States should involve views of the persons with dementia in implementation of the right to euthanasia as their views could show a contrast with that of health-practitioners which are trained to act in best interest of the patient.

The impaired capacity to consent caused by dementia poses a question of balance between the protection and respect for personal autonomy. Persons unable to consent are protected under the Universal Declaration on Bioethics and Human Rights and the Oviedo Convention on Human Rights and Biomedicine. They similarly state that the person concerned should be involved in the decision-making process or refusal to the greatest extent possible. However, both international documents conflict with the supported decision-making regime proposed by the Committee on Rights of Persons with Disabilities.

Now that it has been established how the human right to euthanasia should be practiced in compliance with the human rights of persons with dementia, the following chapter examines the unique challenge that the progression of dementia poses on the proposed right.

6. The Dilemma Surrounding Dementia and Euthanasia

6.1. Introduction

This chapter aims to present the unique challenge accompanying the progression of dementia which has already posed problems in two states that have legalized euthanasia for persons with dementia, Netherlands and Belgium.³³¹ This challenge would persist with the establishment of the human right to euthanasia and its implementation in compliance with the CRPD and all of the above mentioned human rights instruments. In order to explain the limits of legal euthanasia in practice, it will be explained through evidence from Dutch practice while showing how the diminished validity of advance directive pushes persons with dementia to die ‘too early’. The decision to present the Dutch practice is based on the Netherlands being the first country to legalise euthanasia³³², hence it has the longest standing practice, as well as by Dutch euthanasia law being the most regulated.³³³

6.2. Validity and Effectiveness of Advanced Directives in Dementia

The aim of advanced directives is to provide individuals with control over what happens to them at the end of their life when unable to make or voice their own decision.³³⁴ Although advanced directives proved to be very useful instruments regarding incompetent patients³³⁵, their validity in cases of persons with dementia have turned out to be largely debatable.³³⁶ Persons with dementia differ from other incompetent persons in two key ways. First of all, dementia is usually a slow but progressive process which results in diminishing competence through the course of the disease. Secondly, although persons with dementia might be labelled as incompetent, they remain alert, present in their situation and able to interact with the environment surrounding them.³³⁷

In the context of dementia most of the euthanasia requests are based on an anticipated loss of dignity, dependence and unbearable suffering rather than on the contemporaneous situation.³³⁸

³³¹ Dierickx et al. 2017, p. 2.

³³² World Health Organization 2001, p. 580.

³³³ Blanken 2018a.

³³⁴ Davis 2018, p. 745.

³³⁵ De Boer et al. 2010, p. 201.

³³⁶ Gaster et al. 2017, p. 2175.

³³⁷ De Boer et al. 2010, p. 203.

³³⁸ Dresser 2017, p. 107.

Persons with dementia have different concerns about the disease and wishes about at which stage they wish their life to end. Nonetheless many perceive being stuck in a demented state as intolerably degrading well-before the dementia reaches its 'advanced' stage in which the individual becomes completely dependent, fails to recognize their family members, which can already occur in the 'moderate stage', and may be totally incomprehensible.³³⁹

The question is how much validity and effectiveness do advanced directives have after one loses their decision-making capacity, which usually happens in the 'moderate' stage. Unfortunately the Dutch practice shows that they do not have much validity and give persons with dementia no guarantee of fulfilment. As persons with dementia remain alert and able to communicate with their surroundings, they continue to have wishes and preferences and to formulate subjective experiences. As a consequence, it often occurs that the current will and preferences expressed through verbal statements or behaviour contradict their formal will and preferences expressed in the advanced directive.³⁴⁰ This creates a dilemma as to how to comply with the will expressed in the advanced directive while still respecting the wishes and preferences of the person with dementia.³⁴¹ Behind this dilemma lies the moral distress of 'prospective autonomy' or simply the identity problem which poses the validity of advance directives to question.³⁴²

So can it be argued that an individual in the advanced stages of dementia, unable to remember their name, relatives or recall their life, is still the same person as the one that wrote the advance directive?³⁴³

In the philosophical debate surrounding this issue one of the extreme points of view is held by Partif who argues that the loss of individual identity can be caused by the psychological changes. Partif believes that the dementia process may decrease the psychological continuity and connectedness between different stages in life.³⁴⁴ He further claims that one body may, over time, host successive selves.³⁴⁵

³³⁹ Cantor 2017.

³⁴⁰ De Boer et al. 2010, p. 204.

³⁴¹ Ibidem.

³⁴² Dresser 1995, p. 36.

³⁴³ Ibidem.

³⁴⁴ Partif 1984. pp. 219-222.

³⁴⁵ Ibidem, p. 303.

Conversely, Dworkin does not recognize the idea of losing one's personal identity. He suggests that the competent and demented stages are stages in a single life that belong to a single person. He further argues that at a later stage, as persons with dementia lack the capacity to exercise their autonomy, the former decision enshrined in the advance directive should remain in force.³⁴⁶

Crucial to Dworkin's work is the distinction between two types of person's interests, namely the experimental and critical interests. Experimental interests are those that reflect the concerned person's state of mind and their quality of life experiences which entail experiencing a wide array of feelings like happiness, pain, pleasure and fear. Critical interests on the other hand are those reflecting person's determined life goals and plans and refer to aims that give our lives a genuine meaning and coherence.

Despite persons with dementia being incompetent they still form the mentioned experimental interests nonetheless Dworkin's opinion is that priority should be given to the critical interests. He argues that the advanced directives written by the competent individuals are the embodiment of their critical interests and as such should prevail over the preferences of the person with dementia. By stating, '[a] competent person's right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected even if they contradict the desires he has at a later point' he gives primacy to what he calls 'precedent autonomy'.³⁴⁷

Dresser criticized Dworkin's theory by questioning the importance of critical interests. She believes that people do not necessarily differentiate between the two types of interest and that experimental interests should override the advance directive when persons with dementia have a good quality of life based on experimental interests.³⁴⁸ Similar to Dresser, Jaworska also holds that the current interests of persons with dementia should be taken into consideration, but not because they would become a different person as Partif argued, but as she believes that they retain 'the capacity to originate the appropriate bases for one's decisions'. She states that if persons with dementia remain able to give some rationale for the

³⁴⁶ Dworkin 1986, pp. 5-9.

