TALLINN UNIVERSITY OF TECHNOLOGY
School of Business and Governance
Department of Law

Lilli Gross

THE FORM AND LEGAL BASIS OF LIVING WILL: A COMPARATIVE ANALYSIS OF FINLAND AND ITALY. HOW SHOULD THE ESTONIAN LEGISLATION BE AMENDED BASED ON THE LEGAL FINDINGS FROM FINLAND AND ITALY?

Master Thesis
Master Program, International Law

Supervisor: Jenna Tuulia Uusitalo, MA in Law

Tallinn 2022

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Lilli Gross, …….03 January 2022

(signature, date)

Student code: 191910HAJM

Student e-mail address: lilli.gross@gmail.com

Supervisor: Jenna Tuulia Uusitalo, MA in Law:

The paper conforms to requirements in force

……

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ABSTRACT

In today's fast-moving world, diseases and disorders once accepted as terminal are now treatable with new techniques and drugs. As medical technologies make advances and ever more aggressive life-saving treatments continue to become commonly used. Where does the line go between what is life and what is the quality of life, and how do we make those decisions for those who cannot make them for themselves? Physicians take an oath to do no harm and seriously take that pledge. Family members can be single-minded in their drive to save their loved one's life at any cost. The problem arises when a patient cannot decide anymore because of his or her health condition. Hence living will comes into the force when the patient cannot clearly communicate his or her preferences regarding medical treatment. Implementing guidelines for the future gives peace of mind to the patient through the comforting knowledge that difficult decisions that should have been made before the end of life have already been made, thus preventing or reducing disagreements between the involved parties. European Union and its Member States also have very different legal standards that govern living will. The majority of Member States seem to care more about regarding protecting the individual's life than to a person's right to terminate it. In Estonia, everyone can draw up their living will, a power of attorney, and notarize it to ensure proper execution. However, a separate regulation to this effect does not exist in the legislation.

This qualitative research explores the existing regulatory frameworks and legal basis for form, content, and storage timeline of a patient will in Finland and Italy to determine which form of a living will be applicable best for Estonia and how Estonian legislation should be amended based on the legal findings from Finland and Italy. The following keywords were used to find the sources: a living will, advanced directive(s), patient's will+form, Italy, Finland, Estonia, *hoitotahto*, *patsiendi testament*, self-determination, autonomy, consent.

Based on the findings of this paper, for the first of all, given the developments in this field, Estonia would need separate legislation to regulate the living will, as done in Finland and Italy. Next, the formal requirements need to be specified in addition to the current legal bases, which address vital patient elements, such as informed consent and the guarantee of the right to self-determination. For the last, the temporal validity of the living will would also need to be specified. In the light of the rapid development of treatment options, it would be prudent to set an optimal period of validity, after which the patient will need to renew.

INTRODUCTION

Under Estonian Constitutional Law, everyone is entitled to the protection of health[1]. Every person in Estonia has the ultimate right to self-determination and autonomy under constitutional law regarding health and decisions. Respect for this self-determination and independence begins with recognizing the legitimate right and a person's capacity to make personal choices. Both consent and refusal of consent are expressions of the same patients' right to self-determination. Zannoni has found that the patient's right to refuse medical treatment is probably the first bioethical rule established in the post-WW2 period. The role of informed consent as an ethical, deontological, and legal constraint was then progressively strengthened and emphasized therapeutic alliance[2]. In today's fast-moving world, medical advancements are taking place at the speed of light. Diseases and disorders that once were accepted as terminal are now treatable with new techniques and drugs. As medical technologies make advances and ever more aggressive life-saving treatments continue to become commonly used, where is the line between what is life and what is the quality of life, and how do we make those decisions for those who cannot make them for themselves? Physicians take an oath to do no harm and seriously take that pledge. Family members can be single-minded in their drive to save their loved one's life at any cost. When stand-offs occur, it can sometimes be up to the legal system to decide the fate of voiceless victims.

In Estonian law, the patient's right to self-determination in medical care is provided in Law of Obligations[3]; the patient may be examined and health care services may be provided to him or her only with his or her consent. Refusals of medical treatments are also to be respected, even if they might adversely affect patients' health or shorten their life. The problem arises when a patient cannot decide anymore because of her or his health condition. In this situation it has an important role one's living will, the statement about what kind of treatment a person wants or does not want in a situation where he can no longer make his own decisions, such as feeling unconscious or demented[4]. Hence living will comes into the force when the patient cannot communicate what to do. These situations are also emotionally challenging; thus, it is better to make decisions before

[1] RT I, 15.05.2015, 2. §28.
[2] Zannoni, D. (2020). Right or duty to live? Euthanasia and assisted suicide from the perspective of the European convention on human rights. *European Journal of Legal Studies*, 12(2), 193. …"This right was affirmed as early as the 1947 decision in United States of America v. Karl Brandt and others, and then incorporated into the so-called Nuremberg Code."
[3] RT I, 04.01.2021, 19. §766, 767.
[4] Kruus, M., Int, R., Nõmper, A. (2017). Patsienditestament: milleks ja kellele? Vormid, vormistamine ja rakendamise probleemid. *Juridica*, 5, 330.

making them in crises or difficult situations, such as the death of a loved one or a severe illness, when the patient's autonomy and decision-making capacity are still fully present and intact. Even if these issues are complicated to discuss or do not want to be discussed, because a severe illness can be taboo, the previous experience from daily work as a medical care professional shows that the sooner difficult issues are discussed, the better outcome of the problematic situation will be. Implementing guidelines for the future gives peace of mind to the patient through the comforting knowledge that difficult decisions that should be made at the end of life have already been made; it also prevents or reduces disagreements between the patient and relatives.[5] The need for the advanced directive is also emphasized that there are significant inconsistencies between providers and recipients in the planning and implementing end-of-life care.[6]

Through a living will document, the patient will participate in the decision-making process in the end-of-the-life situation. As of 2020, there were less than 10 living wills asserted by the notary in Estonia[7]. The current lack of clarity about the legal meaning of living will hinder its use. There is no separate legal regulation, no particular form or protocol for a living will in Estonia. It is deductible from the provisions in Law of Obligation as shown beforehand and is going to have an empty section for it in the digital health database in future.

Presently, European Union and Member States have ether very different or no legal standards at all that govern living wills. The majority of Member States seem to attach more to protecting the individual's life than to a person's right to terminate it[8]. In Estonia, everyone can draw up their living will, a power of attorney, and notarize it to ensure proper execution. However, as said before, a separate regulation to this effect does not exist in the legislation. From a medical point of view, it is better to make health decisions when the patient's request is formal and clearly expressed. It gives a sense of security to both sides, to the patient and to the physician, because the patient´s final wishes have clearly been communicated and understood by the doctors and the medical staff.

[5] Bruus, I., Kellamäe, M., Kivirüüt, M. (2015). Ravi ja hoolduse planeerimine nn elutestamendi koostamise teel", *Eesti Arst*, 94(2), 92.
[6] Rantalainen, T. (2015). Tekisinkö hoitotahdon? Hoitotahto osana terveydenhuollon asiakkaan valintoja. Yhteiskuntatieteiden ja kauppatieteiden tiedekunta. Itä- Suomen yliopisto, 27.
[7] Int, R. (2020), Patsiendi testament Eesti õiguse kontekstis *The Ethics conference*, 18 september 2020, Tallinn; Estonia.
[8] Zannoni, D. (2020). Right or duty to live? Euthanasia and assisted suicide from the perspective of the European convention on human rights. *European Journal of Legal Studies*, 12 (2), 196.

This research explores the existing regulatory frameworks and legal basis for form, content and storage timeline of living will in Finland and Italy to determine which form of living will be applicable best for Estonia and how Estonian legislation should be amended based on the legal findings from Finland and Italy?

The research will be a qualitative, comparative analysis, literature review. The literature search was performed from HeinOnline and Google Scholar using keywords and time limit (2016 and newer) articles. In the case of Finland, older sources have also been used. International documentation and national legislation search was performed on Google Scholar. Sources from the field of ethics and medicine have also been used in this work. It is entirely impossible to be left alone in the law field research literature by studying the living will. Combining and reviewing the scientific literature of many disciplines concerning the law field literature is justified and necessary. Issues at the end of life are not concerned only with the law field. The center of the topic is more related to bioethics. Here rises also important ancillary policy aspects. Blank (2011) points out that advances in medicine can extend life almost indefinitely, but often it means poor quality and escalating dependence on medical technologies[9].

Comparative analysis is a way to solve the research problem. Evaluating the results based on the literature and findings and discussing the amendments that need to be done in Estonian legislation will answer the following research questions.

- What are the legal basis of the living will in Finland and Italy?
- How has the living will be structured, and form the living will as a document has to exposit in Finland and Italy?
- Could any of these existing forms and structures be applicable in Estonia?
- How should Estonian legislation be amended based on the legal findings from Finland and Italy?

The following is an overview of the concept of living will in general and relevant trends, legal framework, and legislation in Europe. The chapter on the current situation in Estonia provides an overview of the current law, which allows the advanced directive to be drafted and maintained. Also, the bottlenecks that need to be addressed. Separate chapters provide an overview of living will in Finland and Italy. The legal basis and existing forms of the above document are discussed.

[9] Blank, R. H. (2011). End-of-Life Decision Making across Cultures. *Journal of Law, Medicine and Ethics*, 39 (2), 201.

The discussion explores what could be transposed from the legal practice of the two countries, as mentioned earlier, into Estonian law so that living will be a concrete and unambiguous document in its form.

1. CONCEPT OF LIVING WILL

1.1. Living will as a term

The living will also be known by terms advance care planning, advance directives, health care directives, or end-of-life decision-making is by which a patient makes his or her future health decisions.[10] The living will define as "a written advance directive in which a competent person indicates health care preferences while cognitively and physically intact. A living will specifying instructions for care (e.g., feeding tubes, mechanical ventilation, surgery) in life-prolonging situations. A living will take effect when the patient becomes physically or mentally unable to make his or her own decisions and is terminally ill or irreversibly comatose."[11] I use the term "living will" throughout this work, as the term is related to the corresponding term in all three countries I will discuss: Estonia, Finland, and Italy. Finland was one of the first countries to pass a patient rights law. The Act on the Status and Rights of Patients (785/1992) was entered in March 1993[12]. Considering the European legislative framework, the Italian regulation on the advance directive is one of the last laws approved, indicating another vital step towards harmonizing with European laws on this topic[13].

It is important to note that in everyday situations, the living will as such are often combined with a ban on resuscitation or euthanasia; neither of the last two situations has this meaning. However, these three phenomena have the same features: ensuring patient well-being and delimiting treatment and care as the patient approaches death. Also, from the point of view of the meaning of living will or advanced directive, it is essential to specify why the living will is a more accurate linguistic term than, for example, testament. The term living will describe the author's statement of intent in more detail because the living will express the author's will to take care or not take care of one's life and health during the patient's lifetime. A testament is a mortal act that refers to a will relating to things after death, which is not as well suited for health use as the concept of the living will. The purpose of the living will is to provide health care professionals with information about

[10] Bruus *et al. Supra nota* 5, 91.
[11] Crane, M. K., Wittink, M., Doukas, D. J. (2005). Respecting end-of-life treatment preferences. *American family physician*, *72*(7), 1265.
[12] Kattelus, M. (2014). Implementation of the Directive on the Application on Patient's Rights in Cross-Border Healthcare (2011/24/EU) in Finland. European Journal of Health Law, 21 (1), 25.
[13] Ciliberti R., Gorini I., Gazzaniga V., De Stefano F., Gulino M. (2018). The Italian law on informed consent and advance directives: New rules of conduct for the autonomy of doctors and patients in end-of-life care. *J Crit Care*, 48, 179.

the person's will and at the same time to initiate a discussion about the future in cooperation with relatives, care workers, and those who will provide care.[14];[15]. However, the Estonian term during the translation process shows that the words "will" and "testament" have the same meaning in Estonian.

