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INFORMED CONSENT AND EUTHANASIA: AN INTERNATIONAL HUMAN RIGHTS PERSPECTIVE[1]

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Summary: This Paper addresses the right to informed consent regarding euthanasia using international conventions and, to a lesser extent, national laws and policies. Specifically, The United States, Belgium and the Netherlands will be examined. The Paper specifically discusses legal capacity, the right to consent and the right to information. Three stories are used to argue the importance of implementing effective safeguards for these rights and notes that these safeguards are necessary regardless of whether or not euthanasia is legalized in a state. This Paper also argues that patients should not be offered euthanasia for mental illnesses. The ethical debate surrounding whether euthanasia should be permitted generally is not discussed.

Keywords: Informed Consent, Euthanasia, Terminally Ill, Mentally Ill, United States, Belgium, Netherlands, Human Rights

1. Introduction

Death is an inevitable part of human existence that all people must face, and for most of us, the time and place of this death is unknown. But what if someone did know the time and place? What if that someone was a doctor or a nurse, or the very person that was going to experience death? To go a step further, what if these actors actually caused the death to occur at a specific time and place? If this is possible, then the people that are going to experience death at a given time are in great need of protection to ensure that their lives are not ended unwillingly. The best way to provide this protection is to require that patients or their representatives give informed consent. This paper will explore the concept of euthanasia and the right to informed consent through international conventions, current policies and laws and recommendations for effectively protecting patients, particularly focusing on Belgium, the Netherlands and the United States.

1 I would like to thank Professor Cristina Leria and Professor Javier Vasques for their guidance and comments on this paper.

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One topic this paper will not focus on is the ethical debate surrounding euthanasia and whether it should ever be allowed. I do not have the experience or expertise to argue how somebody feels at the end of their life and whether euthanasia should ethically be allowed for terminally ill patients. Instead, this paper will argue that people have the right to informed consent to ensure that their lives are not taken arbitrarily.[2] The right to life is not a focal point of this paper, but is arguably the most important right that can be afforded to a person. The right to life is a human right, and without this right being respected, no other human rights can be fulfilled. The right to informed consent is also an internationally recognized right that has been implicitly and explicitly recognized in several declarations and conventions.[3]

2. Euthanasia

The Merriam-Webster dictionary describes euthanasia as "the act or practice of killing or permitting the death of hopelessly sick or injured individuals (such as persons or domestic animals) in a relatively painless way for reasons of mercy."[4] Although this seems like a straightforward definition, the act of euthanasia can actually be split up into several different categories that are listed below for reference.

A. Voluntary Euthanasia

Voluntary euthanasia is "the action taken by the physician and the patient, who both agree (with informed consent) to end the patient's life."[5] Usually voluntary euthanasia is requested by the patient, and the doctor's role is to provide the patient with sufficient information so that the patient can make an informed decision about going forward with the euthanasia. The doctor then administers a deadly dose of medicine to the patient to hasten, or cause, death.

2 See e.g. *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)*. Organization of American States, 2017, art. 11. [online]. Available at: <http://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp> Accessed: 14.09.2018; *Universal Declaration on Bioethics and Human Rights*. United Nations Educational, Scientific and Cultural Organization, 2005, art. 7(a). [online]. Available at: <http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html> Accessed: 14.09.2018

3 See e.g. GROVER, Anand. *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*. United Nations General Assembly A/64/272, 2009, pp. 7, 15. [online]. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement4> Accessed: 14.09.2018

4 *Euthanasia*. Merriam-Webster, 2017. [online]. Available at: <https://www.merriam-webster.com/dictionary/euthanasia> Accessed: 15.09.2018

5 MORROW, Angela. *What is Euthanasia? Euthanasia and Assisted Suicide Have Important Distinctions*. VeryWell, 2017. [online]. Available at: <https://www.verywell.com/what-is-euthanasia-1132209> Accessed: 15.09.2018

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B. Involuntary (Forced) Euthanasia

Involuntary euthanasia "refers to a third party taking a patient's life without the informed consent of the patient."[6] This term is a main concern in the paper because it refers to an act that would be considered murder outside the context of patients that are considered to be seriously ill or hopelessly incurable. Registered nurse Angela Morrow states that involuntary euthanasia is conceivable.[7] Although this statement makes involuntary euthanasia seem like a small possibility, it fails to consider information available that shows that people with existing mental capacity have indeed had their deaths involuntary hastened. It is possible for involuntary euthanasia to occur in a way that is obvious to a patient or their loved ones, but it oftentimes occurs in a manner that is inconspicuous to the patient. That is why it is so important for explicit and informed consent to be required before a patient's death is hastened by a physician. Involuntary euthanasia, as well as voluntary euthanasia, can occur actively or passively.