³⁴⁷ Ibidem, pp. 10-14.

³⁴⁸ Dresser 1995, pp. 37-38.

chosen activities, they are still able to value them and other experiences in their lives. Therefore these values should be taken seriously and could override the advance directive.³⁴⁹

By giving a strong legal status for advanced directives, the Dutch legislation seems to follow Dworkin's argumentation.³⁵⁰ This statement will be further examined in the following section in which evidence from Dutch practice of advanced directives in the advanced stages of dementia is discussed.

6.3. Evidence from the Dutch practice

In 2001 the Netherlands passed the *Termination of Life on Request and Assisted Suicide Act* (or 'the 2001 Act') which provided physicians the legal ability to terminate life and assist the suicide of a patient provided that all six 'due care' criterion have been met.³⁵¹ These statutory due care criterion include the requirement that the physician must be satisfied that the patient's request is voluntary and well-considered as well as that the patient's suffering must be unbearable, without any prospect of improvement.³⁵²

All physicians' decisions to perform euthanasia or assist in suicide must be reported to the Regional Euthanasia Review Committee (*Regionale Toetsingscommissie Euthanasie* – RTE) whose role is to assess whether the physician's decisions have complied with the due care criterion set in the 2001 Act.³⁵³ RTE published an updated version of 2015 Code of Practice, the Euthanasia Code 2018, which provides guidance to the physicians on how to interpret the due care criterion. The new Code contains clarifications of sections concerning persons with dementia.

6.3.1. Euthanasia Code 2018

In cases concerning persons with dementia, the RTE recognizes that particular caution should be exercised when considering if the statutory due care criterion have been met. Special

³⁴⁹ Jaworska 1999, pp. 106-112.

³⁵⁰ De Boer et al. 2010, p. 206.

³⁵¹ Tuffrey-Wijne et al. 2018, p. 2.

³⁵² RTE 2019a.

³⁵³ RTE 2019b.

attention should be also accorded to the criterion relating to decisional competence and unbearable suffering.³⁵⁴

Nearly all cases in which the Committees were notified about, the concerned person was in the early stages of dementia, at this point the concerned person generally has sufficient understanding and decision-making competence in relation to their euthanasia request. Besides the decline in cognitive ability and capacity to perform everyday activities, the person's suffering is often partly determined by fear of further cognitive decline and the negative impact that it will have on their dignity and autonomy. RTE acknowledges that the prospect of patient's perception of the progressive loss skills, functions, personality and the uncontrollable nature of the process can amount to profound suffering.³⁵⁵

Regarding advanced dementia, the RTE states that it is still possible to grant euthanasia requests to persons in the advanced stages of dementia even when they are no longer able to communicate, provided that they completed an advanced directive when they were still divisionally competent. The directive has to be clear and evidently applicable to the current situation. In these cases the physician must take into consideration the entire course of the disease and other specific circumstances when making a decision. The concerned person's behaviour and utterances must be interpreted throughout the disease process and shortly before the euthanasia is to be performed. At this point the physician must be satisfied that carrying out of euthanasia is in line with the advanced directive, that there are no contraindications to it and that the person is at a stage of unbearable suffering. Of course, the rest of the due criterion must also be met to the greatest extent possible.³⁵⁶

The criterion set in Euthanasia Code 2018 and the first recent case of a doctor facing persecution for breach of euthanasia law after euthanizing a person with severe dementia³⁵⁷ indicates in terms of advanced dementia stages, that law favours Jaworska's position.

³⁵⁴ RTE 2018, pp. 44–45.

³⁵⁵ Ibidem.

³⁵⁶ Ibidem, p. 45.

³⁵⁷ Please see: Boffey, Daniel. 2018. Doctor to face Dutch prosecution for breach of euthanasia law. The Guardian, 9 November. Available at: <https://www.theguardian.com/world/2018/nov/09/doctor-to-face-dutch-prosecution-for-breach-of-euthanasia-law> (last consultation on 12 July 2019).

6.3.2. Early Death as a Guarantee

‘Every year, ten thousand Dutch people with dementia die. About half of them stated that they did not want to die like that. They wanted a dignified death. How many got what they asked for? One hundred. One hundred people on average escape that fate. But only because they request euthanasia in the early stages of dementia.’³⁵⁸ This statement reflects the complexity of the challenge that dementia presents and its diminishing effect on the validity of advanced directives in advanced stages of dementia. Since the Dutch euthanasia laws came into effect, less than 20 persons got their advanced directives respected in the advanced stages of dementia.³⁵⁹ As almost no doctors are willing to perform euthanasia on patients with severe dementia when persons are not able to make a well-considered request³⁶⁰, the fear of having their advanced directives refused is pushing some people to ask to die earlier than they would otherwise have liked to.³⁶¹

6.4. Conclusion

This last chapter aimed to present the unique challenge that the progression of dementia poses on euthanasia practice and would persist even with the establishment of the human right to euthanasia. In the more severe stages of dementia, one can only be euthanized if they completed an advanced directive while still mentally competent. However, the validity and effectiveness of the advance directives, which are supposed to provide individuals with control over what happens at the end of their life, become largely debatable when persons with dementia lose their decision-making capacity.

As persons with dementia remain alert and are able to interact with the surrounding environment throughout the progress of the disease, their verbal statements and behaviour often contradict their formal will and preferences expressed in the advance directive. At this point a question arises, of whether the formerly expressed will and preferences in the advanced directive should be respected or if the newly established preferences of the demented person can override it. The Dutch practice unfortunately shows that an advance directive gives no guarantee of fulfilment once the person entered the advanced stages of dementia and therefore a large importance is given to the preferences of a person in advanced

³⁵⁸ Blanken 2018a.