1.2. Substantive meaning of a living will

Compiling a living will allow people to plan situations they could lose autonomy, dignity, and the ability to make their preferences. The living will is not only advanced medical directions written by a patient; nor are they limited to end-of-life decision-making. It is a life-management document that people may complete in-home, community, hospital, institutional, and aged care settings. Often when people complete a living will, they are not seeking to control their medical treatment or doctors' decisions but hoping to live well and die with dignity by their values.

A patient's will, living will, is the instrument that most strongly guarantees a person's autonomy, the right for self-determination, assuming that the person has drawn it up according to his or her own will. It is a tool designed to ensure compliance with the patient's volition[16]. In essence, the document, made by a person when still legally fit to do so, expresses one's desire to be allowed to die instead of being kept alive by artificial means of being severely disabled or suffering from a terminal illness. The oldest form of advance directive, the living will, was first described in 1969. by an Illinois (USA) attorney Kutner, proposed appending to the patient's consent to treatment form a "...clause providing that if his condition becomes incurable and his bodily state vegetative with no possibility that he could recover his entire faculties, his consent to further treatment would be terminated." The document would be notarized and attested by the witnesses that the individual was of sound mind and acting of his own free will.[17] Given the above, a living will help ascertain the patient's own will. The existence of a patient will prevent disagreements between the patient's loved ones. Also, living will give a loved one's peace of mind because they do not have to constantly doubt whether they think so or whether the patient's expected will is exercised correctly.

[14] Rantalainen, T. (2015). Tekisinkö hoitotahdon? Hoitotahto osana terveydenhuollon asiakkaan valintoja. Yhteiskuntatieteiden ja kauppatieteiden tiedekunta. Itä- Suomen yliopisto, 25.
[15] Kaminsky, M. (2021). *Living Will vs. Last Will & Testament.* Retrived from https://www.legalzoom.com/articles/living-will-vs-last-will, 17 November 2021.
[16] Di Luca, A., Del Rio, a., Bosco, M., Di Luca, N. M. (2018) . Law on advance health care directives: a medical perspective. *Clin Ter*, 169(2), e78.
[17] Wolf, L. E., Caley, S. (2016). Vulnerable patients and end-of-life decision-making. *Asia Pacific Journal of Health Law Ethics*, 10(1), 8.

A living will's existence also simplifies the work doctors who would otherwise have to consider the different opinions of the patient's loved ones and inevitably prefer someone's position.

Legislation must also consider the possibility that the opinion of the patient and a loved one may differ. A study among doctors (n=823) in Switzerland showed that this situation significantly impacts doctors' decisions. It carried out that contradictions between advance directives and proxy opinions result in a weak preference for abstention from treatment and increase the difficulty of the decision.[18]

The patient self-determination is both historically and geographically broad. The patients' right to self-determination in respect of the medical treatment that they receive was affirmed in the landmark case in US of *Schloendoff* v. *Society of New York Hospital* (1914) by Justice Benjamin Cardozo: *"Every human being of adult years and sound mind has a right to determine what shall be done with his own body, and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."* Thus, the patient's consent ensures respect for the patient's autonomy and bodily integrity.[19] For a treatment to be valid, a patient must be fully informed of the medical risks involved and freely consent to treatment because, under the common law doctrine of self-determination, a patient is free from unwanted bodily intrusion.[20]

And last but not least. Previous decisions by the patient also help prevent overutilization of care. In situations where the patient suffers unnecessarily and is likely to incur high treatment costs, we often see in the hospital's daily life. Because in the context of terminal illness, many people believe that more therapeutic care (such as tests, procedures, life support measures, and drug therapies) leads to longer life and improved patient's physical well-being. It is common in the hospital's daily life to hear grieving families assure others that "the doctors did everything they could." "Doing everything" may help alleviate feelings of distress or helplessness on the part of families and physicians, but it is not necessarily in the patient's best interests.[21]

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[18] Escher, M., Perrier, A., Rudaz, S., Dayer, P., Perneger, T. V. (2015). Doctors' decisions when faced with contradictory patient advance directives and health care proxy opinion: a randomized vignette-based study. *Journal of pain and symptom management*, 49 (3), 639.

[19] Chervenak, F., A., McCullough, l., B., Judith Chervenak, J. (2016). Perils of Miscommunication: The Beginnings of Informed Consent. *Donald School Journal of Ultrasound in Obstetrics and Gynecology*, 10 (2), 126.

[20] Tate, K. R. (2017). An Advance Directive: The Elective, Effective Way to Be Protective of Your Rights. *Mercer Law Review*, 68 (2), 526.

[21] Noah, B. A., Feigenson, N. R. (2016). Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent. *Pace Law Review*, 36 (3), 744.

2. THE LEGAL FRAMEWORK, LEGAL BASIS AND THE FORMAL REQUIREMENTS FOR A LIVING WILL IN THE EUROPEAN LEGISLATION

2.1. The legal basis of the living will

The foundations of the healthcare system's organization to the Member States of the European Union are provided in the Treaty on the Functioning of the European Union (TFEU). In developing and keeping up a well-functioning healthcare system, the EU has a rather supporting role, and the Member State has a crucial role. Article 5(3) TFEU provides that The Union may take initiatives to coordinate Member States' social policies. Article 6(a) states that: "The Union shall have competence to carry out actions to support, coordinate or supplement the actions of the Member States." One of the areas of such action at the European level shall be protecting and improving human health. In member states of the European Union, the use of written or oral wishes about future treatment, i.e., guidelines for the future, in health care is relatively a new topic. Over the last ten years, there has been a more active debate on the role those future guidelines could play in European health systems. As a result, the legal documents that support the patient's future treatment decisions also vary considerably from country to country.[22] During the last decade, however, many European countries have adopted legislation on advance decisions to refuse treatment. It has led to law promulgation in many countries of the European Union[23].

Despite the shared appreciation of living will (advanced directives); still, each country accords a different legal status to mentioned documents.[24] Horn (2017) pointed out that countries with a strong emphasis on patient autonomy (England and Germany) have recognized the binding force of advance directives for many years. Countries less concerned with patient autonomy (France) struggled to accord binding legal value to these directives. These differences reflect the different values that are dominant in each country and the different socio-political contexts.[25]

[22] Bruus, Kellamäe, Kivirüüt (2015). *Supranota* 5, 91.
[23] Di Fazio N., Romano S., Del Fante Z., Santoro P., Fineschi V., Frati P. (2021). European Countries' Different Legal Orientation About End-of-Life Issues in Patients Affected With Neurological/Psychiatric Diseases: Does Italian Law n.219/2017 Provide Adequate Options for This Fragile Category of Patients? *Frontiers in Psychiatry*, 12, 1.
[24] Horn, R. (2017). Why should question patient's wish: comparative study on physicians' perspectives on their duties to respect advance directives. *European Journal of Health Law*, 24 (5), 524.
[25] *Ibid.*, 524.

In the context of the living will, also in law, several essential substantive terms need to be considered: patient consent, patient autonomy and the right to self-determination. The patient's consent is understood as the consent given by the patient prior to any treatment, test, or study. The principle of informed consent, aimed at the lawfulness of health assistance, reflects the concept of autonomy and decisional self-determination of the person requiring and requesting medical interventions.

From the point of view of psychology in the context of self-determination theory, autonomy and self-determination can be viewed as essentially separate but still essentially overlapping phenomena[26];[27]. The principle of self-determination appreciates as a cornerstone of clinical ethics overall; it states that it should be the patient who should decide whether or not to accept suggested treatment or care. It is enshrined in legal frameworks and guidelines around the world, and it has had a significant impact on our understanding of how to deal with different issues in the medical field.[28]

As said in the introduction, consent, and refusal of consent are expressions of the same patients' right to self-determination. In the context of this paper, both autonomy and self-determination mean that patients have the right and opportunity to make their own choices and decisions about the treatment they receive and the treatment they receive by the law. More broadly, it can be said that self-determination as a term has been used in a wide variety of contexts. In international law, it is used, for example, to describe the right of peoples and states to exist and appeals to one's democratic instincts and sense of fairness.[29] In the context of data protection in today's digital world, we find the term informational self-determination due to technological and social innovation turbulence.[30] It is a deep-rooted principle espoused in the Charter of the United Nations. Also, many other international instruments emerged as central to the human rights framework established to hold states accountable to those within their jurisdiction.[31]

[26] Vansteenkiste, M., Ryan, R. M. (2013). On psychological growth and vulnerability: Basic psychological need satisfaction and need frustration as a unifying principle. *Journal of Psychotherapy Integration,* 23 (3), 264.
[27] Deci, E., Ryan, R. (2012). *Self-determination theory.* In P. A. Van Lange, A.W. Kruglanski, E. T. Higgins. (Eds.) (2012). *Handbook of theories of social psychology: volume 1*. 1, 416-437. SAGE Publications Ltd.
[28] Lindberg, J., Johansson, M. and Broström, L. (2019). Temporising and respect for patient self-determination. *Journal of medical ethics,* 45 (3), 161.
[29] Klabbers, J. (2006). The Right to Be Taken Seriously: Self-Determination in International Law. *Human Rights Quarterly,* 28 (1), 187.
[30] Hooghiemstra, T. (2019). Informational Self-Determination, Digital Health and New Features of Data Protection. *European Data Protection Law Review (EDPL),* 5 (2), 161.
[31] Mazel, O. (2016). Self-Determination and the Right to Health: Australian Aboriginal Community Controlled Health Services. *Human Rights Law Review,* 16 (2), 326.

The legal basis for self-determination and informed consent is found in article 3 of the Charter of Fundamental Rights of the European Union, which has the same values as the EU Treaties after the approval of the Lisbon Treaty. Everyone is entitled to physical and mental integrity. Also, according to the procedures laid down by law, the free and informed consent of the person concerned must be respected in the fields of medicine and biology.[32] In a real, inside society, the individual's right to self-determination is not absolute. In healthcare, the self-determination of a competent person is limited, for example, so that the patient does not have the full right to choose any treatment or demand individuality in the ward or care facility. Self-determination in care can be more accurately expressed as the right to be involved and thus to decide on matters concerning one's own life and care.[33] The most commonly referred to provision in the Strasbourg Court's case law is Article 8 of the European Convention of Human Rights, which decrees the right to respect for private and family life regarding the issues of consent, private life, and right to information.[34]

Still regarding the international level, the only international legally binding instrument on protecting human rights in the biomedical field is Oviedo Convention[35], adopted by the Council of Europe and signed in Oviedo on 4 April 1997. This framework convention draws on the principles established by the European Convention on Human Rights in biology and medicine, aiming at protecting the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms concerning the application of biology and medicine. It sets out fundamental principles applicable to daily medical practice and is regarded as such at the European treaty on patient's rights[36], where the right to consent is one of the fourteen provided for patient rights.[37] Estonia, Finland, and Italy have signed the convention. Unlike the other two countries, Italy has not ratified or legally forced entry (entry into force)[38]. The above document also sets out both the patient's consent and the right to

[32] Charter of fundamental rights of the European Union. *Official Journal of the European Union,* 18.12.2000. 364/1. § 3.
[33] Rantalainen (2015). *Supra nota* 14, 29.
[34] Serghides, G. (2019). The Oviedo Convention in the case-law of the European Court of Human Rights. *Bio-Juria Βιο-Νομικά*, 1 (1), 2.
[35] 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. Oviedo, 4.IV.1997. Council of Europe. European Treaty Series. No. 164.
[36] European Charter of Patient's Rights. Basis Document. Rome, November 2002. Retrived from https://ec.europa.eu/health/ph_overview/co_operation/mobility/docs/health_services_co108_en.pdf , 10 March 2021.
[37] Oviedo Convention and its Protocols. Retrived from https://www.coe.int/en/web/bioethics/oviedo-convention, 10 March 2021.
[38] Chart of signatures and ratifications of Treaty 164. 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

self-determination. The essential principles regarding discussed topics are dealt with in articles 5 and 9.

