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PROTECTION OF HUMAN DIGNITY AT THE END OF LIFE OF THE TERMINALLY ILL: ETHICAL AND LEGAL CONSIDERATIONS ABOUT THE LAW AND POLICY ON ADVANCE DIRECTIVES IN LITHUANIA

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ABSTRACT

Recently amended legal regulations established the opportunity of application of advance directives for terminally ill patients in Lithuania. Provisionally, advance directives should enhance patient's rights while making complex end of life decisions, however,

implications for legal and moral responsibility to empower a patient's autonomy are not clearly established yet. The article discusses the legal and ethical justification of implementation of advance directives and, in their absence, the surrogate decision making for the best interests of the patient and the best representation of the patient's will. The reflections of recent empirical studies indicate the importance of a patient-centered approach that can provide the hints for harmonization of the national legal system, including a supportive decision-making culture, raising public awareness and confidence, more effective professional communication, and broader public involvement into end-of-life deliberations. Analysis of legal and ethical arguments imposes the conclusion that the specific question of respect of dignity in the end of life is not just a problem of health care management or the quality of health care services, but a fundamental challenge of human rights that should be discussed at the policy decision making level. Overall, we assume that application of advance directives should be elaborated in accordance with the case-law of the European Court of Human Rights (ECHR), the ideals of welfare society, and other national laws as well as public interests.

KEYWORDS

Human rights, human dignity, end of life, health law, advance directives, Lithuania

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INTRODUCTION

The imperative of protection of human dignity remains one of the major notions in current bioethics discourses and in the International Human Rights Law context.[1] Based on classical liberalism the concept of human dignity highlights the request for respect of individual autonomy assuring freedom of decision making at least in the realms of private life. However, the implementation of this notion is particularly challenging in the end-of-life decision making when application of fundamental rights of individuals (patients) could interfere with their individual wellbeing. Despite longitudinal attempts of different scholars – philosophers, sociologists, lawyers, health care professional or politicians - to find out effective political measures and legislative instruments for the management of the end-of-life decision, it remains one of the most debated, yet inconclusive issue at the social, political, and professional level.[2]

The request of protection of dignity of terminally ill patients and assurance of their autonomous choices in health care induced several ethical, legal, and cultural challenges for practitioners, caregivers, health care administrators and policy makers worldwide. They could be generalized into the question of what the right ways are to treat the patients at the very specific context of the end of life. Traditionally, different opinions are based on different arguments of medical ethics and law. However, various studies and surveys show that the relevance of this issue as well as the perception of it in society (and consequently, possible choices of the behavioural model), are changing.[3] Therefore, on the one hand, decision-makers need to respond to the changing attitudes and preferences of society, but on the other hand, certain decisions and possible or prohibited choices must be evaluated very carefully and widely debated for the public to trust and use them in practice. Accordingly, the legitimation of a patient's right to refuse the treatment has significantly questioned the fundamentals of moral and legal provisions to save the patient's life and to do everything possible to uphold the principle of respect for life.[4]

The legal regimes (currently in force in the European Council member states) that establish various possibilities for self-determination are based on respect for the principle of human autonomy, which implements the human right to liberty and free self-determination. In the countries that have legalized euthanasia and assisted

[1] Roberto Andorno, "Human dignity and human rights" (2021): 45-46 // https://www.academia.edu/8973976/Human_Dignity_and_Human_Rights.
[2] Susan M. Wolf, Nancy Berlinger, and Bruce Jennings, "Forty years of work on end-of-life care—from patients' rights to systemic reform" (2015) // DOI: 10.1056/NEJMms1410321.
[3] *Ibid*.
[4] Christian Neuhäuser, "The Right to a Dignified Life on the Relation of Respect, Human Rights, and Justice"; in: *The Human Right to a Dignified Existence in an International Context* (Nomos Verlagsgesellschaft mbH & Co. KG, 2019).