³⁵⁹ Ibidem; RTE 2017, p. 12; RTE 2019, p. 12.

³⁶⁰ Blanken 2018b.

³⁶¹ Bomford 2019.

stages of dementia. As the legal requirements of the Dutch euthanasia law make it nearly impossible for the physician to fully comply with the set criterion, there are almost no physicians willing to perform euthanasia on persons with advanced dementia. Consequently this forces people to ask to die earlier than they would have otherwise liked to.

This grey area that the progress poses on euthanasia practice would need to be addressed and resolved before a human right to euthanasia could be established in order to avoid violations. Advance directives can be in general seen as a great way of giving a voice to the ‘voiceless’ but as this chapter shows, in the case of persons with dementia, their voice is still very often overheard.

7. End Conclusion

This work focused on the case of euthanasia for persons with dementia, which was addressed through two main research questions. For a more detailed analysis of the proposed research questions, I would like to refer to the conclusions at the end of chapters three, five and six.

The first and primary research question was if euthanasia itself could be considered as a possible future human right. Thereby I examined the prospect of this right through the provisions of the already existing human rights network and national developments that could indicate a trajectory towards considering a human right to euthanasia. In general, human rights bodies are still quite reluctant when it comes to active euthanasia and physician-assisted suicide, but on the other hand many positive indications in regard to passive euthanasia have been noticed. However, this does not necessarily exclude the possibility of euthanasia becoming a human right in the future. Developments can be traced through the ECtHR's case law and although they are small, they could someday contribute to a human right to euthanasia. We must remember that no change happens over night and as euthanasia is seen as a highly controversial ethical issue, this might take quite some time. In addition to the mentioned developments in the case law of the ECtHR, a lot of changes reflected in national legal developments are occurring. They might have a transnational effect, both on other States and consequently international human rights bodies. It is impossible to determine when a human right to euthanasia could be established but I would argue that as of this moment the international society is not ready yet.

My second research question addresses how a potential human right to euthanasia concerning persons with dementia could apply in all stages of the disease. My first argument is that while persons with dementia should be granted special protection as a vulnerable group, excluding them from the scope of euthanasia as a universal human right or euthanasia practice on a national level (if a certain State would legalise euthanasia) would be discriminatory. However, the Committee on Rights of Persons with Disabilities shows reluctance to euthanasia by labelling it systematic murder.

In regards to persons with dementia and euthanasia requests a big importance is given to the advanced planning as a form of support. This work outlines a short framework on how the supported decision-making regime envisioned by the Committee should work. Besides the respect of the will and preferences of the individual, another concept that emerged throughout

the research of the relevant rights is the great importance of evaluating a person's wishes, preferences, needs for protection and competences on a case-by-case basis. Not only should the whole process of the disease be taken into consideration but also their life experiences, decisions, relations and everything that contributed to the shaping of the will established in the advance directive. This is extremely important in the advanced stages of dementia when the individual may give conflicting statements, which as shown in the Dutch practice tend to diminish the validity and efficiency of the will established in an advanced directive. Consequently, the most obvious need for further research identified by this conducted research is how to solve the complex problematic that the advanced stages of dementia pose on the euthanasia practice. What is lacking is more empirical research, which would pose persons with dementia in the centre of the research.

To conclude, I would like to remind you of the beginning. My decision to write this master thesis was driven by a personal experience which inspired me to give voice to the voiceless. I hope that I managed to contribute to the discussion of end-of-life choices for persons with dementia by offering a perspective grounded in a human rights network.

References

Case law

European Court of Human Rights. *A. v. the United Kingdom*, no. 100/1997/884/1096, 23 September 1998.

European Court of Human Rights. *Camp and Bourimi v. the Netherlands*, no. 28369/95, 3 October 2000.

European Court of Human Rights. *Gäfgen v. Germany*, no. 22978/05, 1 June 2010.

European Court of Human Rights. *Groni v. Albania*, no. 25336/04, 7 July 2009.

European Court of Human Rights. *Gross v. Switzerland*. no. 67810/10, 14 May 2013.

European Court of Human Rights. *Haas v. Switzerland*, no. 31322/07, 20 January 2011.

European Court of Human Rights. *Herczegfalvy v. Austria*, no. 10533/83, 24 September 1992.

European Court of Human Rights. *Ireland v. the United Kingdom*, no. 5310/71, 18 January 1978.

European Court of Human Rights. *Keenan v. the United Kingdom*, no. 27229/95, 3 April 2001.

European Court of Human Rights. *Kiliç v. Turkey*, no. 22492/93, 28 March 2000.

European Court of Human Rights. *Koch v. Germany*, no. 497/09, 19 July 2012.

European Court of Human Rights. *L.C.B. v. the United Kingdom*, no. 23413/94, 9 June 1998.

European Court of Human Rights. *Lambert and Others v. France*, no. 46043/14, 5 June 2015.

European Court of Human Rights. *Mc Cann and Others v. the United Kingdom*, no. 18984/91, 27 September 1995.

European Court of Human Rights. *Mouvement Raëlien Suisse v. Switzerland*, no. 16354/06, 13 July 2012.

European Court of Human Rights. *Osman v. the United Kingdom*, no. 23452/94, 28 October 1998.

European Court of Human Rights. *Peers v. Greece*, no. 28524/95, 19 April 2001.

European Court of Human Rights. *Pretty v. the United Kingdom*, no. 2346/02, 26 April 2002.

European Court of Human Rights. *Price v. the United Kingdom*, no. 33394/96, 10 July 2001.

European Court of Human Rights. *Schalk and Kopf v. Austria*, no. 30141/04, 24 June 2010.

European Court of Human Rights. *Thlimmenos v. Greece*, no. 34369/973, 6 April 2000.