Article 5 of the convention provides the general rule of patient consent for an intervention in the health field. The consent should be given freely after the appropriate information about the purpose and nature of the intervention and its consequences and risks, and the patient may freely withdraw consent at any time[39]. Regarding the end-of-life decision, it should be emphasized that every patient has the right to self-determination. This right belongs to the "rights strictly bound to a person." The patient has the right to interrogate the treatment be discontinued as well as the right to refuse all treatment. The patient's right to self-determination in this case must be respected[40].

Articles 2 and 4 of the convention broaden the scope of science and drug research, decree the supremacy, welfare and interests of the human being over the social and scientific interests, emphasizing that any intervention in the health field, including research, must be carried out following relevant professional obligations and standards.[41] The principles of beneficence and non-maleficence set out in these articles of the Convention refer to the doctor's dual obligation to seek the maximum potential benefit for the patient and limit any harm as much as possible that might arise from medical intervention.[42] In Article 9, we find an explicit provision on living will. It decrees: "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."[43]

There is another document worth noting, compiled in 2014. The Committee on Bioethics of the Council of Europe published the "Guide on the decision-making process regarding medical

Biomedicine. Retrived from https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures, 10 March 2021.

[39] Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997. *Supra nota* 37, § 5.

[40] Özsunay, E. (2016). End of life decisions from legal perspective, substitute decision-making, continuing powers of attorney, advance directives for incapacity. *End of Life Care Symposium. Introducing the Council of Europe's "Guide on the decision-making process regarding medical treatment in end-of-life care situations"*, 25 October 2016 Istanbul, 7. Council of Europe and Acibadem University, Istanbul, Turkey. Author: The author of this article uses the term "*höchstpersönliche Rechte*" showing the accurancy of the term.

[41] Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997. *Supra nota* 37, § 2 and 4. Article 2 deals with – Primacy of the human being by saying: "The interests and welfare of the human being shall prevail over the sole interest of society or science." Article 4 sets out the professional standards: "Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards."

[42] Veshi, D., Neitzke, G. (2016). Council of Europe: Guide on the decision-making process regarding medical treatment in end-of-life situations. Medical Law International, 16 (1-2), 98.

[43] Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997. *Supra nota* 37, § 9.

treatment in end-of-life situations." This document comprises four chapters, and its goal is to make practical recommendations for implementing the ethical principles set out in the Oviedo Convention. The guide is aimed at medical practitioners rather than governments. While the Oviedo Convention focuses on the concept of "previously expressed wishes," the guide considers this and the role of the patient's family and close friends. Distinct from the Oviedo Convention, the first international legally binding comprehensive treaty which addressed human rights issues in biomedicine, the guide of 2014 is not a hard-law document. It does not take an official position regarding end-of-life issues. Thus, member states should comply with it but are not obliged to do so. [44] The primary value of this guide is instead a judicial in offering an ethical framework for end-of-life decision-making.

2.2. The formal requirements and temporal validity of the living will

The patient will have formal requirements and temporal validity, if any, outlined in each state's law. For example, in France, Germany, and Austria, there is a written requirement for patient will. The document must be dated. As of 2016, patient wills in France are open-ended and do not need to be renewed unless the author wishes to make changes. In Austria, it is recommended to renew it every five years. The formal requirements of the mentioned countries also indicate the signing requirements. In France, for example, if a person can express the wishes but cannot write and sign the document himself or herself, the involvement of witnesses is mandatory. In this case, the third party may sign the document, provided that the two witnesses prove that the document is a free and informed declaration of intent by the patient's testator. The witness certificate must be attached to the patient's will and must state the names and legal capacity of the witnesses.[45] Kruust *et al.* (2017) also point out that a patient's formal requirement will fulfill two purposes. First, the formal requirement reduces the risk that someone else will draw up the patient's will against their will instead of the patient. Second, the formal requirement reduces the risk that the patient will draw up a patient's will in a state where the patient cannot express his absolute will. The fact that a person makes a patient's will in full consciousness according to his will is essential, given that the patient's will is intended to protect the patient's autonomy. In order to ensure the latter, it would be sensible to involve a notary to make clear, unambiguous, and definitive the content of the declaration of intent.

[44] Veshi and Neitzke. *Supra nota* 42, 95.
[45] Kruus *et al*. (2017). *Supra nota* 4, 336.

3. THE CURRENT SITUATION IN ESTONIA

The term "living will" used in Estonian is a “patient will”. The need for and topicality of the living will has begun in Estonia only in recent years. During this time, there has been an active debate in the media. A significant part of the ethics conference was also dedicated to it in September 2020. From the perspective of the effectiveness of the treatment and the doctor's ethics, then the legal perspective is added. "The basic principle of a doctor is not to preserve life, but to act in the best interests of the patient; keeping a person alive without the prospect of improvement is unethical," said Dr. Katrin Elmet, one of the leaders of the topic in Estonia[46]. The topicality and multidimensionality of the topic is reflected in the large number of parties involved in the debate overall: doctors, theologians, lawyers, and other social actors.

3.1. The legal basis of the living will

Although living will not be standard in Estonia, the national legislation allows this, as mentioned in the introduction. As previously briefly described, the living will is not regulated as a separate institute in Estonian legislation and, regardless of its possibility, its not active use in practice. Nor does the concept of a patient's will/living will/advanced directives exist in Estonian legislation. However, the underuse of this option may be due to people's lack of knowledge about its design and implementation. Precisely, the living will derive from the legal rules from the Law of Obligations Act on providing health care services. Kruus et al. (2017 and 2018)[47];[48] have analyzed the situation in Estonia from the legal point according to the Law of Obligation (LOA) articles 766 and 767 through two scientific articles. The authors point out that in the Estonian legal system, the living will is regulated by two provisions of these sections: article 766 (3) and article 767 (1).

In a situation where the patient can decide, there is generally no problem in determining whether or not the patient wishes to receive healthcare. The article 766 (3) in the Law of Obligation provides for this kind of situation the duty to inform and to obtain the patient's consent. It[49] says,

[46] Tammepuu, K. (2018). *Kliinikumi arst: elu lõpetamise juhis peaks olema sama loomulik kui testamendi tegemine.* Retrived from: https://tervis.elu24.ee/4403869/kliinikumi-arst-elu-lopetamise-juhis-peaks-olema-sama-loomulik-kui-testamendi-tegemine, 10. March 2021.
[47] Kruus, M., Int, R., Nõmper, A. (2018). The Patient’s Will – Why and for Whom? Forms, Formalisation, and Implementation Issues. *Juridica International,* 27/2018, 158-169.
[48] Kruus *et al*. (2017). *Supra nota* 4.
[49] RT I, 04.01.2021, 19.

"A patient may be examined and health care services may be provided to him or her only with his or her consent. A patient may withdraw his or her consent within a reasonable period of time after granting consent. At the request of a provider of healthcare services, such consent or an application to withdraw such consent shall be in a format which can be reproduced in writing." Subsection 1 of the same article obliges the healthcare provider to inform the patient of the examination results, health state, and possible diseases and their course, also, about the availability, nature, and purpose of the healthcare, the patient needs, and about the risks and consequences of providing it, and other possible healthcare services. Thus, the patient's consent is valid only if he has been duly informed in advance or if the patient already has a piece of information or one refuses to provide this information. If the patient refuses to give consent, the service may not be provided to the patient, and the patient is responsible for the consequences of not receiving the service in time.[50] However, the second sentence of withdrawal within a reasonable time is contrary to Article 5 of the Oviedo Convention, which provides that the patient may freely withdraw his consent at any time.

The patient retains the right to self-determination be able to refuse healthcare in the future even if one is not a quorate, for example, if the patient is unconscious, demented, or otherwise unable to express his will[51]. These situations are governed by article 767 (1). It provides "If a patient is unconscious or incapable of exercising his or her will for any other reason (a patient without the capacity to exercise his or her will) and if he or she does not have a legal representative or his or her legal representative cannot be reached, the provision of health care services is permitted without the consent of the patient if this is in the interests of the patient and corresponds to the intentions expressed by him or her earlier or to his or her presumed intentions and if failure to provide health care services promptly would put the life of the patient at risk or significantly damage his or her health. The intentions expressed earlier by a patient or his or her presumed intentions shall, if possible, be ascertained using the help of his or her immediate family. The immediate family of the patient shall be informed of his or her state of health, the provision of health care services, and the associated risks if this is possible in the circumstances." This article is mandatory, thus, Kruus *et al* (2017) point out, that living will be able to exclude the provision of health care under the following conditions:

- The provision of healthcare would in itself be indicated to the patient. The provision of healthcare is in the patient's best interests if it is indicated and of good quality for the

[50] Varul, P., Kull, I., Kõve, V., Käerdi, M. (Eds.) (2009), *Võlaõigusseadus III. Kommenteeritud väljaanne. 8. ja 10. osa*. Tallinn: Juura, 305.
[51] Kruus *et al*. (2017). *Supra nota* 4, 331.

patient, which means that it is not a pointless treatment.

- The patient is unconscious or otherwise unable to express his will. Within the meaning of article 767 (1) of the Law of Obligation, the patient is incapacitated in any situation where he or she cannot express his will. Thus, the patient is indecisive for example in the case of mental activity disorder, or he is physically or otherwise unable to express his will. In many cases determining the patient's ability to make decisions.

  would be an easy task. For example, if the patient is unconscious, there is no doubt that the unconscious patient is incapable of making a decision. At the same time, there may sometimes be borderline situations where it is more challenging to determine decision-making power.
- The decision to provide healthcare is urgent, means failure to provide it immediately would be life-threatening, would seriously harm the patient's health, or would be permanently indecisive. This point focuses primarily on the living will's role in a situation where immediate non-provision of healthcare would be dangerous to the patient's life, which means the extension and non-extension of life through a living will.
- The patient's legal representative does not decide for him. That is, the existence of a legal representative precludes the exercise of the living will.
- The patient has expressed his or her will not to provide health care in the living will.

Finally, it is important to point out that according to international law, the values of the European Convention on Human Rights and the Oviedo Convention have been enshrined in law. The Oviedo Convention has been directly transposed based on Article 123 of the Estonian Constitution, which specifies: "(1) The Republic of Estonia shall not conclude foreign treaties which are in conflict with the Constitution. (2) If Estonian laws or other acts are in conflict with foreign treaties ratified by the Parliament, the articles of the foreign treaty shall be applied."[52]

3.2. The formal requirements and temporal validity of the living will

Based on the above, the legal bases for compiling living wills are in place; the form and storage of the document and the temporal and substantive definition turn out to be bottlenecks. Estonian legislation does not provide for a specific form of the living will. Nor has its period of validity

[52] Overview of countries who have ratified the european convention on human rights and biomedicine. Retrieved from http://www.eurogentest.org/fileadmin/templates/eugt/pdf/Overview_of_ratifying_countries_-_EuroGentest_website.pdf, 28 November 2021.

been determined. How to behave in a situation where the living will be prepared years ago and the treatment options at the time of its implementation have changed and allow the patient to live an entire life after the treatment? Making a document available to healthcare professionals needs a solution: where to download or send it so that it is available to the right people at the right time. The content and accuracy of the living will also need to be considered in formulating the patient's wish so that it is the patient's genuine and voluntary wish; and unambiguous to everyone; the living will thus be feasible and would not lead to additional inconvenience to the patient. It can be said that the broader introduction of a living will in Estonia contributes to a person's right to decide for himself or herself on the health care service provided to him or her in a state of indecision. Although the legislation supports the drafting of this document, without precise regulations, it remains a rather theoretical possibility.[53]

As given before, besides the form, sufficient access to the document for the parties is essential. The living will only benefit a person if the will expressed in it reaches the healthcare provider and in time. A possible solution would already exist here. Both conditions would be met by a register already used or required to be used by all healthcare providers. In Estonia, it seems most expedient to take advantage of the possibilities of the health information system (*Digilugu*[54]). There is a solution created with keyword declarations of intent. At present, it is possible to draw up a declaration of intent to donate / not to donate organs, to perform / not to perform a blood transfusion, and to donate / not to donate a corpse for research purposes (Figure 1). The digital form of living will could be added to this same solution. Legal basis of the storage and processing of data in digital records and granting access is specified in Chapter 4 of the Health Information System Statute[55] and Chapter 5 of the Health Services Organization Act[56].