C. Active Euthanasia

Active euthanasia "occurs when the medical professionals, or another person, deliberately do something that causes the patient to die."[8] This usually refers to a physician administering a lethal dose of a drug in order to hasten a patient's death.

D. Passive Euthanasia

Passive euthanasia "occurs when the patient dies because the medical professionals either don't do something necessary to keep the patient alive, or when they stop doing something that is keeping the patient alive."[9] Examples of passive euthanasia include withholding food or water from a patient, not administering medicine to a patient or not performing surgery on a patient that would keep the patient from dying.[10] In BBC's ethics guide, passive euthanasia is specifically described as not giving drugs or performing a surgery that is "life-extending."[11] This is an important word-choice because often the patients that are seen as victims of forced euthanasia are terminally ill.

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6 ibid.

7 ibid. (she states that involuntary euthanasia is usually used by veterinarians, but "could *conceivably* be applied to the act of taking a terminally ill, suffering patient's life who has lost all mental capacity to make his/her own decisions"). (emphasis added).

8 *Ethics Guide: Active and Passive Euthanasia*. BBC. [online]. Available at: <http://www.bbc.co.uk/ethics/euthanasia/overview/activepassive_1.shtml> Accessed 27.11.2017

9 ibid.

10 *See* ibid.

11 ibid.

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E. Physician-Assisted Suicide

Although Physician-Assisted Suicide (PAS) is not the focus of this paper, it is important to define because of its close relation to euthanasia.[12] When euthanasia is performed, a doctor or other health professional administers a medicine to the patient that hastens their death.[13] In contract, when PAS occurs the doctor or other health professional prescribes the medicine to the patient, but the patient administers the medicine themselves.[14] This is an important distinction because, for instance, in the United States PAS is legal in some states, while euthanasia is currently not legal in any state.[15]

F. Palliative Sedation

Palliative sedation is different than the other terms listed above because the medicine, presumably, is not administered with the goal of killing the patient, but rather it is administered to provide a patient relief from suffering via sedation.[16] Angela Morrow argued that because the goal of palliative sedation is not to hasten death, it is not comparable to euthanasia.[17] Even so, she also admits in the same article that whether the cause of death was the illness or the medicine after palliative sedation is often uncertain.[18]

3. Cases

The importance of informed consent will be discussed through three cases. The first case involves an elderly, eighty-year-old woman who was suffering from dementia.[19] The woman was sent to a nursing home and had expressed a want to possibly be euthanized when she thought the time was right.[20] After being in the

12 MORROW, Angela. *Is Palliative Sedation a Form of Euthanasia? The Difference Between Palliative Sedation and Euthanasia*. VeryWell, 2017. [online]. Available at: <https://www.verywell.com/does-palliative-sedation-cause-death-1132043> Accessed: 15.09.2018; See also *Angela Morrow, RN*. VeryWell. [online]. Available at: <https://www.verywell.com/angela-morrow-rn-1131867> Accessed: 15.09.2018 (explaining more about the registered nurse's credentials and experience).

13 ibid.

14 ibid.

15 ibid.

16 ibid.

17 ibid.

18 ibid.

19 COOK, Michael. *Struggling Woman with Dementia Euthanised in Netherlands*. BioEdge, 2017. [online]. Available at: <https://www.bioedge.org/bioethics/struggling-woman-with-dementia-euthanised-in-netherlands/12173> Accessed: 16.09.2018

20 ibid. (explaining that the woman had also apparently stated that she did not want to be placed in a nursing home for elderly dementia patients); See also ROBERTS, Rachel. *Doctor Who Asked Dementia Patent's Family to Hold Her Down While She Gave Lethal Injection Cleared*. Independent, 2017. [online]. Available at: <www.independent.co.uk/news/world/europe/doctor-netherlands-lethal-injection-dementia-euthanasia-a7564061.html> Accessed: 16.09.2018