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

The Supreme Court of India. *Common Cause v. Union of India*, No. 215, 9 March 2018.

The Supreme Court of the United Kingdom. *In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)*, UKSC 2017/0131, 7. June 2018.

Other

Allmark, Peter. 2002. Death with dignity. *J Med Ethics* 28: 255–257.

Alzheimer's Disease International. 2018. World Alzheimer Report 2018 – The state of the art of dementia research: New frontiers. Available at: <https://www.alz.co.uk/research/WorldAlzheimerReport2018.pdf?2> (last consultation on 15 April 2019).

Alzheimer's Association. 2019. Stages of Alzheimer's. Available at: <https://www.alz.org/alzheimers-dementia/stages> (last consultation on 4 May 2019).

Andorno, Roberto. 2009. Human Dignity and Human Rights as a Common Ground for a Global Bioethics. *Journal of Medicine and Philosophy*, 34 (3): 223-40.

Arstein-Kerslake, Anna and Eilionóir Flynn. The Support Model of Legal Capacity: Fact, Fiction, or Fantasy? *Berkley Journal of International Law* 32 (1): 124-143.

Australian Human Rights Commission. 2016. Issues Paper: Euthanasia, human rights and the law. Available at: <https://www.humanrights.gov.au/our-work/age-discrimination/publications/euthanasia-human-rights-and-law> (last consultation on 27 April 2019).

Azize, Joseph. 2007. Human Dignity and Euthanasia Law. *University of Notre Dame Australia Law Review* 9: 47-74.

Bandewar, Sunita, Leni Chaudhuri, Lubna Duggal and Sanjay Nagral. 2018. The Supreme Court of India on euthanasia: Too little, too late. *Indian Journal of Medical Ethics* 3 (2): 91-94.

Barilan, Yechiel Michael. 2012. *Human Dignity, Human Rights, and Responsibility: The New Language of Global Bioethics and Biolaw*. Cambridge, Massachusetts: The MIT Press.

Battin, Margaret P. , Agnes van der Heide, Linda Ganzini, Gerrit van der Wall, Bregje D. Onwuteaka-Philipsen. 2007. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups. *J Med Ethics* 33: 591-597.

BBC. 2014. Ethics guide: Active and passive euthanasia. Available at: http://www.bbc.co.uk/ethics/euthanasia/overview/activepassive_1.shtml (last consultation on 28 April 2019).

Beauchamp, Tom L. 2000. The Right to Privacy and the Right to Die. *Social Philosophy and Policy Foundation* 17 (2): 276-292.

Blanken, Henk. 2018a. TEDx Amsterdam Talk. My Death Is Not My Own. Available at: <https://tedx.amsterdam/talks/watch/?talk=190> (last consultation on 15 April 2019).

Blanken, Henk. 2018b. ‘My death is not my own’: the limits of legal euthanasia. *The Guardian*, 10 August. Available at: <https://www.theguardian.com/news/2018/aug/10/my-death-is-not-my-own-the-limits-of-legal-euthanasia> (last consultation on 15 April 2019).

Boffey, Daniel. 2018. Doctor to face Dutch prosecution for breach of euthanasia law. *The Guardian*, 9 November. Available at: <https://www.theguardian.com/world/2018/nov/09/doctor-to-face-dutch-prosecution-for-breach-of-euthanasia-law> (last consultation on 12 July 2019).

Bomford, Andrew. 2019. Wanting to die at ‘five to midnight’ - before dementia takes over. *BBC*, 30 January. Available at: <https://www.bbc.com/news/stories-47047579> (last consultation on 20 May 2019).

Bratman, Michele E. 2000. Valuing and the Will. In *Philosophical Perspectives: Action and Freedom, Vol. 14*, edit. Tomberlin, E. James, 249-265.

Cahill, Suzanne. 2018. *Dementia and human rights*. Bristol: Bristol University Press.

Cambridge Dictionary. 2019. Catch-22. Available at: <https://dictionary.cambridge.org/dictionary/english/catch-22> (last consultation on 12 April 2019).

Cantor, L. Norman. 2017. Changing the Paradigm of Advance Directives to Avoid Prolonged Dementia. *Bill of Health*, 20 April. Available at: <http://blog.petrieflom.law.harvard.edu/2017/04/20/changing-the-paradigm-of-advance-directives/> (last consultation on 12 July 2019).

CoE Parliamentary Assembly. 2007. *Recommendation 1796: The situation of elderly persons in Europe*. Available at: <http://www.assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=17545&lang=en> (last consultation on 1 July 2019).

Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. 1987. Adopted and opened for ratification by General Assembly Resolution 39/46, 10 December 1984, entry into force on 26 June 1987. Available at: <https://www.refworld.org/docid/3ae6b3a94.html> (last consultation on 26 June 2019).

Convention on Human Rights and Biomedicine. 1997. Opened for signature in Oviedo, 4 April 1997, ratified in 1999. Available at: <https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98> (last consultation on 10 July 2019).

Convention on the Rights of Persons with Disabilities. 2008. Adopted by the UN General Assembly Resolution 61/106, 13 December 2006, entered into force in 2008. Available at: <https://www.refworld.org/docid/45f973632.html> (last consultation on 12 July 2019).

Council of Europe. 2003a. The prohibition of torture: A guide to the implementation of Article 3 of the European Convention on Human Rights. *Human Rights handbooks*, No. 6.

Available at: <https://www.refworld.org/docid/49f1829b2.html> (last consultation on 21 June 2019).

Council of Europe. 2003b. *Recommendation of the Committee of Ministers to member states on the organisation of palliative care*, Rec(2003)24, 12 November 2003. Available at: https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=09000016805de857 (last consultation on 1 July 2019).

Council of Europe. 2008. Digest of the case law of the European committee of social rights. Available at: <https://rm.coe.int/168049159f> (last consultation on 28 June 2019).