[53] Kivioja, A. (2018). Patsienditestament kui üks võimalus kaitsta otsusevõimetu patsiendi enesemääramisõigust. *Perearst*, 08/2018, 15.
[54] https://www.digilugu.ee/login. Digital history or digital health history is a nationwide health information system in Estonia that connects healthcare institutions' existing information systems and is a part of e-health.
[55] RT I, 06.12.2016, 11.
[56] RT I, 2001, 50, 284.

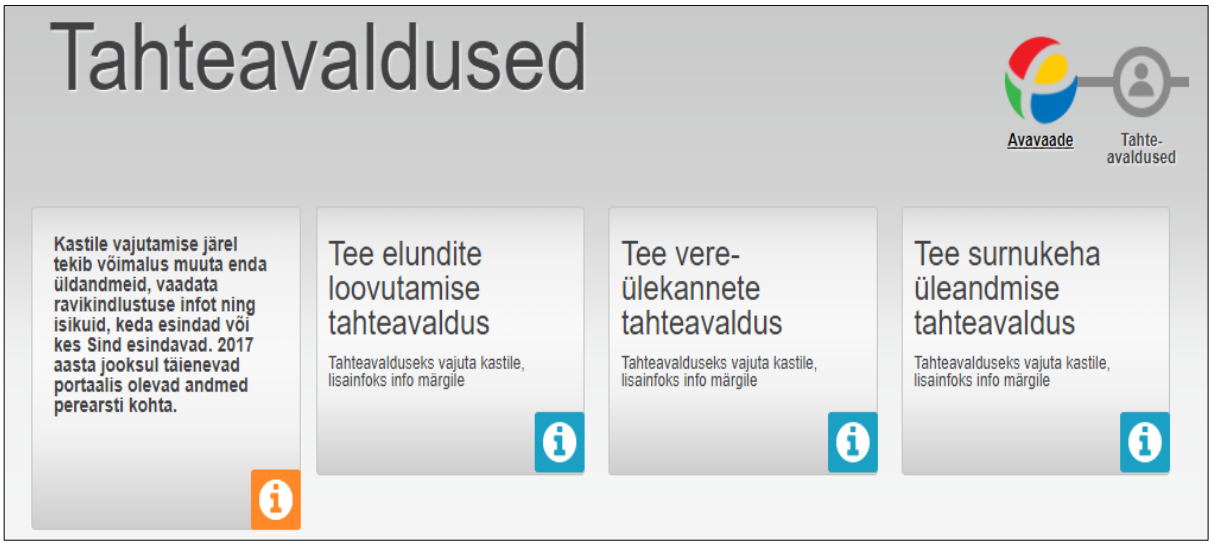

Figure 1. Possibilities of expression of will in Estonian digital history *(Digilugu)*
Source: www.digilugu.ee

The patient has access to all personal data in the health information system. However, to protect the patient's life or health, the healthcare provider may set a time limit of up to six months for the transmission of personal data to the information system, during which the patient may access personal data for the first time only through a healthcare professional. The data in the digital history are permitted by law to be accessed by the healthcare provider. In addition by:

- a medical student who has completed the compulsory fourth-year subjects in the curriculum;
- physiotherapist;
- occupational therapist;
- at the clinical speech therapist;
- clinical psychologist;
- optometrist;
- radiology technician;
- a person is performing an internship directed by Taru University.

The patient has the full right to deny the above specialists access to his or her health data.[57]

[57] RT I, 2001, 50, 284. § 59 (2).

4. THE LEGAL BASIS, FORMS AND PRIMARY STRUCTURE OF LIVING WILL IN ITALY

One country for comparison for this thesis paper was Italy because of the new law. As said above, the Italian Parliament has recently (2017) approved a law on informed consent, advance directives, and advance care planning. Where, it can be said, the form and substantive details of the patient's consent and desire to live are clearly set out.

4.1. The legal basis of the living will

In Italy, health is considered a fundamental right, the principle of voluntariness also applies in this respect.[58]. In December 2017, Law 219/2017, "Provisions for informed consent and advance directives", was approved in Italy, *"Norme in materia di consenso informato e di disposizioni anticipate di trattamento"*[59], came into force in 2018. The law can be viewed as the culmination of a year-long process and the subject of heated debate throughout Italian society. The law covers, as said above, the contentious issues as advance directives, the possibility to refuse medical treatment, the withdrawal of medical treatment, nutrition, and hydration.[60] The term used in Italy for living will is *Disposizioni anticipate di trattamento (DAT)* - the advance provisions of treatment, which is broadly said the living will.[61] Some authors use the term advance care directives. So it may include instructions relating to specific treatments but may also cover a broader scope of expressions of wishes in the medical field concerning a broader and more complex universe of principles and personal values that help shape a person's attitude towards choices in this field.[62]

There is a long process for obtaining such a final law act. The process of passing the law began already in 2004, based on a regulatory framework that clearly states the above mentioned principle

[58] *Constitution of the Italian Republic.* Senato della Repubblica. Given in Rome on this 27th Day of December 1947. §32: "The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent. No one may be obliged to undergo any health treatment except under the provisions of the law. The law may not under any circumstances violate the limits imposed by respect for the human person".
[59] Norme in materia di consenso informato e di disposizioni anticipate di trattamento. LEGGE 22 dicembre 2017, n. 219. GU n.12 del 16-1-2018.
[60] Di Paolo, M., Gori, F., Papi, L., Turillazzi, E. (2019). A review and analysis of new Italian law 219/2017: 'provisions for informed consent and advance directives treatment.' *BMC Med Ethics* 20, (17), 1.
[61] Delbon, P., Cacace, S., Conti, A. (2019). Advance care Directives: Citizens, patients, doctors, institutions. *Journal of Public Health Research,* 8:1675, 97.
[62] *Ibid.,* 97.

of voluntariness of the Italian Constitution. Although national and international documents and the Italian code of medical ethics provide for individual agency in health care, the country was divided politically and culturally on specific fundamental issues such as the withdrawal of life-sustaining treatments, often assimilated to euthanasia, palliative sedation, physicians' conscientious objection, and advanced directives' critical meaning.[63] Even more precisely, already in 2003, the National Bioethics Committee of Italy, in their opinion statement, supported the introduction of advance care directives in The Italian legal system. However, none of the introduced bills in Parliament became a law[64]. Discussed law regulates advance directives and several rights citizens have regarding health care issues, like the right to be fully informed about their health status, give consent to treatment. Every citizen has the right to withhold consent to lifesaving treatments, the right to be assisted until death, and the right to express preferences and wishes through advance directives.[65] Moreover, this law states that the physician must respect the patient's wishes. DePanfilis et al. (2020) point here to possible contradiction; thus, the physician cannot be held liable under civil or penal law for doing so. Nevertheless, this obligation to respect the patient's wishes remains one of the most controversial law issues for healthcare professionals. In the absence of any clear legislative definition, fear of litigation may have contributed in the past to an increased risk of not respecting the patient's wishes.[66]

The public debate in Italy before the law is drafted, refers to two prominent cases; the case of Eluana Englaro and Piergiorgio Welby. Eluana Englaro's death occurred in 2009, after 18 years in a vegetative state caused by a car accident. After the withdrawal of artificial hydration and nutrition, she died after the Italian Supreme Court had ruled that treatment should be stopped, it was a precedent, for the first time in Italy.[67];[68] This case caused considerable political turmoil and involved several institutions; the government of Italy, the president (Giorgio Napolitano), the Constitutional Court, and the European Court of Human Rights.[69]

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[63] De Panfilis, L., Rossi, P. G., Mazzini, E., Pistolesi, L., Ghirotto, L., Noto, A., , Cuocolo, S., Costantini, M. (2020). Knowledge, Opinion, and Attitude About the Italian Law on Advance Directives: A Population-Based Survey. *Journal of Pain and Symptom Management*, 60 (5), 907.
[64] Morati, S. (2010). The Englaro Case: Withdrawal of Treatment from a Patient in a Permanent Vegetative State in Italy. *Cambridge Quarterly of Healthcare Ethics*. 19, 372.
[65] De Panfilis, L., Rossi, P. G., Mazzini, E., Pistolesi, L., Ghirotto, L., Noto, A., , Cuocolo, S., Costantini, M. (2020). Knowledge, Opinion, and Attitude About the Italian Law on Advance Directives: A Population-Based Survey. *Journal of Pain and Symptom Management*, 60 (5), 907.
[66] *Ibid.*, 907.
[67] *Ibid.*, 907.
[68] Biondi, S. "Can Good Law Make up for Bad Politics - The Case of Eluana Englaro." *Medical Law Review*, vol. 17, (3), 453.
[69] Morati, S. (2010). The Englaro Case: Withdrawal of Treatment from a Patient in a Permanent Vegetative State in Italy. *Cambridge Quarterly of Healthcare Ethics*. 19, 372.

In the second case, Piergiorgio Welby was diagnosed with facioscapulohumeral dystrophy. Over 35 years, after his condition gradually deteriorated to the point that he could no longer breathe independently, he was kept alive by invasive mechanical ventilation against his will. He was competent and asked for the withdrawal of ventilation and palliative sedation. After many fruitless legal appeals, Welby died in 2006 with the only Italian physician's assistance to help him. After Welby's death, the physician was charged with consensual murder. The case was dismissed against the doctor.[70] Moreover, the man's story raised a pretty intense debate in public opinion and pointed out the challenging dilemmas that physicians, relatives, and severely ill patients face daily to realize a substantial part of the constitutional right to self-determination.[71]

Before close looking at the above law, it must be pointed out that the starting point for designing the legal basis for regulating end-of-life matters in Italian law is still constitutional principles. Article 32[72] in the Italian Constitution is dedicated to the right to health and has particular relevance in end-of-life issues. This wording represents the basis for acknowledging the individual right to refuse medical treatments as a matter of individual liberty regarding any medical treatment on the person. The Constitutional grounds of informed consent are also based on the rights affirmed by the Constitution; by the Court rulings the articles 2, 13, and 32 of the Constitution represent the perimeter of individual liberty in decisions concerning health.[73] Also the law 219/2017 has not been translated into English, and the author does not speak Italian; its review and legal analysis have been made based on articles.