suicide procedures, the definitions and conditions of the latter are quite similar, and the case law of the ECHR has undoubtedly contributed to this. In order not to raise questions about legal conflicts in the assessment of the protection of the right to life and the provisions on the application of severe penalties for attempted human life, the criminal law norms are adjusted accordingly. It should be noted that the decisions and good practices of some states show that it is also in favour of establishing palliative care arrangements in the 'package' of these policy decisions and legal provisions. Only in the totality of such complex solutions and measures can we hope to create a legal environment that enables not only human autonomy, but also the principle of dignity. One of the ways to deal with issue is the idea of "living wills" (hereinafter we discuss this type of document as "advance directive"), which has been increasingly implemented in legal systems as the instrument for protection of autonomy of the terminally ill.[5]

The aim of this paper is to analyse the discrepancies between normative legal provisions and real practices concerning protection of dignity in end-of-life care while applying advance directives in Lithuania. We assume that some provisional recommendations can be extracted from the legal and ethical analysis of dignified care.

The paper is based on a systematic document analysis and employs the methods of logical interpretations of the facts. This contribution is addressed to those interested health care professionals, lawyers, and policy decision makers as well as scholars in humanities and social sciences.

First we will discuss how the limited autonomy of terminally ill patients can be enhanced and their end-of-life decision making may be improved on the basis advance directives. The case studies from the practice of the ECHR and some data from recent empirical studies will be analysed and argued.

In the second part, some problematic aspects of proxy decision making issues and distinguish between possible ways of implementing the decisions of a terminally ill patients are revealed.

1. REGULATION ENHANCING AUTONOMY AND SELF–DETERMINATION AT THE END-OF-LIFE OF TERMINALLY ILL PATIENTS

Undoubtedly, most of terminally ill people face the moment of the end of life in health care, nursing, or assisted living facilities as patients, who are in in need of receiving various kinds of medical services. Healthcare tends to be an increasingly

[5] WMA, "The World Medical Association Statement On Advance Directives ('Living Wills')", by the WMA General Assembly, Helsinki (2003) // https://www.wma.net/policies-post/wma-statement-on-advance-directives-living-wills/.

regulated practice in order not to risk the perils of self-regulation; nevertheless, exactly self–regulating practice is what can sometimes be observed in the healthcare services concerning end of life care.

One of the most important problems facing a terminally patient is that once in a whirlwind of medical procedures, patient might lose the autonomous ability to decide and interrupt the accelerated process of treatment, which, at the end becomes only supportive and not leading to any health improvement. A dying person becomes no longer a "dying man" but a "sick person with an incurable disease" with limited competence to decide upon her or his interests. Dying with dignity is the implementation of personal values and preferences, it is a subjective experience and also a influenced by others; it signifies a dying process with the following characteristics: dying with minimal symptom distress and limited invasive treatment, being human and being self, maintaining autonomy and independence to the greatest extent, achieving existential and spiritual goals, having self-respect and being respected by others, having privacy, maintaining meaningful relationships with significant others, and receiving dignified care in a calm and safe environment. Health professionals should normally respect the patient's will only if the patient "can articulate their values and goals, identify what treatments would align or not align with those goals, and those wishes could be documented or shared with a trusted surrogate decision maker," even if their preferences "would avoid unwanted treatments".[6] For instance, recent qualitative studies revealed in Lithuania "that patients are likely to have something to express at the end of life and professionals can enhance dignity by sincerely hearing and responding. This finding might not be so significant if participants did not identify it so often by its absence. Hearing patients in this sense can occur while dealing with pain or planning or adjusting to institutional care."[7]

The need of self-determination and decisions about the end-of-life context is also usually linked to the impact of social factors such as global aging, increasing life expectancy, or the emergence of new technologies or superficial medicines to dramatically prolong human life. Diseases such as Alzheimer's disease or degenerative disease or cancer, have led to discussions on new aspects of quality of life, leading to the formulation of the concept of advance directives.[8] The patient's right to refuse the treatment or to ask for help to die significantly challenged the traditional rule of medical ethics and law to save patient's life and do everything

[6] Rūta Butkevičienė, *et al*., "Being Heard: A Qualitative Study of Lithuanian Health Care Professionals' Perceptions of Dignity at the End-of-Life," *Medicina* 57(12) (2021): 1318.
[7] *Ibid*.
[8] David Gabes Miller, Rebecca Dresser, and Scot YH Kim, "Advance euthanasia directives: a controversial case and its ethical implications," *Journal of medical ethics* 45(2) (2019).

