

Meanings of “Right to Die with Dignity”: A Study in a European Context

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Abstract: There has been the suspicion that doctors in Europe, due to the prevalence of medical paternalism in European culture, have interpreted the idea of “patient’s right to die with dignity” in reference to their inability to treat or giving up on treating the dying patients. Meanwhile, some European countries took a pragmatic position and legalized euthanasia and assisted suicide tailored to their social context, which is the move that acknowledges patients’ right than the doctors’ inability to provide cure for their patients. This paper visits briefly the historical developments of patient’s right and dying with dignity in Europe and explores some conceptual options how European doctors can understand such right in a clinical context.

I. INTRODUCTION

The advance of science and technology in the last decades has drastically changed our lifestyle. Due to the change, we have come to hold different perceptions about our own death and how much control we have on it. Many who are not medically trained professionals do not accept or understand the fact that modern medicine has limits and thus make impossible demands from their doctors. Though it is true that the medicine makes it possible that a person’s biological life can continue indefinitely, we should think philosophically the meaning and value of the mere extension of the physical life of an incompetent person who has no possibility of biographic life at all. In a hospital setting, accepting palliative care is the recognition of humanity’s fate as mortal beings and of the limit of medicine. No medicine can offer eternity and invincible health.

The authors of this paper are physicians based in Slovenia, and we are writing within the context of Europe in general and Slovenia in particular. As clinicians treating patients some of whom are terminally ill and conversing with the patient’s family, we find the following patterns of thought in terms of doctor-patient relationship when the patient is found in a medically futile condition: the doctors feel that they betrayed their patients’ trust or doubt about their own professional medical knowledge; the patients and/or family doubt about their doctors’ capability or diagnosis; the patient is considered mentally ill or unstable by his/her own family or doctors when the patient asks for physician-assisted suicide (which is not legal in Slovenia). All this, we believe, has to do with our society’s fear or denial of death. In a sense, it seems as if we have lost our way of dealing with death as medical science and technology is getting advanced.

On the other hand, we see a way of coping with death in our society from the demand of a patient’s right to die. When we see “medicine fails you” in the sense that it cannot restore your health, we want medicine to help us die without going through the

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painful death that all human beings had gone through before the rise of modern medicine, and we tend to call this type of death “death with dignity.” Whether or not the concept of the “right to die with dignity” does exist may be a separate philosophical question. But assume that such a right exists, we are interested to know how the notion can be understood in the light of other bioethical concepts we conventionally use in our society, particularly from the European/Slovenian perspective. To do so, we will first make a brief account about how “patient’s right” in Europe arose against the backdrop of the intentional atmosphere, and then introduce the meaning of the term, “right die with dignity,” in bioethical and legal literature in Europe. Last, we will investigate how the “right to die with dignity” can be understood in relation to or in conjunction with “informed consent,” “patient’s cultural and religious right,” and “personalized medical care over standardized medical procedure.”

II. A BRIEF ACCOUNT OF THE RISE OF PATIENT’S RIGHT IN EUROPE

In Europe, the patient’s right in the form of physician’s moral responsibility to “respect for patient’s will” was first introduced in the late 19th century, as some physicians used their own patients for medical experimentations the fact of which was revealed by the works of scholars like Lassa Oppenheim, a professor of criminology at Basel University, and Albert Moll, a medical doctor in Berlin. In 1892, the Prussian professor of dermatology, Albert Neisser, had injected syphilis-infected blood serum into eight female patients without their consents. Neisser later justified his act by stating that the research was conducted to develop vaccines for the disease. None of these patients had suffered from syphilis by the time of the experiment in 1892 but hospitalized because of skin disease or other venereal diseases. All eight subjects were prostitutes and some of them were minors. After the experiments, four among the patients developed syphilis some years later. However, the question was raised whether the infection had been caused by the injection or through their occupation, prostitution.¹