Law 219/2017 regulates, in addition, the patient will several rights citizens have regarding health care issues, including the patient right to be fully informed about health status and to give consent

[70] De Panfilis. *Supra nota* 63, 907.
[71] Busatta, L. "End of Life Issues in Italy: Between Case Law and (Still Missing) Legislation." Digest: *National Italian American Bar Association Law Journal*, 25, 67.
[72] *Ibid*., 60. Article 32 states, "[...] No one may be obliged to undergo any health treatment except under the provisions of the law. The law may not under any circumstances violate the limits imposed by respect for the human person".
[73] *Ibid*., 60. The court ruled "... it is important to point out that informed consent, understood as an expression of the informed acceptance of the medical treatment proposed by the doctor, has the status of a full-scale right of the person and is grounded in the principles expressed in Article 2 of the Constitution, which protects and promotes fundamental rights, and Articles 13 and 32 of the Constitution which provide, respectively, that 'personal freedom is inviolable' and that 'nobody may be forcefully submitted to medical treatment except as provided by law.' [...] The fact that informed consent is grounded in Articles 2, 13 and 32 of the Constitution gives prominence to its role as a synthesis of two fundamental rights of the person - the right to self-determination and the right to healthcare [ ]".

or refusal to treatment, the right to withhold consent to life saving treatments, the right to be assisted until death and the right to express preferences and wishes through advance directives.[74]

DiPaolo *et al* (2019) has analyzed law 219/2017 on a broad basis. They describe that the mentioned law presents a series of issues that profoundly affect the substance of the care relationship. "Concepts that emerge clearly from the law are quality of life, autonomy, and the right to accept or refuse any medical treatment – concepts that should be part of an optimal relationship between the patient and healthcare professionals", they pointed out. The most outstanding merit of the law is that it maximizes the value of the patient's time to decide. Every patient can and should have the time to decide which will prevail even in the future when the choice may be partially or wholly prevented by illness. The law recognizes that every patient has the right to have adequate time to discuss healthcare-related values, goals, and preferences with physicians to have the chance to decide on health treatment that may be current or future, and foreseeable or otherwise. Every patient can choose to consent or refuse a current treatment for the present and the future. Draw up as a continuation of the present, and determine what comes next, based on what the patient already knows.[75]

In April and May 2019, the structured questionnaire interview, based on the literature review, was conducted in Italy to determine the citizens' attitude toward the law no 219/2017. The sample included 2000 valid interviews, in 70.1% of which (N=1403) the respondent declared they had heard about the law, and of the total sample, 76% had a positive attitude toward making advance directives. 4.9% declared they had already made an advance directive.[76]

A qualitative study was also carried out in the same year among Italian healthcare professionals to investigate the implications of the new law in clinical practice from the perspective of those who deal with this delicate ethical issue every day. The results showed, as a whole, healthcare professionals perceived the new law as a legal instrument that shows both strengths and weaknesses in its present form, with space for future improvement. The participants described it as a tool to use in daily clinical practice. They affirmed that it is a good, positive, and needed regulation to provide healthcare according to the patient's will and has the means to guarantee the person's self-determination. For future suggestions to better the law, some healthcare professionals

[74] De Panfilis. *Supra nota* 63, 907.
[75] Di Paolo *et al. Supra nota* 60, 2.
[76] De Panfilis. *Supra nota* 63, 907-910.

proposed simplifying it and clarifying some controversial points that could lead to misunderstandings or misinterpretation. Also, to promote awareness and information campaigns about the law, explain its characteristics, content, and boundaries to both patients and caregivers to minimize the risk of misunderstanding. Besides strengths, participants found some critical points. First of all, the healthcare professionals reported uncertainty and difficulty in implementing advance directives for various reasons. Being a recent law, it was not always easy for the clinicians to trace a patient's advance directive or for citizens to understand where and how to register their wishes. Some interviewed nurses declared that they did not know the content of the law on an advance directive, and some of them expressed a wish to deepen their knowledge. [77]

The law 219/2917 consists of eight articles giving clear indications:

- for informed consent, setting out the terms of the patients receiving information, the possible forms of expression of consent, the usefulness of the patient's will regarding the unwanted health treatments, indications regarding hydration and artificial nutrition, professional medical liability implications concerning the refusal of a medical act or therapies;
- about access to pain therapy and dignity in the final stage of life;
- the possibility of giving consent or dissent to medical acts and treatments before the occurrence of pathologies, that could lead to a loss of autonomy.[78]

Patient consent and related matters are set out in Article 1. It states that no medical treatment can be initiated and continued without the free and informed consent of the person concerned, except in cases expressly provided for by law. It clearly refers here to the constitutional and fundamental rights of every citizen, recognizing the full extent of self-determination up to the right of a person to live at all stages of his or her life without treatment. Paragraph 6 of the same article also establishes that "The doctor is obliged to respect the wish expressed by the patient to refuse health treatment or to withdraw from it and, as a result, is exempt from civil or criminal liability." Di Paolo *et al* (2019) point out that one of the main advantages of this law is that it provides a kind of guarantee: if a patient refuses any treatment or even asks a doctor to give up treatment, the doctor's behavior is legitimate and guarantees the patient's rights. However, this Act does not

[77] Maffoni M., Argentero P., Giorgi I., Giardini A. (2020). Healthcare professionals' perceptions about the Italian law on advance directives. *Nursing ethics*, 27 (3), 800-802.
[78] Bolcato, M., Fassina, G., Sanavio, M., Aprile, A. (2020), The new Italian law 219/2017: an extraordinary clinical tool in internal medicine. *Italian Journal of Medicine*, 14, 184.

prescribe the content or form of information provided to patients. Also who should provide information to the patient.[79]. Based on the above, it is worth mentioning that this law explicitly recognizes in article 1, paragraph 5 the artificial nutrition and artificial hydration as health treatment given on medical prescription through medical devices; this aims to resolve the ethical and bio-juridical debate following the Englaro case.[80]

Article 4 defines an entirely new legal instrument that healthcare professionals will face in clinical practice: the anticipated provisions of treatment. It can be said to be the most innovative part of this law.[81] Paragraph 1 of that article states that any person of legal age and capable of understanding and wanting, in prevision of any future inability to determine themselves and after having acquired adequate medical information on the consequences of their choices, can, through this document, express their own will in the matter of health treatments, as well as consent or refusal concerning diagnostic tests or therapeutic choices and individual health treatments. It also indicates a trusted person who takes his place and represents him in relations with the doctor and with the healthcare facilities.[82] The law does not explicitly stipulate what can and cannot be included in a living will. However, article 4 refers to that expressed in the introductory article on informed consent, evoking the general principle that a patient can- not demand treatments contrary to the law, professional ethics, or good clinical practices. If faced with such requests, physicians have no professional obligations.[83]

The personal requirements for documents drawn up based on the above provisions are the person's adulthood and total mental capacity, which raises the legal basis for determining that legal capacity. The law does not contain any references to the legal capacity of the signatory.[84]

This Act also supplements legislation already adopted. Analyzing the Gelli-Bianco Law (released in March 2017, dealing with the liability of the healthcare professionals), nevertheless, it does not explicitly deal with the issue of informed consent. Although the two problems are closely interlinked, the lack of patient information could, in the worst case, lead to the criminal liability of

[79] Di Paolo *et al. Supra nota* 60, 2.
[80] Bolcato *et al. Supra nota* 78, 185.
[81] Delbon, P., Cacace, S., Conti, A. (2019). Advance care Directives: Citizens, patients, doctors, institutions. *Journal of Public Health Research,* vol 8:1675, 97.
[82] Bolcato *et al. Supra nota* 78, 186.
[83] Di Paolo *et al. Supra nota* 60, 4.
[84] Delbon *et al. Supra nota* 61, 96.

the healthcare professional. Franciosi (2018) clarifies that 219/2017 Law (released in December 2017) fills this cap by its subsequent legal provisions.[85]

Busatta (2017) points out in analyzing the Italian Constitution and comparing it to international law that the international conventions affirm the legal value of informed consent to which Italy adheres. Article 3 of the Charter of Fundamental Rights of the European Union, which has the same values as the EU Treaties after the approval of the Lisbon Treaty. Even though the Charter is not legally binding in this context because the living will not enshrine from the EU legislation, the EU Charter nevertheless lays down principles which the EU member states should follow in every case. At the same time, the relevant articles found in the Oviedo Convention could not be considered a source of Italian law[86], as the instrument of ratification has not (yet) been filed at the Council of Europe.[87]

Conclusively, the law carries the value of acknowledging and giving the legislative body the autonomous patient's right to make healthcare-related decisions. In the context of the treatment process through the diagnostic and treatment consent/refusal tool and the prevention of future events through joint care planning and previous directives.[88] The research findings amongst the healthcare workers showed another critical point: the new legal instrument supports both sides: clinicians and guarantees patients' self-determination rights. However, some weaknesses persisted, and there is room for future improvement[89].

4.2. The formal requirements and temporal validity of the living will

The form of a living will is set out in Article 4 subsection 6, where the formal requirements of the living will are much more rigorous than for informed consent.[90] The living will has greater rigidity in its formulation. Despite the informed consent, the document must be drawn up by public deed, by authenticated private writing, or by private writing personally delivered by the settlor to the registry office of the municipality of residence, which provides for the annotation in a special

[85] Franciosi, L. (2018). The new Italian regime for healthcare liability and the role of clinical practice guidelines: dialogue among legal formants. *Journal of Civil Law Studies*, 11 (2), 407.
[86] The Oviedo Convention was authorized for ratification by the Italian Parliament in 2001, but not ratified to this day, *(author).*
[87] Busatta. *Supra nota* 71, 61.
[88] Di Paolo *et al. Supra nota* 60, 2.
[89] Maffoni *et al. Supra nota* 77, 805.
[90] *Ibid.*, 97.

register. If the patient's physical condition does not allow it, the living will can be expressed through video recording or devices that allow the person with disabilities to communicate. With the same forms, they are renewable, modifiable, and revocable at any time. According to the Ministerial Decree in 2019, regarding the regulation concerning the national database destined for the living wills, a computed database has been founded to register the living will that any hospital in the national territory can consult.[91];[92] However, up to 2020, this national database of Advance Directives Declaration is not available; therefore, it is impossible to estimate how many people have already written their declaration.[93]

[91] Bolcato *et al. Supra nota* 72, 186.
[92] Delbon *et al. Supra nota* 65, 98.
[93] Maffoni M., Argentero P., Giorgi I., Giardini A. (2020). Healthcare professionals' perceptions about the Italian law on advance directives. *Nursing ethics*, 27 (3), 789.

5. THE LEGAL BASIS, FORMS AND PRIMARY STRUCTURE OF LIVING WILL IN FINLAND

As mentioned in the introduction, Finland was one of the first countries to pass a patient rights law; it was entered in March 1993. In Finland, the term living will or advance directives is used *hoitotahdo* in native language. This document is part of patient-centeredness, representing preventive decision-making.[94] As discussed above, the living will in Finland is also a form of the patient's right to self-determination, in which case one decides on the provision of services ahead of time for a given situation. Legislation protects the right to self-determination, but as a fundamental moral right, respect for the right to self-determination is binding on healthcare professionals regardless of the law.[95] There is no legal requirement in Finland that a lawyer draws up the patient's will. A living will is a document that anyone can draw up. However, it is essential to write the document as clearly and unambiguously as possible so there is no doubt about the person's will. Its form and other requirements are provided in the different law acts.

Tahvanainen has described the process of drawing up the patient's will as follows: "The patient usually discusses the need for a living will with a doctor. Some principles can be used to address the living will. The first thing is to discuss the importance of the living will with the patient. The patient can fill in the form later with a supervisor or refuse to assist. When talking to the client or patient about the living will, it is good to remember that the will to care is the patient's right, not the obligation." She brings out that living will improve patient autonomy and facilitate decision-making from a doctor's perspective. Also the problematic points may occur: the changing nature of the living will and the wrong reason for doing the care can be considered a problem. Wrong causes include depression, economic factors, or feeling a burden to loved ones. Sometimes also the content of the living will is not applicable in practice.[96]

[94] Rantalainen. *Supra nota* 14, 2.
[95] *Ibid.*, 29.
[96] Tahvanainen, E. (2016). *Sähköinen hoitotahdo terveydenhuollossa.* (Garaduation thesis). Lapland University of Applied Sciences. 11.