possible to uphold the principle of respect for life.[9] Individual self-determination and choice in decision-making is one of the essential notions in medical ethics, but unlike in the concept of individualistic autonomy, relational autonomy emphasizes the moment that occurs when is the result of a process involving the patient and the family.[10] Another problem is that "decisions near end of life are not simple, not logical, and not linear. They are complex, uncertain, emotionally laden, and can change rapidly with changes in clinical conditions."[11] One of the ways to deal with issue is the idea of the advance decisions, which have been increasingly implemented in the legal systems to keep with recognition of individual autonomy in the context of patient rights and a patient-centered approach in care and nursing.[12] Because the situations where principle of autonomy should be applied in the end-of-life decisions are evidently exceptionally complex and sensitive, inquiring into the peculiarities of legal regulation we first look at the applicable principles and rules coming from the framework of human rights.

As the member states of the Council of Europe are sovereign and pursue common objectives by signing international conventions, the common or even harmonized legal regime providing for the common measures and procedures for the end-of-life decisions is still not agreed upon, or, even not even possible due to cultural, religious, and other differences between the states.[13] A majority of central and eastern European countries including Lithuania have developed the legislation process of advance directives in accordance to European human rights framework. However, some recent studies have shown that its application may encounter such issues as the compatibility with other legal regulations, cultural acceptance, miscommunication between physician and patients and, finally, the differences among patients', public and professionals' attitudes on advance directives.[14]

The one applicable requirement from the framework of human rights in the application of biomedicine practices is general rule in the art. 5 of Oviedo Convention (The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Council of Europe, 1997), that any intervention in the health field may only be carried out only after the person

[9] Christian Neuhäuser, *supra* note 4.
[10] Janet Delgado, "Re-thinking relational autonomy: Challenging the triumph of autonomy through vulnerability," *Bioethics Update* 5(1) (2019).
[11] R. Sean Morrison, "Advance directives/care planning: clear, simple, and wrong," *Journal of Palliative Medicine* 23(7) (2020).
[12] WMA, *supra* note 5.
[13] Roberto Andorno, "Regulating Advance Directives at the Council of Europe", *Queen Mary studies in international law* (2012) // https://doi.org/10.5167/UZH-68937.
[14] Laraine Winter, "Patient values and preferences for end-of-life treatments: are values better predictors than a living will?" *Journal of palliative medicine* 16(4) (2013); Stefana Moisă, *et al*., "Advance directives in Romania and Lithuania," *Studia Universitatis Babes-Bolyai, Philosophia* 64.1 (2019); Eimantas Peicius, Aurelija Blazeviciene, and Raimondas Kaminskas, "Are advance directives helpful for good end of life decision making: a cross sectional survey of health professionals," *BMC medical ethics* 18(1) (2017) // DOI: 10.1186/s12910-017-0197-6.

concerned has given free and informed consent to it and "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."[15] This rule corresponds with one of the most important provisions of health care ethics, namely, the respect for the patient's autonomy and, accordingly, the patient's right to choose in making decisions about health care in health care is realized by legitimizing the concept of patients' rights. Among other things, this includes the possibility for patients to refuse medical decisions that may be considered contrary to the patient's values, their culturally determined (e.g., religious) beliefs, customs, and traditions.[16] Accordingly, on the issues of decisions about the end of life, each state has a wide variety of legal regulations, both permitting or prohibiting one or other way to control the moment of the end of life. Therefore, it is worth inquiring into the decisions of the ECHR on the end-of-life care and self-determination, to clarify the requirements and limits set by this court, when assessing whether member states, having established one or another legal regime, do not violate human dignity and autonomy, as well as the rights and freedoms provided for in the European Convention on Human Rights and Fundamental Freedoms.