In 1891, the Prussian Minister of the Interior issued a directive to all prisons that tuberculin for the treatment of tuberculosis “must in no case be used against the patient’s will.” But it was not until 1900 when the Minister for Religious, Educational, and Medical Affairs issued a directive to all hospitals and clinics that the specific content of the directive was spelled out in detail. In accordance with the legal enjoinder, all physicians in Prussia were advised also that all medical interventions other than for diagnosis, healing, and immunization were not to be performed under all circumstances if “the human subject was a minor or not competent ” or if the competent patient had not given his or her “unambiguous consent” after a “proper explanation of the possible negative consequences” of the intervention.²

In 1931 the German Reich government issued detailed “guidelines for new therapy and human experimentation” which distinguished between therapeutic (“new therapy”) and nontherapeutic research (“human experimentation”) while emphasizing strict precautions about the nontherapeutic experiment. Also, the new therapy which is therapeutic may be applied only when the doctors obtain the patient’s consent or proxy’s consent (when the patient is incompetent). However, the new therapy may be introduced without consent in the urgent situation where the therapy would not be “postponed because of the need to save life or prevent severe damage to health” the case of which must be documented as well. On the other hand, the non-therapeutic research was “under no circumstances permissible without consent.”³

However, with the rise of Nazi government, this ethical climate was changed in Germany. As we all know, the infamous human experimentation on human subjects performed by the Nazi physicians at the concentration camps is the paradigmatic example, which led to the formation of the first international ethical commitment, the Nuremberg Code in 1947. Its Ten Code emphasized the patient’s right to informed consent as necessary, specifying that the research conducted based on the informed consent must have the aim to produce benefits for the society while making sure that the risks to research subjects are minimal. It also pointed out that each research subject has the right to terminate participation in an experiment at any time, and that the researchers are immediately to terminate it if the subject is perceived to be placed in harm’s way.⁴ In 1966, the United Nation promulgated a multilateral treaty

¹ Jochen Vollman and Rolf Winau, “Informed Consent in Human Experimentation Before the Nuremberg Code,” *British Medical Journal* 313 (1996): 1445-1447; See also Andreas-Holger Maehler, *Doctors, Honour and the Law: Medical Ethics in Imperial Germany* (London: Palgrave Macmillan, 2009) and Maehler, “God’s Ethicist”: Albert Moll and His Medical Ethics in Theory and Practice,” *Medical History* 56 (2002): 217-236.

² Vollman et al, “Informed Consent.”

³ Ibid.

⁴ *The Nuremberg Code*, National Institute of Health (Bethesda, MD: Office of National Institute of Health History, 2016), <https://history.nih.gov/about/timelines/nuremberg.html>.

International Covenant on Civil and Political Rights (ICCPR) which became in force since 1976, Article 7 of which states that “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.”⁵

In Europe, the first legal document dealing with patient’s rights was the *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* which the member states of the Council of Europe adopted at Oviedo Convention in 1998. The convention introduced the rule of informed consent with regard to the application of biology and medicine, as the convention set the basic standards:

[A]n intervention in the health field may only be carried out after the person concerned has given free and informed consent to it; to person concerned shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks; the person concerned may freely withdraw consent at any time; there are special regulations for persons not able to consent, persons with mental disorder and emergency situations; the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account; person concerned can execute also the right “not to know.”⁶

In 2005, UNESCO adopted the *Universal Declaration on Bioethics and Human Rights*. This international legal document set the same standards as Oviedo Convention. However, it introduced also some new legal principles. In Article 5, the principle of autonomy and individual responsibility was introduced. Article 10 introduced the principle of equality, justice, and equity: “The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.”⁷ The summary of the declaration may be found in the following passage:

[P]atient’s informed consent is obligatory in all cases of medical research; patient’s informed consent is required in any intervention in the health field except in the cases treating persons without the capacity to consent; patient could exercise also the right “not to know” and thus partially or fully excluding the informed consent principle.⁸

III. RIGHT TO DIE WITH DIGNITY IN EUROPE

As we can see from above, in the European context in conjunction with the international legal terms, the patient right has always been construed in a negative sense: the patients have right *not* to get harmed by doctors, *not* to get used for research, etc. However, interestingly, in the contemporary European culture, the right to die with dignity is being used as it appeals to the patient’s positive right to euthanasia and assisted suicide. In fact, the term “right to die with dignity” was first introduced by the American physician, Timothy E. Quill, specializing in palliative care at the University of Rochester Medical Center in Rochester, New York, as he wrote his 1991 letter to *New England Journal of Medicine*. In the writing, Quill presented the case of Diane who had a type of leukemia that only one in every four patients survived. Diane declined treatment because she claimed to wish to live the rest of her life according to her own conscience, in a dignified manner, and not as a prisoner of medical technology.⁹ After that, we witness in Europe that scholars and physicians began using the same concept.