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nursing home for several weeks, walking around aimlessly at night and seeming unhappy, the doctor euthanized the elderly woman.[21] In order to euthanize her, the doctor secretly slipped a sleeping pill into the woman's drink and then began the process of injecting her with a deadly medicine.[22] The woman began to struggle and the doctor had the woman's family members hold her down so that the euthanasia could be completed.[23] A Regional Review Committee for euthanasia in the Netherlands found that the doctor who performed the euthanasia had good intentions.[24] The euthanasia had not been discussed with the woman before it was performed.[25]

One man has taken his case to the European Court of Human Rights after his mother was euthanized in Belgium because her depression was reportedly untreatable; however, one article states two reasons that may have contributed to her condition: the end of a relationship and not being engaged with her family.[26] The father of at least one of her children had also committed suicide decades earlier.[27] Although her long-time family doctor refused to perform the euthanasia, another doctor agreed to perform the procedure.[28] The question for this case is whether someone can provide consent for euthanasia when the condition's symptoms include thoughts of suicide.

Although euthanasia is not legal anywhere in the United States, there are still reports that it is practiced.[29] One case in particular was discussed by a doctor in a 1997 New York Times article about the prevalence of passive euthanasia in the

21 ibid.

22 SHADENBERG, Alex. *Doctor Euthanizes Patient with Dementia, Secretly Put Drugs in her Coffee*. Life News, 2017. [online]. Available at: <www.lifenews.com/2017/01/30/doctor-euthanizes-patient-with-dementia-secretly-put-lethal-drugs-in-her-coffee/#> Accessed: 16.09.2018

23 ibid.

24 ibid. (explaining that the Regional Review Committee specifically said that the doctor had 'acted in good faith' and also that the committee wants the court to review the case to decide how situations similar to this one should be handled by doctors in the future).

25 ibid.

26 HARKNESS, Kelsey. *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia*. The Daily Signal, 2015. [online]. Available at: <http://dailysignal.com/2015/01/02/doctors-killed-mom-depressed-now-speaks-euthanasia/> Accessed: 16.09.2018

27 ibid.

28 ibid.

29 See Generally KOLATA, Gina. *'Passive Euthanasia' in Hospitals Is the Norm, Doctors Say*. New York Times, 1997. [online]. Available at: <http://www.nytimes.com/1997/06/28/us/passive-euthanasia-in-hospitals-is-the-norm-doctors-say.html> Accessed: 16.09.2018; PANZER, Ron. *Stealth Euthanasia: Health Care Tyranny in America (Hospice, Palliative Care and Health Care Reform)*. Hospice Patients Alliance, Inc. [online]. Available at: <http://www.hospicepatients.org/this-thing-called-hospice.html#Hastening Death at the End-of-Life> Accessed 16.09.2018; *Actual Reports of Involuntary Euthanasia Cases in Hospice Settings – (Eleven Letters)*. Hospice Patients Alliance. [online]. Available at: <http://www.hospicepatients.org/actual-hosp-euth-cases.html> Accessed: 04.12.2017

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United States.[30] Dr. Beth Y. Karlin described one case involving an ovarian cancer patient who was 40-years-old.[31] The woman did not want to succumb to the disease, but it had spread and death was closing in on her.[32] Dr. Karlin decided to send the patient home with a morphine drip that helped with the pain, but also caused her death to be hastened.[33] Dr. Karlin admits that she never asked for consent from the woman to quicken her death with morphine.[34] The New York Times article also discussed doctors withholding medical treatments that could lengthen patients' lives, in order to hasten their deaths.[35]

4. Informed Consent

Anand Grover, who was the United Nations (UN) Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health from 2008 to 2014, wrote an annual report on informed consent and health that laid out three elements of informed consent: respect for legal capacity, respect for personal autonomy and completeness of information.[36]

Grover described informed consent as "a voluntary and sufficiently informed decision[that] protect[s] the right of the patient to be involved in medical decision-making and assign[s] associated duties and obligations to health-care providers."[37] Grover stated that legal capacity is when a person can believe, weigh, comprehend and retain information to make a decision.[38] He also noted that adults are assumed to have legal capacity.[39]

Grover went on to describe personal autonomy as consent that is given voluntarily and is not coerced or given because of misleading information or inappropriate influence.[40] There must also be documentation that proves consent was provided before medical treatment occurs.[41] Although he noted that some simple procedures could impliedly be consented to, that does not apply to the topic discussed in this paper because euthanasia is a more complicated procedure.[42]