Council of Europe. 2014. *Explanatory Memorandum of Recommendation of the Committee of Ministers to member States on the promotion of human rights of older persons*, CM/Rec(2014)2, 24 February 2014. Available at: https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=09000016805c6318 (last consultation on 1 July 2019).

Council of Europe. 2015. European Social Charter: Collected texts (7th edition). Available at: <https://rm.coe.int/168048b059> (last consultation on 30 June 2019).

Council of Europe. 2017. Prohibition of torture: Article 3. Available at: <https://www.coe.int/en/web/echr-toolkit/interdiction-de-la-torture> (last consultation on 28 June 2019).

Council of Europe. 2018. Draft Additional Protocol concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment. Available at: <https://rm.coe.int/inf-2018-7-psy-draft-prot-e/16808c58a3> (last consultation on 12 July 2019).

Council of Europe. 2019. Margin of Appreciation. Available at: https://www.coe.int/t/dghl/cooperation/lisbonnetwork/themis/echr/paper2_en.asp (last consultation on 13 June 2019).

Darby, R. Ryan and Bradford C. Dickerson. 2017. Dementia, Decision Making, and Capacity. *Harvard Review of Psychiatry* 25 (6): 270–278.

Darby, Ryan R. and Bradford C. Dickerson. 2017. Dementia, Decision Making, and Capacity. *Harvard Review of Psychiatry* 25 (6): 270–278.

Daskal, Steven. 2018. Support for Voluntary Euthanasia with No Logical Slippery Slope to Non-Voluntary Euthanasia. *Kennedy Institute of Ethics Journal* 28 (1): 23-48.

Davis, Deena S. 2018. Advance Directives and Alzheimer's Disease. *The Journal of Law, Medicine & Ethics* 46: 744-748.

De Boer, Marike E., Cees M. P. M. Hertogh, Rose-Marie Dröes, Cees Jonker and Jan A. Eefsting. 2010. Advance directives in dementia: issues of validity and effectiveness. *International Psychogeriatrics* 22 (2): 201-208.

DEEP. 2014. Dementia words matter: Guidelines on language about dementia. Available at: <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf> (last consultation on 12 July 2019).

Dementia Care Central. 2018. Stages of Alzheimer's & Dementia: Durations & Scales Used to Measure Progression: GDS, FAST & CDR. Available at: <https://www.dementiacarecentral.com/aboutdementia/facts/stages/> (last consultation on 4 May 2019).

Dierickx, Sigrid, Luc Deliens, Joachim Cohen and Kenneth Chambaere. 2017. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. *BMC Psychiatry* 17 (203) 1-9.

Dimmock, Mark and Andrew Fisher. 2017. *Ethics for A-level*. Cambridge: Open Book Publishers.

Doron, Israel, Perla Werner, Benny Spanier and Ori Lazar. 2017. The legal appearances of dementia in court rulings: mapping the terrain. *International Psychogeriatrics*: 1-9.

Dowbiggin, Ian. 2003. *A merciful end: The euthanasia movement in modern America*. New York: Oxford University Press.

Dresser, Rebecca. 1995. Dworkin on Dementia: Elegant Theory, Questionable Policy. *Hastings Center Report* 25: 32-38.

Dresser, Rebecca. 2018. Dementia, Dignity, and Physician-Assisted Death. In *Human Dignity and Assisted Death*, edit. Sebastian Muders, 105-124. New York: Oxford University Press.

Dresser, Rebecca. 2018. Dementia, Dignity, and Physician-Assisted Death. In *Human Dignity and Assisted Death*, editor Sebastian Muders, 105–124. Oxford: Oxford Scholarship Online.

Dupre, Catherine. 2009. Unlocking human dignity: towards a theory for the 21st century. *European Human Rights Law Review* 3: 190-205.

Dworkin, Ronald. 1986. Autonomy and the Demented Self. *The Milbank Quarterly* 64 (2): 4-16.

Dzehtsiarou, Kanstantsin. 2015. *European Consensus and the Legitimacy of the European Court of Human Rights*. Cambridge: Cambridge University Press.

European Court on Human Rights. 2015. Factsheet - End of life and the European Convention on Human Rights. Available at: https://www.echr.coe.int/Documents/FS_Euthanasia_ENG.pdf (last consultation on 18 June 2019).

European Social Charter. 1996. Adopted by the Council of Europe in 1961, revised on 3 May 1996. Available at: <https://www.refworld.org/docid/3ae6b3678.html> (last consultation on 29 June 2019).

Euthanasia.com. 2019. Euthanasia Definitions. Available at: <http://www.euthanasia.com/definitions.html> (last consultation on 28 April 2019).

Fine, Sean. 2018. Supreme Court rules Canadians have right to doctor-assisted suicide. *The Globe and Mail*, 15 May. Available at: <https://www.theglobeandmail.com/news/national/supreme-court-rules-on-doctor-assisted-suicide/article22828437/> (last consultation on 1 July 2019).

Foster, Charles. 2011. *Human Dignity in Bioethics and Law*. Oxford: Hart Publishing Ltd.

Garrard, E. and S. Wilkinson. 2005. Passive Euthanasia. *Journal of Medical Ethics* 31 (2): 64–68.

Gaster, Barak, Eric B. Larson and J. Randall Curtis. 2017. Advance Directives for Dementia: Meeting a Unique Challenge. *JAMA* 318 (22): 2175-2176.

Government of the Netherlands. 2019. Euthanasia. Available at: <https://www.government.nl/topics/euthanasia> (last consultation on 20 June 2019).

Greer, Steven. 2000. *The Margin of Appreciation: Interpretation and Discretion under the European Convention on Human Rights*. Strasbourg: Council of Europe Publishing.

Groenhuijsen Marc. 2007. Euthanasia and the Criminal Justice System. *Electronic Journal of Comparative Law* 11 (3): 1–25. Available at: <https://www.ejcl.org/113/article113-33.pdf> (last consultation on 26 April 2019).