A sophisticated version of the discussion is found in the British physician-scholar Peter Allmark’s 2002 article published in *Journal of Medical Ethics*. Allmark argues that dignity is a function of one’s personal qualities and that a death with dignity is a personal achievement. He adds that dignity is not something that can be conferred by others like health care professionals and indignity is an

⁵ *International Covenant on Civil and Political Rights*, the Office of the High Commissioner for Human Rights (OHCHR), accessed July 12, 2016, <http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>.

⁶ “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” in *European Treaty Series No. 164*. (Strasbourg, France: Council of Europe, 2016), accessed July 13, 2016, <http://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98>.

⁷ “Universal Declaration on Bioethics and Human Rights” UNESCO Legal Instruments (2016), accessed July 13, 2016, http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html.

⁸ Ibid.

⁹ Timothy Quill, “Death and Dignity: A Case of Individualized Decision Making,” *New England Journal of Medicine* 324 no. 10 (1991): 691-694.

affront to personal dignity. In other words, indignity is what prevents or impedes one from living with dignity, mainly because it prevents one from taking an active, reasoned part in one's own life. Therefore, health care professionals have a twin role here – the first is not to impose indignity and the second is to minimize it wherever possible.¹⁰

The British physicians, John Ellershaw and Chris Ward, give an alternative meaning of “death with dignity.” They introduced the notion of “good death” which may be used the most effectively among hospice workers. Good death, they argue, is the notion emerging from not only the perspectives but also the patient's family since it is not just limited to the point of the patient's death but extends the moment after it. Thus, the hospice's “intensive palliative care” should come into action, providing physical, psychological, social, and spiritual care for the patient and the relatives.¹¹ For Ellershaw and Ward, good death includes quality of life and dying when the patient is in the process of dying and quality of care provided at bedside.¹² A group of researchers find that “bad death” should be understood as the antithesis to Ellershaw and Ward's “good death.” Richard Smith argues that Bad death, which is death without dignity, is dying in loneliness.¹³ Charles Corr defines bad death as a long dying with suffering.¹⁴ Thus, a certain type of treatment was seen important when someone dying to ensure good death. To have good death, the patient should be in a pain-free condition, well-washed, clothed, in clean bedding, allowed privacy, and in contact with human persons. These elements are essential to dignified care which leads to death with dignity.¹⁵

However, legally, “death with dignity” is not clearly defined. European countries, which include the developed industrialized Western European nations like Belgium, Luxembourg, Holland, Germany, and Switzerland, have different legal regulations on physician-assisted suicide, and passive and active euthanasia without referring to what dignified death is. In Holland, the Dutch law since 1993 allows voluntary active euthanasia and physician-assisted suicide.¹⁶ In Germany, voluntary active euthanasia is expressly forbidden but physician-assisted suicide is legal while other privately assisted suicide is being legally tolerated.¹⁷ In Swiss, Article 115 of the Swiss Penal Code considers assisted suicide a crime if the physician's motive is selfish and thus condones the act only for altruistic reasons. However, interestingly, the Swiss Academy of Medical Sciences states in its ethical recommendations that assisting others with suicide should not be part of a physician's activity. But this statement should be understood to place assisted suicide outside the purview of professional oversight and to refer to physicians as citizens under the law. This allows physicians as citizens to altruistically assist their patients with suicide.¹⁸ Belgium introduced the assisted-suicide law in 2002 which allowed doctors to help end their patients' life upon their patients' requests. But the Belgian legislation may have the most liberal tendency in Europe in that the physicians can provide assisted-suicide for patients when they are in full mental capacity but suffering from constant, unbearable physical as well as mental pains.¹⁹ Thus, mentally ill depressed people can access physician assisted-suicide in Belgium. Luxembourg also introduced laws on euthanasia and physician-assisted suicide in 2009 according to which euthanasia is regulated by advance directives including living

¹⁰ Peter Allmark, “Death with Dignity,” *Journal of Medical Ethics* 28 no. 4 (2002): 255-257.