30 *'Passive Euthanasia' in Hospitals Is the Norm, Doctors Say* (note 29).
31 ibid.
32 ibid.
33 ibid.
34 ibid.
35 ibid.
36 *See Anand Grover*. Georgetown Law. [online]. Available at: <https://www.law.georgetown.edu/faculty/grover-anand.cfm#> Accessed: 04.12.2017; *Annual Reports – Health*. United Nations Human Rights Office of the High Commissioner. [online]. Available at: <www.ohchr.org/EN/Issues/Health/Pages/AnnualReports.aspx> Accessed: 04.12.2017
37 *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, supra* (note 3), pp. 5.
38 ibid.
39 ibid.
40 ibid.
41 ibid.
42 See ibid.

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Grover also provided examples of coercion, which include a patient being under stress or fatigued, or believing that something bad might happen if they do not consent.[43]

The last element Grover described, completeness of information, explains that informed consent cannot occur without the patient being told about alternatives, benefits and risks of medical treatments.[44] The United States requires that this information be disclosed to the patient before consent is obtained, while Canada also requires that a patients' subjective understanding of the information be accounted for.[45] This element is more readily understood when looked at in conjunction with Principle 11(2)(a)-(d) of the United Nations Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care.[46] Although these principles are nonbinding and focus primarily on mental health care, the provisions are nonetheless important to view when assessing the scope of the right to completeness of information for all patients, including those patients that are mentally and/or terminally ill. Principle 11(2)(a)-(d) provides a list of information that should be disclosed to a patient to allow the patient to give informed consent.[47] The information includes "(a) [t]he diagnostic assessment; (b) [t]he purpose, method, likely duration and expected benefit of the proposed treatment; (c) [a]lternative modes of treatment, including those less intrusive; (d) [and p]ossible pain or discomfort, risks and side-effects of the proposed treatment."[48] Principle 11(2)(a)-(d) is an important tool that can be used by national and state legislatures, and medical personnel, to help ensure that patients are receiving enough information to adequately provide informed consent.[49] Principle 11(2) is also important to the other two elements of informed consent discussed by Grover. Specifically, Principle 11(2) describes voluntary consent, which is required to respect personal autonomy, and states that information should be presented to patients in a way that is understandable to them, which is important for patients of varying capacities.[50]

The right to informed consent not only consists of the right to give consent, but also the right to withdraw consent. This right is exemplified in the Universal Declaration on Bioethics and Human Rights (UDBHR), the Inter-American Convention on Protecting the Human Rights of Older Persons and the Convention for the Protection of Human Rights and Dignity of the Human Being

43 ibid.
44 ibid.
45 ibid.
46 *UN Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care*. General Assembly, 1991, art. 11(2)(a)-(d). [online]. Available at: <http://www.un.org/documents/ga/res/46/a46r119.htm> Accessed: 14.09.2018
47 *See* ibid.
48 ibid.
49 See ibid.
50 ibid. at art. 11(2).

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with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Convention on Human Rights and Biomedicine). Article 7(a) of UDBHR describes the rights of persons who do not have the capacity to consent and states that these patients should still be involved as much as possible in the process of consenting or terminating consent.[51] The Convention on Human Rights and Biomedicine goes a step further by stating that a patient is free to terminate consent at any point.[52] Article 11 of the Inter-American Convention on Protecting the Human Rights of Older Persons expresses that patients have the right to terminate or alter consent.[53] No medical procedure can be performed under the auspices of informed consent if a patient that originally consented no longer agrees to the procedure but is still required to endure it. This makes a procedure involuntary and against patients' right to informed consent.

4.1 Respect for Legal Capacity

A medical personnel's responsibility to respect a patient's legal capacity is not waived if the patient's capacity to understand the information and make an informed decision is diminished because of the patient's illness or for other unrelated reasons, such as education level.[54] A patient's legal capacity needs to be determined and information needs to be presented to the patient in accordance with their capacity so that an informed decision can be made by the patient, if at all possible. The UDBHR expresses that patients who are unable to consent should be provided special protections and should be allowed to participate in the process of consenting or terminating consent as much as possible.[55] The Convention on Human Rights and Biomedicine requires that a representative give informed consent if the patient does not have the capacity to consent and still requires that the patient be part of the consenting process to the extent possible.[56]

The elderly dementia patient who was held down by her family and given a deadly drug dose did not have her legal capacity respected.[57] The doctor purposely did not tell the patient about plans to euthanize her because the doctor did not want to cause undue stress to the patient.[58] If the patient would have been stressed out or troubled by being told that she was going to be euthanized, then this seems to demonstrate that the patient had some capacity to understand the

51 *Universal Declaration on Bioethics and Human Rights* (note 2) art. 7(a).