5.1. The legal basis of the living will

Several legal acts create a legal basis for living in Finland. First, the right to life and liberty are enshrined as fundamental human rights in the Finnish Constitution[97]. Validity of the living will is listed in articles 6 and 8 of the Act on the Status and Rights of Patients, which provides for the patient's right to plan one's treatment and make decisions regarding emergency care. The most straightforward task of the living will is to act as a means of self-determination in situations where a person who has previously been self-sufficient is unable to give consent to treatment.[98] Mention should also be made of Article 5 of the same law, which provides an explanation and information to be provided to the patient on his or her condition and essential aspects of his or her treatment and care. It is also the healthcare professional's responsibility to ensure that the patient understands the information provided[99]. Article 6 expresses clearly that the patient should be treated according to the common understanding of the parties. In case the patient refuses a particular treatment or procedure, he or she should, if possible, be treated in another medically acceptable way in agreement with the patient.[100] Article 8 provides that even in a critical situation, if the patient has previously expressed a stable and valid desire to treat, the patient should not be given treatment that is against his or her will. From the point of view of the law, the advanced directives role in the healthcare system is prominent; it carries the purpose of limiting treatment according to the patient's prior declarations.[101]

According to previous, the advanced directive is an expression of a person's will about his or her future care in the event that he or she is unable to participate in care solutions himself or herself due to unconsciousness, old age, or other similar causes. By this document, a person ensures that

[97] *The Constitution of the Republic of Finland.* (1999), Suomen Peruslaki. *Finlex,* 11.6.1999/731. §7: "Jokaisella on oikeus elämään sekä henkilökohtaiseen vapauteen, koskemattomuuteen ja turvallisuuteen…"
[98] Rantalainen. *Supra nota* 14. 24.
[99] *The Act on the Status and Rights of Patients.* (1992), Laki potilaan asemistan ja oikeuksistan. *Finlex,* 785/1992. Article 5:"Potilaalle on annettava selvitys hänen terveydentilastaan, hoidon merkityksestä, eri hoitovaihtoehdoista ja niiden vaikutuksista sekä muista hänen hoitoonsa liittyvistä seikoista, joilla on merkitystä päätettäessä hänen hoitamisestaan. Selvitystä ei kuitenkaan tule antaa vastoin potilaan tahtoa tai silloin, kun on ilmeistä, että selvityksen antamisesta aiheutuisi vakavaa vaaraa potilaan hengelle tai terveydelle.
Terveydenhuollon ammattihenkilön on annettava selvitys siten, että potilas riittävästi ymmärtää sen sisällön. Jos terveydenhuollon ammattihenkilö ei osaa potilaan käyttämää kieltä taikka potilas ei aisti- tai puhevian vuoksi voi tulla ymmärretyksi, on mahdollisuuksien mukaan huolehdittava tulkitsemisesta.
[100] *The Act on the Status and Rights of Patients.* (1992), Laki potilaan asemistan ja oikeuksistan. *Finlex,* 785/1992. §6 Potilan itsemääräämisoikeus: "Potilasta on hoidettava yhteisymmärryksessä hänen kanssaan. Jos potilas kieltäytyy tietystä hoidosta tai hoitotoimenpiteestä, häntä on mahdollisuuksien mukaan hoidettava yhteisymmärryksessä hänen kanssaan muulla lääketieteellisesti hyväksyttävällä tavalla."
[101] Laki potilaan asemistan ja oikeuksistan. *Supra nota* 92. §8 Kiireellinen hoito: "Potilaalle on annettava hänen henkeään tai terveyttään uhkaavan vaaran torjumiseksi tarpeellinen hoito, vaikka potilaan tahdosta ei tajuttomuuden tai muun syyn vuoksi voi saada selvitystä. Jos potilas on aikaisemmin vakaasti ja pätevästi ilmaissut hoitoa koskevan tahtonsa, potilaalle ei kuitenkaan saa antaa sellaista hoitoa, joka on vastoin hänen tahtoaan."

his or her wishes are taken into account in the treatment when he or she is unable to express them himself or herself. The will to care reduces the uncertainty and anxiety of relatives in treatment solutions and thus facilitates the work of doctors, as this allows healthcare professionals to take the patient's wishes into account when making their treatment decisions and care policies. In essence, the document described above may express requirements for special treatment or may refuse specified medical measures. Requests may also be related to other than medical issues. For example, a patient may authorize another person to make necessary care decisions for a person seeking care.[102]

The living will is only valid and in force, if the patient cannot make decisions about their treatment. The patient's will is intended to guide the treatment of long-term diseases in which the hope of recovery is lost. The patient should note that this only applies to situations where measures could only prolong the suffering patient's life. In this case, the patient has unconsciously been hospitalized due to a sudden illness or accident that can be cured; this will not apply.

The person can withdraw the advance directive at any time or change its contents. Due to advances in medicine, there are no clear rules about how long the advance directive can be valid. The treatment options and prognosis for a severe illness have changed between the time the living will is written and the time it is fulfilled. The prescriber can review the contents periodically, preferably less frequently than every ten years. The date of the inspection, also the change or cancellation dates should be recorded.[103] This requirement arises from the Regulation of the Ministry of Social Affairs and Health of patient data, where it decreed that the patient records stored in the archiving service must form a complete set of documents using the identified service transaction and service unit identifiers. When destroying the documents of a service event or service unit, an entry in the archives must be left about the destruction.[104] In particular, the procedure for recording, amending, and deleting any patient documentation lays down in the relevant regulation, which states that If the patient wishes to express his or her will in the future, this must be clearly stated in the patient's documents or attached to a separate document showing the patient's will. Also, the patient's records

[102] Halila, R., Mustajoki, P. (2016). *Hoitatahdo-käytännön ohjeita.* Retrieved from https://www.terveyskirjasto.fi/dlk00809, 30 October, 2021.
[103] *Ibid.*
[104] *Regulation of the Ministry of Social Affairs and Health of patient data.* (2009). Sosiaali- ja terveysministeriön asetus potilasasiakirjoista. *Finlex,* 30.3. 298/2009. §2: "Arkistointipalveluun tallennettavien sähköisten potilasasiakirjojen tulee muodostaa ehyt asiakirjakokonaisuus yksilöityjen palvelutapahtuma- ja palvelukokonaisuustunnusten avulla. Kun palvelutapahtumasta tai palvelukokonaisuudesta hävitetään asiakirjoja, hävittämisestä tulee jäädä merkintä arkistoon."

must state that the patient has been adequately informed of the consequences of complying with a living will. The entries for the patient's data modification and cancellation will apply article 20 in the same regulation. That article sets out two crucial moments. First, corrections to the patient's records must be made so that the original and corrected entries can be read later, including the modifier and date. Second, when deleting information that is not necessary for patient care, the author's folders and the date of deletion must be noted on the patient's folders.[105] In situations where it is suspected that the patient's statement of intent has changed, the legitimacy of the document may be weakened, and the interpretation of the Patients' Law is contradictory to the situation. In such a case, it may ultimately be the responsibility of close relatives and other decision-makers to prohibit and authorize treatment.[106] Refusal of active treatment expressed in the patient's will is binding on the doctor, other health care professionals, and specialists unless there is reason to suspect that the patient's will has changed after the will has been drafted.[107]

Rantalainen (2015) studied the information, making, and functioning of living will among Finnish citizens aged 66-80 in practice. According to the study participants, it was made clear that that living will turn out to be a private matter. It is considered part of the essential documents and is kept in a well-defined place. Informing the living will outside the home has not become a straightforward practice, and not all people seeking care pay attention to the fact that talking about the need for care in health care is an important activity. Recording a living will on a blank form instead of a free one shows that support is needed in drawing up the living will. It might be that a specific form is needed to structure one's views or that the possibility of free-form of the living will is not communicated as clearly as the existence of a particular form.[108]

The living will in Finland is also recognized in the context of international law. In Europe, Oviedo Convention has marked it in article 9 regarding respect for the patient's previously expressed will

[105] *Regulation of the Ministry of Social Affairs and Health of patient data.* (2009). Sosiaali- ja terveysministeriön asetus potilasasiakirjoista. *Finlex,* 30.3. 298/2009. §18; 20. §18: *"Jos potilas haluaa ilmaista hoitoa koskevan vakaan tahtonsa tulevaisuuden varalle, tästä tulee tehdä selkeä, potilaan itsensä varmentama merkintä potilasasiakirjoihin tai liittää niihin erillinen potilaan tahdon ilmaiseva asiakirja. Potilasasiakirjoihin tulee lisäksi tehdä merkinnät siitä, että potilaalle on annettu riittävä selvitys hänen tahtonsa noudattamisen vaikutuksista. Hoitotahdon muuttamista ja peruuttamista koskeviin merkintöihin sovelletaan, mitä potilasasiakirjoissa olevan virheen korjaamisesta 20 §:ssä säädetään." §20: "Potilasasiakirjamerkintöjen korjaaminen tulee tehdä siten, että alkuperäinen ja korjattu merkintä ovat myöhemmin luettavissa. Korjauksen tekijän nimi, virka-asema, korjauksentekopäivä ja korjauksen peruste tulee merkitä potilasasiakirjoihin. Jos potilasasiakirjoista poistetaan potilaan hoidon kannalta tarpeeton tieto, potilasasiakirjoihin tulee tehdä merkintä siitä, sen tekijästä ja poistamisajankohdasta."*

[106] Rantalainen. *Supra nota* 14, 28.

[107] Halila and Mustajoki. *Supra nota* 102.

[108] Rantalainen. *Supra nota* 14, 63.

in both urgent and ongoing care situations.[109];[110] There is more to mention in the Charter of fundamental Rights of the European Union in articles 3 and 25. Article 3 provides the right to the integrity of the person. In article 25, the rights of the elderly were found by saying "the Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and participate in social and cultural life."[111] As before in the case of Italy, even though the Charter is not legally binding in this context because the living will not enshrine from the EU legislation, the EU Charter nevertheless lays down principles which the EU member states should follow in every single case.

5.2. The formal requirements and temporal validity of the living will

The exact form of the living will in Finland is not defined, nor the temporal validity. The matter regarding the validity of the living will all over was discussed in the previous chapter. By the law the date of the inspection of the document, also the change or the cancellation should be recorded. However the law does not govern rules for the time retention.

There are several ways and ready-made models for submitting a declaration of intent. The advance directive care is usually in written form (Appendix 1), with the author's handwritten signature and date. It is valid without witnesses, but it is still, from a legal point of view, recommended using two witnesses who do not belong to a family or close relative; to avoid the above problems (compiling the living will for the wrong reasons). A written request for treatment may be registered as an appendix to the health report or may accompany the patient. In the latter case, the medical statement must state the intention to treat. According to the law, a person may also express his or her will also orally. In this case, it should be recorded by writing in the patient's medical report and, if possible, signed or otherwise verified.[112]

Everyone can keep their care timely in the national health archive, *Kanta* managed by K*ela* (a Finnish government agency in charge of settling benefits under national social security programs). Kanta produces digital services for the social welfare and healthcare sector. The users of the Kanta

[109] Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997. *Supra nota* 32. §9 Previously expressed wishes. "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."
[110] Rantalainen. *Supra nota* 14, 28.
[111] European Charter of Patient's Rights. *Supra nota 32.* § 3; 25.
[112] Halila & Mustajoki. *Supra nota* 102.

services include citizens, pharmacies, healthcare services, and social welfare services. In addition, Kanta provides information on treatment requests given and stored as the patient progresses in the healthcare system.[113] The introduction of My Kanta Pages has brought out that all patient data systems used in Finland can record and browse living wills. Anyone using My Kanta Pages can draw up their living will in this service. When the living wills have been drawn up through My Kanta Pages, it is guaranteed that the healthcare services will always have the latest versions. Through the My Kanta Pages, the uploaded living wills are accessible and available at the national level in the same format in all patient data systems.[114]

[113] *Ibid.*

[114] Kanta. (2019, Sep 05). Save a living will and organ donation testament in My Kanta Pages. [Blog post]. Retrieved from https://www.kanta.fi/en/blog/-/asset_publisher/1QjC602jKPR6/content/omakantaan-voi-tallentaa-hoito-ja-elinluovutustahdon, 26 December 2021.

6. COMPARISON AND THE AMENDMENTS SUITABLE FOR ESTONIA

The purpose of the previous five chapters was to provide an overview of the concept of the living will in general—also, the legal framework and legislation in Europe. The chapter on the current situation in Estonia gave an overview of the current legislation, which makes it possible to compile a living will. It also referred to bottlenecks that should be addressed. Separate chapters gave an overview of the living will in Finland and Italy. The legal bases and formal requirements were set out. The following will discuss what could be transferred from the legal practice of the two countries, as mentioned earlier, to Estonian law so that living will be a concrete and unambiguous document in its form.