¹¹ J. Ellershaw J. and C. Ward “Care of the Dying Patient: The Last Hours or Days of Life,” *British Medical Journal* 326 no. 7379 (2003): 30-35

¹² Karen A. Kehl “Moving Towards Peace: An Analysis of the Concept of a Good Death,” *American Journal of Hospice and Palliative Medicine* 23 no. 4 (2006): 277-286.

¹³ Smith Richard, “Death, Come Closer.” *British Medical Journal* 327 no. 7408 (2003).

¹⁴ Charles A. Corr, Kenneth J. Doka, and Robert Kastenbaum. “Dying and its interpreters: A review of selected literature and some comments on the state of the field.” *OMEGA-Journal of Death and Dying* 39 no. 4 (1999): 239-259

¹⁵ Win Tadd, “Dignity and Older Europeans” in *Ethics, Law and Society* Vol. 1, edited by Gunning Jennifer and Holm Søren, (London, UK: Routledge, 2017), 73-91.

¹⁶ The Dutch Termination of Life on Request and Assisted Suicide Act sets the criteria under which active voluntary euthanasia and assisted suicide are legal. In the case of the euthanasia, the physician administers a fatal dose of a suitable drug to the patient while in assisted suicide the physician supplies the lethal drug so that the patients can administer it themselves. “Euthanasia, Assisted Suicide and Non-Resuscitation on Request,” the Government of Netherlands, accessed April 15, 2018, <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>.

¹⁷ It has only meaning that the doctor cannot assist to suicide when he is on duty. Margaret P. Battin, “Assisted Suicide: Can We Learn from Germany?” *Hastings Center Report* 992: 44-45.

¹⁸ Samia A. Hurst and Alex Mauron, “Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-Physicians.” *British Medical Journal* 326 no. 7383 (2003): 271-273

¹⁹ Raphael Cohen-Almagor, “Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement” *Issues in Law & Medicine* 24 no 3 (2009): 187-218

will. Doctors are required to consult with their colleagues to ensure that the patient has a terminal illness and is in a "grave and incurable condition" before the provision of assisted suicide and active euthanasia.²⁰

IV. CONCEPTUAL ANALYSIS OF RIGHT TO DIE WITH DIGNITY

As shown above, the scholarly bioethics suggests the notion of dignified death which may appeal to the palliative and hospice professionals, By contrast, the laws of various European countries regulate euthanasia and assisted suicide in their own fashions without clear reference to the meanings of death with dignity or an individual's right to it. That being said, we will attempt to explore the meanings of dignified death and one's right to it by reference to some philosophical notions which can be invoked in a clinical setting, that is, "informed consent," "patient's cultural and religious right," and "personalized medical care over standardized medical procedure."

A. Right to Die with Dignity and Informed Consent

To begin with the conceptual proximity between right to die with dignity and informed consent, there have been some research that recognize the patient's will exercised on the basis of informed consent, such as the patient's right to reject life sustaining treatments through the measures like do-not-resuscitate and do-not-intubate orders.²¹ It is conceived that patient autonomy is one kind of patient autonomy and integrity. The bioethicists like R. Macklin, E. Verbakel, E. Jaspers, and E.T. Loggers, say that dying with dignity is nothing more than respect for patient autonomy and integrity.²² When respecting the patient's autonomy and integrity, the doctors make sure to get informed consent from the patients.

But there seems no literature that explores *to what extent* the patient can demand the autonomous right to informed consent. If the idea behind the informed consent is that patient is actively included in treatment decisions, we wonder if the part of such right can be also the patient's demand for the treatment that shortens patient's life and thus preventing the unnecessary pain and unwanted dependence from others, particularly their beloveds. Given that the line between assisted suicide/euthanasia and medical treatment, particularly for terminally-ill patients is not clear, it is possible that the patients' right to die with dignity can be viewed their rights to decide their treatments based on informed consent.