52 *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. Council of Europe, 1997, art. 5. [online]. Available at: <https://rm.coe.int/168007cf98> Accessed: 14.09.2018

53 See *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11.

54 See ibid.

55 *Universal Declaration on Bioethics and Human Rights* (note 2) art. 7(a).

56 *Convention on Human Rights and Biomedicine* (note 52) art. 6, para. 3.

57 *Doctor Euthanizes Patient with Dementia, Secretly Put Drugs in her Coffee* (note 22).

58 ibid.

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consequences of such an action.[59] If this is the case, then the doctor had an obligation to seek the patient's consent in a format that was understandable to the patient.[60] Even if the elderly dementia patient was unable to consent, the Convention on Human Rights and Biomedicine only allows for performing medical procedures without consent in accordance with domestic law.[61] In this case, the doctor did not follow the Netherlands law on Euthanasia.[62] According to Netherlands' law, if the patient was unable to consent, then before the patient became incapacitated, they had to have written down their request to be euthanized.[63] In this case, the elderly dementia patient made a vague statement that she would like the ability to request euthanasia if she so decided.[64] Her statement was not a request and did not give the doctor authority to make the decision of when euthanasia should be performed.[65] Unfortunately, there are not adequate safeguards against this type of departure from informed consent, as a review board found the doctor to have acted with good intentions.[66]

If a patient is found to have capacity, albeit limited, then medical personnel have the responsibility to present the necessary information to the patient in a way that is understandable to the patient, as expressed in some international conventions. Article 21(a) of the Convention on the Rights of Persons with Disabilities (CRPD) requires that general public information be provided in formats that are understandable to people with disabilities within a reasonable time, and without these people incurring extra expenses.[67] Additionally, Article 21(b) states that all obtainable communication formats should be utilized, and people with disabilities should be allowed to choose their preferred method of communication for formal interactions.[68] Article 11 of the Inter-American Convention on Protecting the Human Rights of Older Persons requires that information be provided in a format that is easy to understand and access and that

59 See ibid.

60 See ibid.

61 *Convention on Human Rights and Biomedicine* (note 52) art. 6, para. 3.

62 See Generally *Review Procedures for the Termination of Life on Request and Assisted Suicide and Amendment of the Criminal Code and the Burial and Cremation Act (Termination of Life on Request and Assisted Suicide (Review Procedures) Act)*. Patients Rights Council, 2002. [online]. Available at: <http://www.patientsrightscouncil.org/site/wp-content/uploads/2012/05/Dutch_law_04_12.pdf> Accessed: 14.09.2018

63 ibid, sec. 2(2)

64 *Doctor Euthanizes Patient with Dementia, Secretly Put Drugs in her Coffee* (note 22).

65 ibid.

66 ibid (in other words, to have 'acted in good faith').

67 *Convention on the Rights of Persons with Disabilities and Optional Protocol*. United Nations – Disability: Department of Economic and Social Affairs, 2006, art. 21(a). [online]. Available at: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> Accessed: 14.09.2018; See also *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11, para. 3.

68 *Convention on the Rights of Persons with Disabilities and Optional Protocol* (note 67) art. 21(b).

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corresponds with older peoples' education level, cultural identity and communication requirements.[69] Because patients have the right to informed consent, which includes the right to impart information, these conventions provide helpful guidelines to national and state legislatures, and to medical personnel, on how to provide information in an understandable way to patients with varying capacities in order to allow them to give informed consent.