Hefler, Jan. 2019. 'Aid-in-Dying' Bill Becomes Law in New Jersey. *Governing*, 15 April. Available at: <https://www.governing.com/topics/health-human-services/tns-aid-in-dying-bill-signed-new-jersey.html> (last consultation on 4 July 2019).

Hendriks, Arend Cornelis. 2018. End-of-life decisions, Recent jurisprudence of the European Court of Human Rights. *ERA Forum* 19: 561-570.

International Covenant on Civil and Political Rights. 1976. Opened for ratification and accession by General Assembly resolution 2200A (XXI), 16 December 1966, entry into force, 23 March 1976. Available at: <https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx> (last consultation on 12 June 2019).

International Covenant on Economic, Social and Cultural Rights. 1976. Opened for ratification and accession by General Assembly resolution 2200A (XXI), 16 December 1966, entry into force 3 January 1976. Available at: <https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx> (last consultation on 28 June 2019).

Jaworska, Agnieszka. 1999. Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value. *Philosophy and Public Affairs* 28 (2): 105-138.

Kaczor, Christopher and Robert P. George. 2017. Death with Dignity. In *Human Dignity and Assisted Death*, edit. Sebastian Muders, 68-84. New York: Oxford University Press.

Kateb, George. 2011. *Human Dignity*. Cambridge, Massachusetts: Harvard University Press.

Kilda, Gusha and Irena Shala. 2016. The Debate Over Euthanasia and Human Rights. In *European Scientific Journal* 12 (3): 73-81.

- Klein, Sandra S. 1994. The Right to Die as an Issue of Privacy: A Selective Bibliography. *Legal Reference Services Quarterly* 13 (4): 137-143.
- Lerner, Barron H. and Arthur L. Caplan. 2015. Euthanasia in Belgium and the Netherlands: On a Slippery Slope? *JAMA Internal Medicine* 175 (10): 1640-1641.
- Lewis, Penney. 2007. The Empirical Slippery Slope from Voluntary to Non-Voluntary Euthanasia. *The Journal of Law, Medicine & Ethics* 35 (1): 197-210.
- Litins'ka, Yana. 2018. Assessing capacity to decide on medical treatment: On human rights and the use of medical knowledge in the laws of England, Russia and Sweden. Doctoral Thesis. University of Uppsala.
- Martin, Lisa. 2019. Assisted dying explained: Victoria's new laws, the safeguards and the Catholic resistance. *The Guardian*, 19 June. Available at: <https://www.theguardian.com/society/2019/jun/19/assisted-dying-explained-victorias-new-laws-the-safeguards-and-the-catholic-resistance> (last consultation on 2 July 2019).
- McCrudden, Christopher. 2008. Human Dignity and Judicial Interpretation of Human Rights. *The European Journal of International Law* 19 (4): 655-724.
- McGoldrick, Dominic. 2016. A Defence of the Margin of Appreciation and an Argument for its Application by the Human Rights Committee. *International & Comparative Law Quarterly* 65: 21-60.
- Mental Health Foundation. 2015. Dementia, rights, and the social model of disability: A new direction for policy and practice? Available at: <https://www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability> (last consultation on 7 July 2019).
- Murray, Malcom. 2017. *Morals and Consent: Contractarian Solutions to Ethical Woes*. Montreal: McGill-Queen's University Press.
- NZ Herald. 2019. Euthanasia bill passes second reading. Available at: https://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=12244205 (last consultation on 3 July 2019).

O'Mahony, Conor. 2012. There is no such thing as a right to dignity. *International Journal of Constitutional Law* 10 (2): 551-574.

Onwuteaka-Philipsen, Bregje D, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen JF de Jong-Krul, Johannes JM van Delden and Agnes van der Heide. 2012. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *The Lancet* 380 (9845): 908–915.

Oxford English Dictionary. 2019. Preference. Available at: <https://www.lexico.com/en/definition/preference> (last consultation on 9 July 2019).

Partif, Derek. 1984. *Reasons and Persons*. New York: Oxford University Press.

Pennington, Catherine, Katie Davey, Ruud ter Meulen, Elizabeth Coulthard and Patrick Gavin Kehoe. 2018. Tools for testing decision-making capacity in dementia. *Age and Ageing* 47: 778–784.

Polaris, J.J.Z. and L.S. Lehmann. 2016. Medical Ethics: Euthanasia and Assisted Suicide. In *Encyclopedia of Forensic and Legal Medicine (Second Edition)*, 321–329.

Potter, Jordan. 2018. The psychological slippery slope from physician-assisted death to active euthanasia: a paragon of fallacious reasoning. *Medicine, Health Care and Philosophy* 22: 239-244.

Rodgers, Joshua J. and Joseph S. Kass. 2018. Assessment of Medical Decision-making Capacity in Patients With Dementia. *Continuum: Behavioral Neurology and Psychiatry* 24 (3): 920–925.

RTE. 2017. Annual Report 2017. Available at: <https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports> (last consultation on 12 July 2019).

RTE. 2018a. Euthanasia Code: Review Procedures in Practice. Available at: <https://english.euthanasiecommissie.nl/the-committees/code-of-practice> (last consultation on 12 July 2019).

RTE. 2019. Jaarverslag (Annual Report) 2018. Available at: <https://www.euthanasiecommissie.nl/de->

toetsingscommissies/uitspraken/jaarverslagen/2018/april/11/jaarverslag-2018 (last consultation on 12 July 2019).

RTE. 2019a. Due care criteria. Available at: <https://english.euthanasiecommissie.nl/due-care-criteria> (last consultation on 10 July 2019).

RTE. 2019b. The committees. Available at: <https://english.euthanasiecommissie.nl/the-committees> (last consultation on 10 July 2019).