Before going on to a substantive discussion, I need to go into a brief analysis of the sources cited. The search was performed on Google Scholar, PubMed and HeineOnline using keywords. There found more ethical debate than a legal analysis, which is logical given the issue's sensitivity. The decision-making at the end-of-life raises broad and challenging ethical issues that touch the patients, their families, and the health care professionals. There were few scientific articles regarding Finland, but legislation on the subject was well found. Finding sources about Finland turned out to be more difficult than expected, as the search words in English yielded very few results. The best results were obtained using exact Finnish search terms. The author's outstanding Finnish language skills were sufficient to understand and analyze the found legislation to an ample extent. While in Italy, there were many analytical research articles on patient will. Probably because the law was new at the end of 2017, and the issue caused many repercussions among ordinary citizens and researchers. It is also important to note here that there was a so-called saturation effect concerning the Italian sources, i.e., the authors refer to each other's previously published works. Unlike in Estonia, neither Finnish nor Italian legislation, with the exception of the Italian Constitution, has been translated into English. Therefore, the review of the Italian legislation on patient will is based on scientific articles.

As for Italy, here has to highlight that important point. However, only a few scientific articles can be found in Finland and Estonia. Italy has adopted a law on a patient will only recently. Since the entry into force of the new law in 2018, it has been continuously analyzed by researchers. The research has been conducted in target groups. The feedback from the target groups is mandatory to understand how the law could be a barrier or a facilitator for the empowerment of citizens and

healthcare professionals. For example, the opinions and attitudes of nurses regarding the implementation of the patient will in clinical practice and influencing factors have also been studied based on a narrative review of the literature. The survey revealed that the nurse or attitudes considered be decisive in administering the living will, and the quality of the patient's end-of-life care. However, implementing the living will ideas may be questionable without the necessary training and more comprehensive consultation by healthcare professionals. In Italy, where nurses had a recent experience with the law governing the patient's will, the opinion expressed was that the texts of the law were complicated for people and could be interpreted in various ways.[115]

From European Union law the living will's legal basis can be found from the Charter of Fundamental Rights of the European Union, in Article 3, which has the same values as the EU Treaties after the approval of the Lisbon Treaty. Even though for the three countries concerned, the Charter is not legally binding in the context of living will because the living will not enshrine from the EU legislation, the EU Charter nevertheless lays down principles which the EU member states should follow in every single case. Another main source is the Oviedo Convention, which is the only international legally binding instrument on protecting human rights regarding biomedicine. The convention aims to secure the dignity of human beings within this field. All three countries had signed the convention. Estonia in 1997, ratified in 2002, and the convention is directly applicable based on the Constitution. Finland signed the convention in 1997, ratified it in 2009. The act entered into force in 2010. As brought above, Italy signed the document in 1997 but did not ratify it.

The European Union legislation governing the living will of all three countries is in line with the two documents mentioned above. Analyzing the Italian Constitution and comparing it with international law, it can be said that the international conventions confirm the legal value of informed consent, which Italy observes. As Italy has not ratified the Oviedo Convention, the relevant articles found in this document could not be considered a source of Italian law.

The patient must be objectively informed, both regarding the competent consent and the part of the patient will to implement the principle of self-determination in full. The importance of informing the patient has been highlighted in all three countries' legislation, and in almost all

[115] Lahi, S., Laul, M., Merimaa, M. (2021). *Õdede arvamused ja hoiakud seoses ptasiendi testamendi rakendamisega kliinilises praktikas ja neid mõjutavad tegurid - kirjanduse narratiivne ülevaade.* (Graduating Thesis). Tallinna Tervishoiu Kõrgkool, Tallinn. 18.

scientific articles used in this work. What matters is who does this, the quality of the information, and how it is communicated to the patient. Because each person's will, and therefore the living will, is unique. Here, exhaustive and evidence-based information helps people decide what to consider when writing living will and what to write there. Kruus et al. (2017; 2018) brought out that having enough information also helps to think through all sorts of situations and scenarios with the help of healthcare professionals and close ones and find the exact wording that can be used to write down your will. The obligation to provide sufficient information to the patient was reflected in the legislation of all three countries.

Sufficient and adequate information is an essential precondition for supporting the integrity of patient decision-making, enhancing patients' right to self-determination, and facilitating patient autonomy. Studies among oncology palliative care patients showed that patients who discussed their preferences with their oncologists were more frequently involved in the decision-making process and more likely to receive a treatment that concurred with their preferences. Overall, these patients were infrequently referred to an intensive care unit, more frequently re-received palliative or hospice care, and more commonly died at home[116]. In Italy, the Law 219/2017 sets out the terms of the patients receiving information. Article 1 of mentioned law focuses on determining the discipline of informed consent, stipulates that every person has the right to know his or her personal health conditions and to be informed in a complete, updated, and understandable way regarding the diagnosis, prognosis, benefits, and risks of the diagnostic tests and indicated health treatments, as well as regarding possible alternatives and the consequences of any refusal of the medical treatment or the diagnostic assessment.[117] The sections of Finnish and Estonian legislation providing for patient information have the same content. Estonian legislation also stipulates that, at the request of a patient, the healthcare provider must provide this information in a form that can be reproduced in writing[118]. The Finnish Act on the Status and Rights of Patients article 5 also states that information may not be provided against the patient's will or if it is clear that it would pose a severe risk to the patient's life or health. The principle of self-determination can also be found in the legal provisions concerning patient will in all three countries covered. As self-

[116] Laryionava K, Winkler E.C. (2019). Patients' preferences in non-curable cancer disease. *Oncology research and treatment*, 42 (1-2), 31.
[117] Bolcato *et al. Supra nota* 72, 184.
[118] RT I, 04.01.2021, 19. §766 (1): "The provider of health care services shall inform the patient of the results of the examination of the patient and the state of his or her health, any possible illnesses and the development thereof, the availability, nature and purpose of the health care services required, the risks and consequences associated with the provision of such health care services and of other available health care services. At the request of the patient, the provider of health care services shall submit the specified information in a format which can be reproduced in writing."

determination in care can be more accurately expressed as the right to be involved and thus to decide on matters concerning one's own life and care, the patient should give the consent and refusal of consent under the laws of all three countries.

There are differences between the laws of the three countries. In Estonia, the patient will be derived from the Law of Obligations Act provisions, while in both Finland and Italy, it is provided for in separate legislation. In Finnish law, we find these provisions in The Act on the Status and Rights of Patients, in Articles five and six, includes both informed consent and the patient's right to self-determination. The Finnish law was adopted as early as 1992, but it is less detailed than Italian law. In Italy, the patient will be provided for in a separate law from December 2017 (entered into force in 2018). In this law the form and substantive details of the patient's consent and desire to live are clearly set out. Also the findings showed that this new legal instrument supports both sides: the patients and the medical staff. There are separate provisions for informed consent, to establish clear rules for consent and refusal of any medical treatment, the form of informed consent. Also, to establish the role of public and private healthcare facilities in the training of healthcare professionals in relationships and communication with the patient. The separate provisions for patient will and pain therapy, prohibition of unreasonable obstinacy in treatment, and dignity at the end of life establish rules on the value of prior requests placed by patients before becoming incapable of expressing their will and avoiding non-beneficial treatments and disproportionate means in end-of-life care. Italian law is the clearest and most recent of the three and only provides the patient's will in essence and also informed consent.

The living will should set out in as much detail as possible but not over-regulated. Including all other aspects, the risk of criminal prosecution of a healthcare professional must be minimized, the provision in the current Penal Code without assistance may lead to a medical decision on the spot if the details of living will leave room for dispute.[119] Regarding Italy, the researchers point out that one of the main advantages of this law is that it provides a kind of guarantee: if a patient refuses any treatment or even asks a doctor to give up treatment, the doctor's behavior is legitimate and guarantees the patient's rights[120]. The doctor is also not obliged to comply with the patient's declared wish for treatment, which is contrary to current legislation. The legitimate behavior

[119] RT I 2001, 61, 364. §124 (1): "Knowing refusal to provide assistance to a person who is in a life-threatening situation due to an accident or general danger, although such assistance could be provided without endangering the person providing assistance, is punishable by a pecuniary punishment or up to three years' imprisonment."
[120] Di Paolo *et al. Supra nota* 60. 2.

should also be stated very clearly in Estonian legislation. When the next episode of the refusal to assist by the doctor is confirmed, article 124 of the Penal Code in Estonia applies, with a maximum term of three years imprisonment.

The form of the patient will is not regulated in Estonian nor Finnish legislation but in Italian legislation. Still, even if regulations exist, questions may also be raised in terms of form, such as how to deal with jewelry that patients occasionally wear. For example, medallions are engraved with "not to revive." Can they be considered as a patient request? Can this also be considered a resuscitation ban? This category also includes personal diaries and other written notes describing the person's wishes. The case of Englaro, set out above, makes it clear that as many situations as possible must be taken into account. Here, however, there is a risk of over-regulation, which will be an obstacle to implementing this regulation.

As said above, in Finland, the exact form of the living will is not defined. There are several ways and ready-made models for submitting a declaration of intent as brought in Appendix 1. There find several sample forms online. The patient's will is usually in written form**,** with the author's handwritten signature and date. It is valid without witnesses, but there is the recommendation to use two witnesses who do not belong to a family or close relative. The presence of neutral witnesses reduces the risk that the production of such a document would be a forced act or that the document would be forged. A written request for treatment may be an appendix to the health report and may accompany the patient. In the latter case, the medical statement must state the intention to treat. According to the law, a person may also express his or her will also orally. In this case, it should be recorded by writing in the patient's medical report and, if possible, signed or otherwise verified. In contrast, in Italy, the living will form set out in Article 4 subsection 6. The document must be drawn up by public deed, by authenticated private writing, or by private writing personally delivered by the settlor to the registry office of the municipality of residence, which provides for the annotation in a special register. This law also allows different devices for expressing the patient's will. If the patient's physical condition does not allow to draw a written form, the living can express through video recording or devices that allow the person with disabilities to communicate. Notarial certification is not provided for in Italian law.

There is currently no formal requirement for a patient`s will in Estonia, although this provision would be needed. End-of-life situations are delicate, and it is appropriate to provide in the form of a patient will to avoid possible disputes between the parties. Kruus et al. (2017) point out that the

effectiveness of a patient's will and compliance with the patient's actual will is likely to be greater if it is drawn up individually[121]. Adequate and sufficient information from healthcare professionals contributes to this, but the patient will still be a legal document, so it is reasonable to document the situation discussed with a doctor through legal aid. The possible forms should also be considered. The most certain would probably be a written notarial, but at the same time, a reasonable solution can be found for people with disabilities. It is possible to follow the example of Italian legislation that allows compiling the living using various devices that allow a person with a disability to communicate. It is also crucial that the legislation created is well understood and supports healthcare professionals' daily work. Based on the example of Italy, we can see that this may be somewhat difficult at first, making doctors more careful. As mentioned above, account must be taken of the risk that a patient's will may be forged. People may also be forced to write it under the pressure of a threat, or the person may write it in a state of indecision, not following the actual will. In order to protect patients and provide the necessary assurance to the healthcare provider, it is essential to lay down formal requirements for the patient's will.[122] Attention should also be paid to treating the symbolism (jewelry, tattoos) that patients have or carry with them.

The living will is a vital document and can be considered a risky expression of will. Therefore, the involvement of a notary and a written notarial formality could be considered to ensure full validity; it would significantly mitigate the above risks. For example, in Switzerland, which is not a member of the European Union, but the patient will be actively used, the doctors can refuse to follow advance directives if they doubt their validity[123]. The purpose of involving a notary in drawing up a patient will be to establish, unambiguously and definitively, the content of the declaration of intent. The notary's role is to increase the protection of the rights of individuals, and the legal certainty of individuals ensures the stability of relations between persons and thus prevent litigation burdensome for the courts. The requirement for notarial certification also has a probative function and, in the case of typically risky declarations of intent, a warning function - a function of ensuring discretion.[124]

In its judgment of 28 January 2015, the Supreme Court of Estonia has highlighted the functions of notarial certification of a transaction:

[121] Kruus *et al*. (2017). *Supra nota* 4, 334.
[122] *Ibid.*, 336.
[123] Escher *et al*. *Supra nota* 17, 637.
[124] Kruus *et al*. (2017). *Supra nota* 4, 336.