Article 6, paragraph 3 of the Convention on Human Rights and Biomedicine states that if an adult patient lacks capacity, then medical decisions shall be made by a representative, but the patient shall still be involved in the consenting process as much as possible.[70] These mentioned articles seem to solidify the right of terminally ill patients to be presented information in a way that allows them to provide informed consent, even if their capacity to do so is limited.[71]

Although a patient should be found to have legal capacity to provide informed consent whenever possible, it can become important in certain circumstances to find that a patient does not have legal capacity; for instance, in the case of 65-year-old Godelieva De Troyer, who suffered from chronic depression for over 20 years and was found to be incurable.[72] Although Troyer was found to be incurable, her son Tom Mortier was able to express two reasons that may have contributed to her depression shortly before her death, including being distant from her children and the dissolution of a long-term relationship.[73] Unfortunately, a first look at the Belgian Act on Euthanasia of May, 28, 2002 seems to show that most of the main elements of the law were followed in Troyer's case.

Troyer's consent seemed to be well-thought-out, voluntary and consistent, and struggling with chronic depression for over 20 years does lend itself to the argument that alleviation for the mental suffering was not possible.[74] But, in order for the law to be completely followed, a doctor would also have to prove that the suffering was constant and have an independent physician come to the same conclusion.[75] It would be difficult to find that the suffering was constant in this case, and the physician that conducted the secondary review was reportedly

69 *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11, para. 3.

70 *Convention on Human Rights and Biomedicine* (note 52) art. 6, para. 3. (a patient may lack capacity "because of a mental disability, a disease or for similar reasons").

71 *Convention on Human Rights and Biomedicine* (note 52) art. 6, para. 3; *Inter-American Convention on Protecting the Human Rights of Older Persons* (A-70) (note 2) art. 11, para. 3.

72 *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia* (note 26).

73 ibid.

74 See The Belgian Act on Euthanasia of May, 28th 2002. *Ethical Perspectives*, 2002, vol. 9, pp. 182–183. (Dale Kidd Trans.). [online]. Available at: <http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59> Accessed: 14.09.2018; *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia* (note 26).

75 The Belgian Act on Euthanasia of May, 28th 2002 (note 74), pp. 182–183.

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not independent from the doctor that conducted the euthanasia.[76] On top of that, another psychiatrist, who had known Troyer in a professional capacity for over 20 years and was independent of the doctor who performed the euthanasia, did believe that Troyer's condition was treatable.[77]

A doctor should not have found that there were no other reasonable options to alleviate the patient's situation and Troyer should not have been found to have the legal capacity to decide to end her life through euthanasia, especially because there were at least two external factors that could have been addressed before Troyer was euthanized for incurable depression.[78] Legal capacity to consent to euthanasia should not be granted to patients who suffer from depression because one of the symptoms of this mental illness is feelings of suicide. In recognition of a patient's difficulty in making a sound decision about their health when they are suffering from a mental disorder, the Convention on Human Rights and Biomedicine allows for the treatment of a mental disorder, with or without the patient's consent, if the patient is likely to be seriously harmed otherwise.[79]

4.2 Respect for Personal Autonomy – The Right to Consent

The right to consent is related but distinct from the right to information. The latter mentioned right refers to the right to receive and understand information. The right to consent refers to the right to voluntarily make an informed decision about whether to allow or disallow a medical treatment. There are a few conventions that explicitly discuss the right of an adult to provide consent before medical procedures are performed. Article 25 of CRPD states that people with disabilities should receive the same quality of care as other patients, including by providing voluntary informed consent.[80] The Inter-American Convention on Protecting the Human Rights of Older Persons expresses elderly peoples' right to voluntary informed consent in Article 6 and Article 11.[81] Article 5 of the Convention on Human Rights and Biomedicine requires informed consent before medical treatments can be performed.[82] Grover also released two reports while he was Special Rapporteur for the Enjoyment of the Highest Attainable Standard of Mental and Physical health that discussed the right to consent.

The right of patients to informed consent includes the right to decline medical and life-saving treatment. If patients were not allowed to deny such treatments,

76 *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia* (note 26).

77 ibid.

78 See The Belgian Act on Euthanasia of May, 28th 2002 (note 74), pp. 182; *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia* (note 25).

79 *Convention on Human Rights and Biomedicine* (note 52) art. 7.

80 *Convention on the Rights of Persons with Disabilities and Optional Protocol* (note 66).

81 See *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 6, 11.

82 *Convention on Human Rights and Biomedicine* (note 52) art. 5.