Sanchini, Virginia, Cecilia Nardini and Giovanni Boniolo. 2014. The withholding/withdrawing distinction in the end-of-life debate. *Multidisciplinary Respiratory Medicine* 13 (9): 1–3. Available at: <https://mrmjournal.biomedcentral.com/articles/10.1186/2049-6958-9-13> (last consultation on 26 April 2019).

Sandland, Ralph. 2003. Crossing and not crossing: Gender, sexuality and melancholy in the European Court of Human Rights. *Feminist Legal Studies* 11: 191-209.

Sarafis, P., A. Tsounis and M. Malliarou. 2013. Euthanasia An Active Area Of Research In Contemporary Bioethics: Challenges For The Society And The Professionals Of Health-Care. *Ελληνικό Περιοδικό της Νοσηλευτικής Επιστήμης (Greek Journal of Nursing Science)*. Available at: http://journal-ene.gr/wp-content/uploads/2013/02/euthanasia_an_active_area.pdf (last consultation on 2 May 2019).

Sartori, Daria. 2018. End-of-life issues and the European Court of Human Rights. The value of personal autonomy within a 'proceduralized' review. *Questions of International Law* 52: 23-43.

Schachter, Oscar. 1983. Human dignity as a normative concept. *The American Journal of International Law* 77 (4): 848-854.

Schneewind, JB. 2004. Kant on the will. In *The Will and Human Action: From Antiquity to the Present Day*, edit. Pink, Thomas and M.W.F. Stone, 154-172. London: Routledge.

Shala, Irena and Kilda Gusha. 2016. The Debate Over Euthanasia and Human Rights. *European Scientific Journal* 12 (8): 73–81.

Smith, W. Steven. 2012. *End-of-Life decisions in Medical Care: Principles and Policies for Regulating the Dying Process*. New York: Cambridge University Press.

Stoecker, Ralf. 2017. Dignity and the Case in Favour of Assisted Suicide. In *Human Dignity and Assisted Death*, edit. Sebastian Muders, 30-48. New York: Oxford University Press.

Strinic, Visnja. 2015. Arguments in Support and Against Euthanasia. *British Journal of Medicine & Medical Research* 9 (7): 1–12.

Sulmasy, Daniel P. 2008. Dignity and Bioethics: History, Theory and Selected Applications. In *Human Dignity and Bioethics*, edit. Adam Schulman. Washington: Government Printing Office.

Szmukler, George. 2019. ‘Capacity’, ‘best interest’, ‘will and preferences’ and the UN Convention on the Rights of Persons with Disabilities. *World Psychiatry* 18: 34-41.

Taylor, Charles. 2007. *A Secular Age*. Cambridge: Belknap Press.

Taylor, Morag E. and Jacqueline C.T. Close. 2018. Dementia. In *Handbook of Clinical Neurology*, editors B.L. Day and S.R. Lord, 159 (3): 303–321. Amsterdam: Elsevier B.V.

Ten Have, Henk A. M. J. and Jos Welie. 2015. *Death and Medical Power: An Ethical Analysis of Dutch Euthanasia Practice*. New York: McGraw-Hill Education.

The Irish Council for Bioethics. 2018. Euthanasia: Your Body, Your Death, Your Choice? Available at: https://www.rte.ie/science/euthanasia_leaflet.pdf (last consultation on 25 June 2019).

The University of Queensland Australia. 2017. Queensland Brain Institute: What is dementia? Available at: <https://qbi.uq.edu.au/dementia/what-is-dementia> (last consultation on 4 May 2019).

Tretyakov, Konstantin. 2015. From Therapeutic Abstention to the Right to Die? The case of Lambert and Others v. France. Available at: <https://strasbourgobservers.com/2015/07/06/from-therapeutic-abstention-to-the-right-to-die-the-case-of-lambert-and-others-v-france/> (last consultation on 18 June 2019).

Tretyakov, Konstantin. 2015. From Therapeutic Abstention to the Right to Die? The Case of Lambert and Others v. France. Available at: <https://strasbourgobservers.com/2015/07/06/from-therapeutic-abstention-to-the-right-to-die-the-case-of-lambert-and-others-v-france/> (last consultation on 30 May 2019).

Tuffrey-Wijne, Leopold Curfs, Ilora Finlay and Sheila Hollins. 2018. Euthanasia and assisted suicide for people with intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012-2016). *BMC Medical Ethics* 19 (17): 1-21.

UN Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Background Paper Prepared by the Division for Social Policy and Development of the United Nations Secretariat for the 'Informal Consultative Meetings on International Norms and Standards for Persons with Disabilities', A/AC.265/CRP.2, 9 February 2011. Available at: <https://www.un.org/esa/socdev/enable/rights/humanrights.htm> (last consultation on 11 July 2019).

UN Committee Against Torture, *General Comment No. 2 on Implementation of article 2 by State parties*, CAT/C/GC/2, 24 January 2008. Available at: <https://www.refworld.org/docid/47ac78ce2.html> (last consultation on 24 June 2019).

UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14 on the Right to the Highest Attainable Standard of Health (Art. 12)*, 11 August 2000. Available at: <https://www.refworld.org/pdfid/4538838d0.pdf> (last consultation 14 June 2019).

UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 on Article 12: Equal recognition before the law*, CRPD/C/GC/1, 19 May 2014. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement> (last consultation on 10 July 2019).

UN Committee on the Rights of Persons with Disabilities, *General comment No. 6 on equality and non-discrimination*, CRPD/C/GC/6, 26 April 2018. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en (last consultation on 8 July 2019).

UN Committee on the Rights of Persons with Disabilities. 2018. *Statement by the Committee on the Rights of Persons with Disabilities calling States parties to oppose the draft Additional Protocol to the Oviedo Convention*. Available at: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDStatements.aspx> (last consultation on 10 July 2019).

UN General Assembly. *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175*, 28 July 2008. Available at: https://www.apt.ch/content/files/region/unlegal/rapporteur_disabilities.pdf (last consultation on 26 June 2019).