B. Right to Die with Dignity as Patient's Cultural and Religious Right

Right to die with dignity could be also an expression of patient's cultural or religious rights. The promotion and protection of an individual's culture and religion in the form of human rights have been the center of European societies since 1990s, as citizens claim their rights in the society. Thus, it is suspected that some patients in the hospital use the claimed right as they demand right to die with dignity. However, to invoke the right to die by reference to an individual's culture or religion, we believe that one should be able to adduce the case where one's religious and cultural authority sanctions such right. Without the absence of that, it seems difficult to conceive the right to die with dignity from this perspective.

²⁰ Thaddeus M. Baklinski "Luxembourg Legalizes Euthanasia" *Life Site*, Mar 18, 2019, <https://www.lifesitenews.com/news/luxembourg-legalizes-euthanasia>

²¹ Aart Osinski, Gerard Vreugdenhil, Jan de Koning, and Johannes G. van der Hoeven, "Do-Not-Resuscitate Orders in Cancer Patients: a Review of Literature," *Supportive Care in Cancer* 25 no. 2 (2017): 677-685; Tzu-Chien Shih, Hsiao-Ting Chang, Ming-Hwai Lin, Chun-Ku Chen, Tzeng-Ji Chen, and Shinn-Jang Hwang Hwang, "Differences in Do-Not-Resuscitate Orders, Hospice Care Utilization, and Late Referral to Hospice Care between Cancer and Non-Cancer Decedents in a Tertiary Hospital in Taiwan between 2010 and 2015: A Hospital-Based Observational Study." *MC Palliative Care* 17 no. 1 (2018): 18; Elisabeth Wong, Abass Noor, and M. B. E. Kathryn DeCarli, "Balancing Patient Autonomy, Surrogate Decision Making, and Physician Non-Maleficence When Considering Do-Not-Resuscitate Orders: An Ethics Case Analysis," *Rhode Island Medical Journal* 100 no. 10 (2017): 32.

²² R. Macklin, "Dignity is a Useless Concept: it Means No More Than Respect for Persons or Their Autonomy," *British Medical Journal* 327 no 7429 (2003): 1419-1420; E. Verbakel and E. Jaspers, "A Comparative Study on Permissiveness toward Euthanasia Religiosity, Slippery Slope, Autonomy, and Death with Dignity," *Public Opinion Quarterly* 74 no. 1 (2010): 109-139; E. T. Loggers, H. Starks, M. Shannon-Dudley, A.L. Back, F.R. Appelbaum, and F.M. Stewart, "Implementing a Death with Dignity Program at a Comprehensive Cancer Center," *New England Journal of Medicine* 368 no. 15 (2013): 1417-1424

C. Right to Die with Dignity as Right to Personalized Medical Care over Standardized Medical Procedure.

Right to die with dignity could also be a demand for personalized medical treatment. In the last decades, we have witnessed the trend that external organizations and patients rate healthcare providers and their services. Due to that, healthcare providers are pressured to show that they have maintained certain standards, thereby preventing unwanted events like lawsuits or loss of patients. As a result, standardizing medical services has occurred in the sense that patients with similar or same symptoms are grouped in certain categories and treated in the same manner according to the standards. However, we reckon that terminally-ill patients have their unique needs and expectations. It is certain that dying patients do not want to feel that they are categorized as a group with certain symptoms. The dying patient wants to be treated *as a person* because dying is a highly personal experience. They want their physicians (not just hospice workers) to come close to them as their physicians *as their own doctors* provide palliative services for them and help end their life when their pain becomes unbearable. The patients may think that they have right to the personalized treatment and care.

Originally, it was considered that the relationship between doctors and patients is a personal one. The 19th century German physician, Albert Moll, was the one who first introduced the concept of a contractual relationship between doctor and patient as a client.²³ However, if the doctor-patient relation is contractual, then there are questions who the third-party authority is which binds the contract and on what condition the two parties could avoid their contractual obligations. It is presumed that the patient's right to die with dignity may be the patient's demand to return to the original doctor-patient relationship.

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²³ Maehle Anderas-Holger, *Doctors, Honour and the Law: Medical Ethics in Imperial Germany* (London: Palgrave Macmillan, 2009).

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