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then it would be impossible to realize the right to informed consent. This specific element of the right to informed consent is exemplified in the Inter-American Convention on Protecting the Human Rights of Older Persons.[83] Article 11 of the convention states older peoples' right to voluntarily consent to, deny or postpone medical care.[84] Article 11 also includes the right to be informed about risks and consequences of medical treatment decisions.[85] In the case of Troyer, the 65-year-old woman in Belgium who had suffered chronic depression for 20 years, it would be difficult to make the case that she should be forced to endure life-saving medical treatments.[86] For instance, if Troyer was told she had cancer and only had a chance of surviving the disease if she completed chemotherapy treatments, it would be very difficult, if not impossible, to justify forcing her to complete the treatments. The argument for Troyer's case is that there should not have been a life-ending procedure, euthanasia, posed as an option for Troyer that warranted her free and express informed consent.[87] in short, although there is not a justification for revoking someone's right to informed consent, the medical options available to patients that are mentally ill should not include euthanasia.

In the case of the elderly dementia patient, the woman was unable to give free, informed and explicit consent because she was never told by the doctor that she was going to be euthanized.[88] Although the assumption from the article is that the elderly dementia patient was unable to give consent because of diminished capacity, that does not mean that the patient should have been euthanized, especially without an explicit and detailed directive by the patient explaining when and how the euthanasia could occur.[89] On the contrary, without the woman being able to give her free, informed and explicit consent, the doctor should have never euthanized the patient.[90] To add to the argument against euthanasia in this case, the fact that the doctor did not tell the woman how, when or even that she would be euthanized because the doctor did not want to worry the patient, seems to show that the elderly dementia patient had at least limited capacity to understand.[91] The right to personal autonomy includes the right not to be coerced or tricked into consenting by a misrepresentation of information; but in this case, the elderly dementia patient did not even have the opportunity to be coerced because the subject of her being euthanized was not discussed before her coffee was drugged and she was held down by her family and injected

83 *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11.
84 ibid.
85 ibid.
86 *Doctors Killed His Mom Because She Was Depressed. Now He Speaks Out Against Euthanasia* (note 26).
87 ibid.
88 *Doctor Euthanizes Patient with Dementia, Secretly Put Drugs in her Coffee* (note 22).
89 See ibid.
90 See ibid.
91 See ibid.

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with a deadly dose of a drug.[92] The right to personal autonomy involves the right to give explicit and informed consent, and also includes the right to be able to freely withdraw that consent. Even if the doctor had mistakenly believed that the elderly dementia patient consented to be euthanized in a manner consistent with slipping a sedative into her coffee and then injecting her with a drug to kill her, the doctor should have taken the woman's physical struggle as an indication that the elderly patient had withdrawn her consent.[93]

The 40-year-old cervical patient was also denied her right to personal autonomy because she was given a morphine drip, that the doctor knew would hasten her death, without clearly understanding the risks and consequences of taking the medicine.[94] This case is different from the elderly dementia patient's case, because the elderly dementia patient was not told about the impending euthanasia, so she was unable to provide consent. In this case, the cervical cancer patient was told about the morphine drip and consented to take it, but the consent was not informed, and was therefore invalid, because the facts surrounding the morphine drip were misrepresented.[95]

4.3 Completeness of Information – Right to Information

The right to information is probably the most prolific right discussed in this paper. The right to information is declared in the Universal Declaration of Human Rights, the CRPD, the International Covenant on Civil and Political Rights and the American Convention on Human Rights.[96] In conventions that focus on informed consent, more detail is provided on the type of medical information that should be provided to patients. For instance, the Convention on Human Rights and Biomedicine states that a "[p]erson shall *beforehand* be given appropriate information as to the *purpose* and *nature* of the intervention as well as on its *consequences* and *risks*."[97] (emphasis added). The CRPD and the Inter-

92 See ibid.

93 See ibid.

94 *'Passive Euthanasia' in Hospitals Is the Norm, Doctors Say* (note 29).

95 See ibid*; Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 3), pp. 5.

96 See *Convention on the Rights of Persons with Disabilities and Optional Protocol* (note 66) art. 2; See *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11; *Universal Declaration of Human Rights*. United Nations: General Assembly, 1948, art. 19. [online]. Available at: <http://www.un.org/en/universal-declaration-human-rights/> Accessed: 14.09.2018; *International Covenant on Civil and Political Rights*. United Nations Human Rights Offices of the High Commissioner, 1976, art. 19(2). [online]. Available at: <www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx> Accessed: 14.09.2018; *American Convention on Human Rights*. Organization of American States, 1969, art. 13(1). [online]. Available at: <http://www.oas.org/dil/treaties_B-32_American_Convention_on_Human_Rights.htm> Accessed: 14.09.2018 (these conventions specifically state the right "to seek, receive and impart information").