UN General Assembly. *Report of the Special Rapporteur on the promotion and protection of human rights and fundamental freedoms while countering terrorism, Martin Scheinin, A/HRC/13/37*, 28 December 2009. Available at: <https://www2.ohchr.org/english/bodies/hrcouncil/docs/13session/A-HRC-13-37.pdf> (last consultation on 12 July 2019).

UN General Assembly. *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, A/HRC/11/12*, 31 March 2009. Available at: <https://www.refworld.org/docid/49faf7652.html> (last consultation on 27 June 2019).

UN General Assembly. *Report of the Special Rapporteur on the rights of persons with disabilities, A/73/161*, 16 July 2018. Available at: https://www.ohchr.org/Documents/Issues/Disability/A_73_161_EN.pdf (last consultation on 9 July 2019).

UN Human Rights Committee, *CCPR General comment No.14 on Article 6 (Right to Life) Nuclear Weapons and the Right to Life*, 9 November 1984. Available at: <https://www.refworld.org/docid/453883f911.html> (last consultation on 12 June 2019).

UN Human Rights Committee, *End of Mission Statement by the United Nations Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas-Aguilar, on her visit to Canada*, 12 April 2019. Available at: <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=24481&LangID=E> (last consultation on 9 July 2019).

UN Human Rights Committee, *General comment No. 35 on Article 9 (Liberty and security of person) of the International Covenant on Civil and Political Rights*, CCPR/C/GC/35, 16 December 2014. Available at: <https://www.refworld.org/docid/553e0f984.html> (last consultation on 12 June 2019).

UN Human Rights Committee, *General comment No. 36 on Article 6 of the International Covenant on Civil and Political Rights, on the right to life*, CCPR/C/GC/36, 30 October 2018. Available at: https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/1_Global/CCPR_C_GC_36_8785_E.pdf (last consultation on 12 June 2019).

UN Human Rights Committee, *General comment No. 6 on Article 6 (Right to Life)*, 30 April 1982. Available at: <https://www.refworld.org/docid/45388400a.html> (last consultation on 12 June 2019).

UN Human Rights Committee. *CCPR General Comment No. 16: Article 17 (Right to Privacy) The Right to Respect of Privacy, Family, Home and Correspondence, and protection of Honour and Reputation*, 8 April 1988. Available at: <https://www.refworld.org/docid/453883f922.html> (last consultation on 20. June 2019).

UN Human Rights Committee. *CCPR General Comment No. 20: Article 7 (Prohibition of Torture, or Other Cruel, Inhuman or Degrading Treatment or Punishment)*, 10 March 1992. Available at: <https://www.refworld.org/docid/453883fb0.html> (last consultation on 26 June 2019).

UN Human Rights Committee. *Concluding observations of the Human Rights Committee: Netherlands*, 25 August 2009. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=8&DocTypeID=5 (last consultation on 14 June 2019).

UN Human Rights Council. *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez*, A/HRC/22/53, 1 February 2013. Available at: https://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (last consultation on 24 June 2019).

UN Human Rights Council. *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/13/39*, 9 February 2010. Available at: <https://www2.ohchr.org/english/bodies/hrcouncil/docs/13session/A-HRC-13-39.pdf> (last consultation on 28 June 2019).

UNDESA. 2019. Open-ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons. Available at: <https://social.un.org/ageing-working-group/> (last consultation on 9 July 2019).

United Nations. 2019. Ageing. Available at: <https://www.un.org/en/sections/issues-depth/ageing/> (last consultation on 7 July 2019).

Universal Declaration of Human Rights. 1948. Proclaimed with the United Nations General Assembly resolution 217 A (III), 10 December. Available at: https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf (last consultation on 15 April 2019).

Universal Declaration on Bioethics and Human Rights. 2005. Adopted at the General Conference, 19 October. Available at: http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html (last consultation on 3 May 2019).

Universal Declaration on Bioethics and Human Rights. 2005. Adopted by UNESCO's General Conference, 19 October 2005. Available at: http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html (last consultation on 10 July 2019).

Verhofstadt, Monica, Lieve Thienpont and Gjalt-Jorn Ygram Peters. 2017. When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study. *The British Journal of Psychiatry* 211 (4): 238–245.

Villeneuve, Marina. 2019. Maine becomes 8th state to legalize assisted suicide. *AP News*, 13 June. Available at: <https://www.apnews.com/7f0fe9d789294a02852c1669c892f382> (last consultation on 4 July 2019).

Watson, Gary. 2003. The Work of the Will. In *Weakness of Will and Practical Irrationality*, edit. Stroud, Sarah and Christine Tappolet, 172-200. Oxford: Oxford University Press.

Wicks, Elizabeth. 2012. The Meaning of 'Life': Dignity and the Right to Life in International Human Rights Treaties. *Human Rights Law Review* 12 (2): 199-219.

World Health Organization. 2001. Netherlands, first country to legalize euthanasia. *Bulletin of the World Health Organization* 79 (6): 580-581.

World Health Organization. 2012. Dementia: A Public Health Priority. Available at: https://www.who.int/mental_health/publications/dementia_report_2012/en/ (last consultation on 10 July 2019).

World Health Organization. 2017a. Global action plan on the public health response to dementia: 2017 – 2025. Available at: https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ (last consultation on 29 April 2019).

World Health Organization. 2017b. Dementia. Available at: <https://www.who.int/news-room/fact-sheets/detail/dementia> (last consultation on 29 April 2019).

World Health Organization. 2018. Towards a dementia plan: a WHO guide. Available at: <https://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf?ua=1> (last consultation on 29 April 2019).

World Health Organization. 2019. WHO Definition of Palliative Care. Available at: <https://www.who.int/cancer/palliative/definition/en/> (last consultation on 2 July 2019).

Ziebertz, Hans-Georg and Francesco Zaccaria. 2019. *Euthanasia, Abortion, Death Penalty and Religion - The Right to Life and its Limitations*. Switzerland: Springer Nature Switzerland.