- The notary shall ascertain the validity of the circumstances essential for the conclusion of a valid transaction, including the identity of the parties to the notarial act;
- the notary warns the parties about the risks arising from the applicable law;
- the notary explains to the parties impartially how to achieve the result that best meets the will of the participants in the transaction and the consequences of the requested transaction;
- the notary formulates the declaration of intent and the notarial deed containing his or her explanations, ensuring that they are unambiguous;
- as a competent official, the notary certifies the content of the declaration of intent and the verified circumstances;
- the notary archives the original of the notarial deed in the office allows to examine it and receive copies thereof.[125]

Here, the requirement of notarization of a declaration of intent may be aimed at protecting the counterparty from reckless actions and having an advising function.

Based on the above, we can see that the problem of the temporal validity and renewal of the living will has also been raised regarding all three countries. Due to advances in medicine in Finland, there are no clear rules about how long exactly the living will can be temporally valid, however, by the law the date of the inspection of the document, also the change or the cancellation should be recorded. Nor the temporal validity provided for in Italian law. Thus, it can refer as a bottleneck in their legislation. The legislation of both countries mentions the possibility of withdrawing consent at any time. Although there is no requirement in Finland for a patient's will to be valid for a while, it is recommended that the compiler review this document and, if necessary, amend it no later than ten years after it has been drawn up, in the light of medical developments. As said, the inspection date and the change or cancellation dates should be recorded by law. Also, when destroying the documents of a service event or service unit, an entry in the archives must be left about the destruction. In these situations where it is suspected that the patient's statement of intent has changed, the document's legitimacy may be weakened, and the interpretation of the Patients' Law is contradictory to the situation. In such a case, it may ultimately be the responsibility of close relatives and other decision-makers to prohibit and authorize treatment. Estonian legislation also does not specify the validity period of the patient's will.

[125] RKTKo 28.01.2015, 3-2-1-141-14. 31-32, p31-32.

However, regular updating of a vital document is essential as medical opportunities evolve at the speed of light. Ten years ago, these opportunities were now replaced by new ones. A digital facility has been created for the living will to upload and store in Estonia, Finland, and Italy. Therefore, it would probably allow regular reminders to update the document, as in the case of a passport or driving license expiring. Also all actions performed on a living will leave a digital imprint, which is also required by data protection regulations. Such a log allows possible malicious and misconduct to be identified if necessary.

As a remark that there is in Estonian Law of Obligation also a violation of the Oviedo Convention in the case of patient consent; convention provides that the patient may freely withdraw his consent at any time, while Estonian law uses the term within a reasonable time, provides that the patient may withdraw his or her consent within a reasonable period after granting consent. Although the temporal validity of the patient will from the perspective of renewal not be determined in Italy and Finland, can conclude that it is essential to set it out clearly in Estonia. Again, when faced with end-of-life decisions, physicians have to make decisions according to the current state of medical science. Outdated documents are a stumbling block in this process.

Based on the practice of Italy and Finland, it can be argued that Estonia needs a separate regulation of the living will, the law which set out the substantial requirements, form and the temporal validity of it. A simple example is also the search results from the vastness of the Estonian language Internet. When entering the term "living will" results in page-by-page statements from doctors, lawyers, and pastors confirming this need. As said, although the current legal system does not prevent the patient from drawing up a living will and does not consider it to be individual, at the same time, there is no relevant regulation that solves the main problems related to the use of a living will. The Estonian Medical Association and the Ministry of Social Affairs have discussed the living will for two last decades, seeking to create a societal debate. A working group has been set up at the Estonian Ministry of Social Affairs, which establishes a regulation concerning the patient's will. The goal is that in 2023, patients will be able to register their living will in the digital system. The findings from this work would draw attention to existing but avoidable bottlenecks.

CONCLUSION

The legal concerns are possible barriers to implementing patient will routinely, so clear legal bases are essential and how important it is to bring this knowledge to those in need. Based on the above, we can see that the legal basis for drawing up a patient's will in Estonia has been created and exists. The form and storage of the document and the temporal and substantive definition turn out to be bottlenecks. Regarding Estonia, I would outline three main aspects compared to Italy and Finland. First of all, given the developments in this field, Estonia would need separate legislation to regulate the patient's will, as done in Finland and Italy. In light of the previous, it would be easier to introduce a patient's will if there were a separate legal provision for that purpose. The separate legal instrument supports involved parties. In addition, the patient will improve the quality of life in the last days, involve more participation in the treatment process, and ensure self-determination; it also may reduce medical care costs.

Next, the formal requirements need to be specified in addition to the current legal bases, which address vital patient elements, such as informed consent and the guarantee of the right to self-determination. A written form with witnesses would be preferable; this would ensure the transparency of the document drafting process and would also reduce the risk of coercion or possible forgery. The form of a video could be considered, as there are many medical conditions where a person cannot write on their own—also, the measures to prevent counterfeiting and human pressure. In the drafting process of the patient's will, it would be valuable to provide for the role of both doctors and lawyers in who provides what information and help and in what form. Regarding the formative norms, the involvement of a notary and a written notarial formality could be considered; this would reduce the risk of counterfeiting and forced drafting. The requirement of notarization of a declaration of intent may protect the counterparty from reckless actions and as has an advising function.

Besides the right to withdraw the consent at every time, the temporal validity of the document would also need to be specified, that outdated documents do not become a stumbling block in treatment decisions. In the light of the rapid development of treatment options, it would be prudent to set an optimal period of validity, after which the patient will need to renew. People must always have the possibility to keep their health decisions continuously up to date. To ensure that the document is always updated at the required time, various IT technologies can be used.

Notifications in SMS to the phone or e-mail to the mailbox. Automatic document renewal may also be considered.

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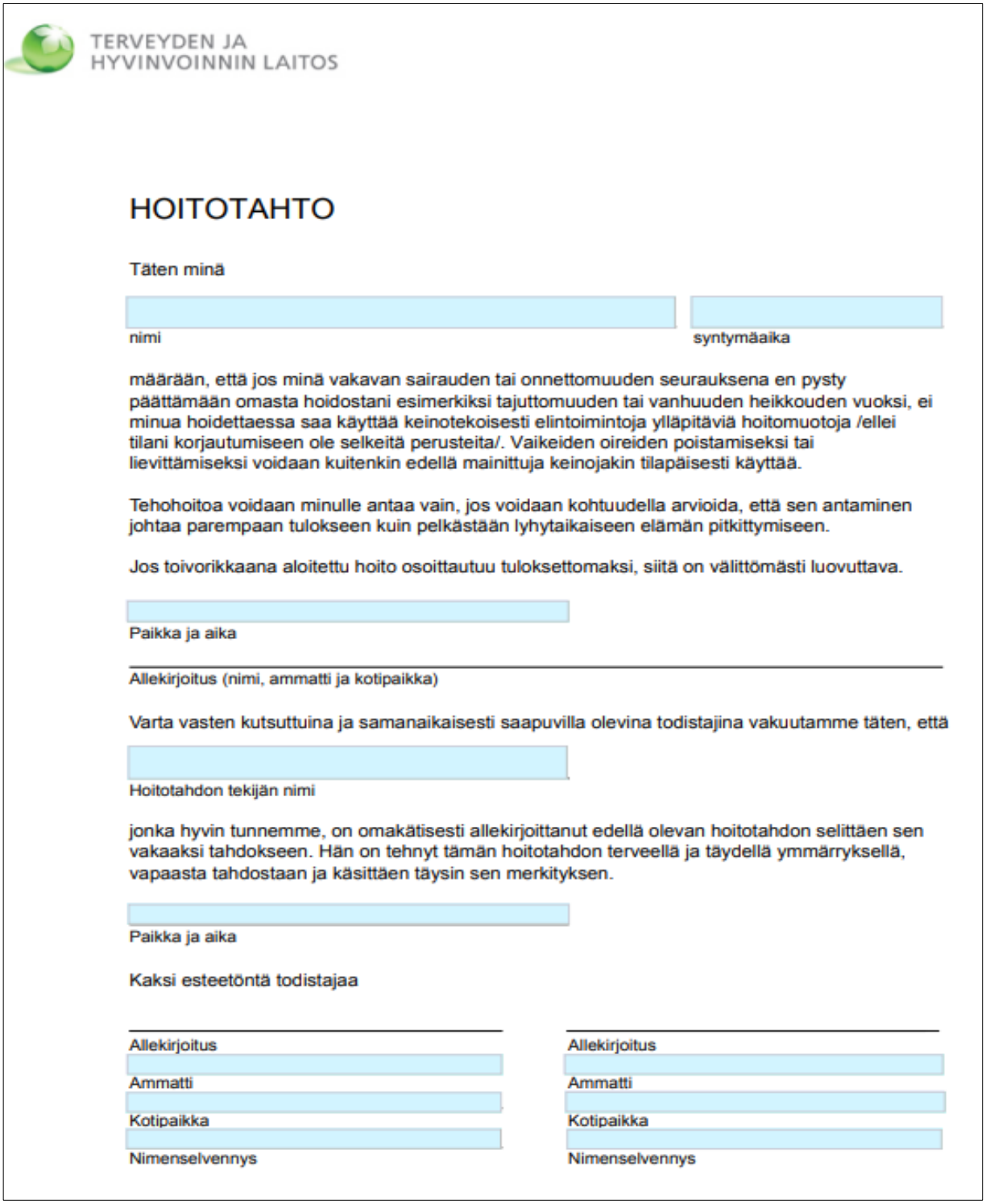
APPENDICES

Appendix 1. A sample form of patient will by Department of Health and Welfare of Finland[126]



TERVEYDEN JA HYVINVOINNIN LAITOS

HOITOTAHTO

Täten minä

nimi | syntymäaika

määrään, että jos minä vakavan sairauden tai onnettomuuden seurauksena en pysty päättämään omasta hoidostani esimerkiksi tajuttomuuden tai vanhuuden heikkouden vuoksi, ei minua hoidettaessa saa käyttää keinotekoisesti elintoimintoja ylläpitäviä hoitomuotoja /ellei tilani korjautumiseen ole selkeitä perusteita/. Vaikeiden oireiden poistamiseksi tai lievittämiseksi voidaan kuitenkin edellä mainittuja keinojakin tilapäisesti käyttää.

Tehohoitoa voidaan minulle antaa vain, jos voidaan kohtuudella arvioida, että sen antaminen johtaa parempaan tulokseen kuin pelkästään lyhytaikaiseen elämän pitkittymiseen.

Jos toivorikkaana aloitettu hoito osoittautuu tuloksettomaksi, siitä on välittömästi luovuttava.

Paikka ja aika

Allekirjoitus (nimi, ammatti ja kotipaikka)

Varta vasten kutsuttuina ja samanaikaisesti saapuvilla olevina todistajina vakuutamme täten, että

Hoitotahdon tekijän nimi

jonka hyvin tunnemme, on omakätisesti allekirjoittanut edellä olevan hoitotahdon selittäen sen vakaaksi tahdokseen. Hän on tehnyt tämän hoitotahdon terveellä ja täydellä ymmärryksellä, vapaasta tahdostaan ja käsittäen täysin sen merkityksen.

Paikka ja aika

Kaksi esteetöntä todistajaa

Allekirjoitus
Ammatti
Kotipaikka
Nimenselvennys

Allekirjoitus
Ammatti
Kotipaikka
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[126] Retrived from https://thl.fi/documents/920256/1449649/Hoitotahto_2015_04_17.pdf/b64267af-e05d-4cbd-80c8-91c8109aebf3, 01 November 2021.

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