97 *Universal Declaration on Bioethics and Human Rights* (note 1) art. 5; See *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11, para. 6

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American Convention on Protecting the Human Rights of Older Persons can be referenced to make a sound conclusion about the meaning of "beforehand". These conventions express that information should be presented to patients in a *timely* manner.[98]

Without these five elements of information, a patient does not have the ability to make an informed decision about whether to proceed with a medical treatment. For instance, in the case of the 40-year-old cervical cancer patient, if she had been told by the doctor that the purpose of the morphine drip was to ease her pain and that the nature of the drug was to sedate her until her death, the patient may have opted not to take the treatment.[99] Based on information provided by the doctor, stating that the patient did not want to die, it is even less likely that the patient would have agreed to take the morphine drip if she had been told that the consequence of taking the drug would be a hastened death, and that the risk of hastened death was high.[100] The doctor in this case admits that she never explicitly consulted the patient about whether she wanted a hastened and tranquil death.[101] This was a violation of the patient's right to receive proper information so that she could give informed consent about how she wanted to live and die.

5. Recommendations

In two reports that the former Special Rapporteur on the right to the highest attainable standard of physical and mental health published, he laid out recommendations regarding informed consent.[102] Although the reports do not specifically link protection of informed consent to terminally ill patients, the rights and recommendations laid out also apply to this group. As this paper demonstrates, terminally ill patients are at a high risk of being misinformed and left out of decision-making that will affect the quality and quantity of their life. Therefore, terminally ill patients should be considered a vulnerable group alongside other vulnerable populations that Grover lays out and discusses in his reports on the

(expressing the right to know "about the potential consequences and risks of such a decision").

98 *Convention on the Rights of Persons with Disabilities and Optional Protocol* (note 67) art. 21(a); See *Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)* (note 2) art. 11.

99 See *'Passive Euthanasia' in Hospitals Is the Norm, Doctors Say* (note 29).

100 See ibid.

101 ibid.

102 See *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 2); GROVER, Anand. *Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*. United Nations: General Assembly A/HRC/28/37, 2011. [online]. Available at: <https://undocs.org/a/hrc/18/37> Accessed: 14.09.2018

right to informed consent and the rights of older persons.[103] The recommendations discussed in Grover's reports about informed consent include determining the capacity of patients, providing adequate information, training medical personnel, regulating and monitoring informed consent procedures and repercussions for medical personnel that do not follow such procedures.[104]

Countries and states are responsible for establishing legislation and regulations that ensure patients are receiving adequate support that allows them to provide informed consent. Legislation should include specific elements that must be met before a patient is deemed to be lacking capacity to give informed consent, and express that diminished capacity does not automatically trigger representative rights.[105] Legislation should also require that the patient be involved in the consenting process as much as possible.[106] Additionally, enacted legislation should be monitored in hospitals, hospices and other medical facilities for compliance; efficient judicial remedies should be established for patients and their representatives to seek in the event that their right to informed consent is denied; and accountability measures should be established for medical personnel.[107]

6. Conclusion

Euthanasia without proper informed consent is a problem that needs to be safeguarded against with effective protections in all states, because issues surrounding euthanasia and informed consent are present in societies that have legalized the procedure, like Belgium and the Netherlands, and societies that have not, like the United States. Without informed consent protections that are enforced with proper penalties, patients will continue to be forcefully euthanized and euthanized for mental illnesses. Patients will also continue to be euthanized by being denied sufficient information to understand the consequences of taking medications that hasten death or the consequences of not having certain life-sustaining procedures performed.

103 *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 3), pp. 14–24 (discussing different groups that are vulnerable to informed consent issues: ethnic minorities, children, persons deprived of liberty, indigenous peoples, persons with HIV/AIDS, the elderly, sex workers, drug users, persons with disabilities and women).

104 See *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 3), pp. 24–25; *Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 102), pp. 16–17.

105 See *Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 102), pp. 17.

106 See *Convention on Human Rights and Biomedicine* (note 51) art. 6 para. 3.

107 See *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 3) pp. 25; see also *Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* (note 102) pp. 18–19.

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