The case of Pretty vs. the United Kingdom[17] was the first complaint relating to an advance decision on the end of life and the best interests of the patient, which ECHR accepted to hear. The court did not support the arguments that the right to life, in a situation where a person does not have the opportunity experience a quality of life, may be restricted in the sense that a person, by the autonomous decision, acquires the right to die, and the person assisting him/her in committing suicide should unequivocally avoid legal liability. However, in the issue we are discussing here, it is particularly important to mention the court's recognition that person's decisions aimed at avoiding the loss of dignity at the end of life should be considered as the part of private life of a person. However, in this and in several subsequent decisions, the court establishes that each member state of the Council of Europe has a discretion as to the extent to which the right to privacy concerning end-of -life decisions will be determined by national legal regulation, applying the principles of proportionality and balance between human rights and the public interest.

Later, as the diversity of complaints regarding end-of-life decisions increased, the ECHR examined the issues related to the passive inaction (abstinence from the action) meant to accelerate the death of a seriously and incurably ill patient who is no longer able to express any kind of preference or consent. Such practice is

[15] *The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*, Council of Europe (1997).
[16] *Ibid*.
[17] *Pretty v the United Kingdom*, 2346/02, ECHR 2002.

explained differently in the discussions concerning passive euthanasia and refusal of treatment (if the life support procedures are classified as medical treatment in the certain state). The use of different concepts might prevent mutual understanding and brings a lot of uncertainty in clinical practice and is therefore to be considered harmful in general.[18] It is important to emphasize the fact that in cases of abstinence from the potentially lifesaving healthcare services the ECHR assesses whether the state has a comprehensive legal regulation of such a procedure, which would not violate the human right to life established in the Article 2 of the European Convention on Human Rights and Fundamental Freedoms. Account must also be taken of whether the patient's previously known will and the preferences of patient's family should be considered when deciding on the termination of medical services, and whether it is possible, using certain legal procedures, to appeal against or examine the relevant decisions of the health professionals. These criteria, formulated in the Lambert v. France[19] case, have also been applied in the recent Gard v. the United Kingdom case.[20] In these cases, the ECHR does not expressly refer to the balance between the application or non-application of the healthcare services in futile treatment situations and the individual's autonomy, dignity, or to the discretion of the family members to influence decisions, again, because of the lack of consensus among the member states of the Council of Europe on this issue. So, the essential requirement which can be derived from the international human rights legal framework is the necessity of comprehensive legal framework that both prevents violations of the human right to life but protects autonomy and privacy regarding the end-of-life decision making, with the accessible complaint and review procedures.

Significant differences in the regulation, which allow for advance care planning of the aspects for the provision of health care services at the end of life, even in neighbouring countries, raise questions about the compliance of one or another legal regulation with the general agreements on the protection of human rights and freedoms. In 2014, the Council of Europe issued guidelines[21] for decision-making in end-of-life situations. It is not a legally binding instrument, but it is undoubtedly a useful tool for discussing and deciding on the establishment or amendment of national regulations, taking into account the indisputable fact, that the challenge of any healthcare decision at the end of life is to ensure that the autonomy and overall dignity of the patient are respected, and also that a balance is established between

[18] This problem is out of the topic in this article and just presented for illustration of the issue.
[19] *Lambert and Others v France*, 46043/14 ECHR 2015.
[20] *Gard and Others v the United Kingdom*, 39793/17 ECTHR 2017.
[21] *Guide on the decision-making process regarding medical treatment in end-of-life situations*, Council of Europe (May 2014).

the protection of life and the right of the individual not to suffer as much as is possible in certain situation.[22]

While the first Lithuanian law regarding do not resuscitate directives was inoperable for more than twenty years due to the lack of additional guidelines, and was amended only in 2020, the public discussions together with the scientific research long before showed that the advance directives for end-of-life decisions are necessary for filling obvious gaps in the informed consent and decision-making application in healthcare practice.[23] Since 2020, the possibility to issue the advance directive not to resuscitate in Lithuania was established in the law on the critical conditions and the moment of death of the human being.[24] Currently, the patients may express the written disagreements to be resuscitated in a state of critical condition. Such a decision must be backed up with a conclusion made by the doctors' concilium, stating that the patient's resuscitation would amount to a futile treatment. After this amendment, the legal regulation and subsequent legal acts of the government[25] define the concept of "hopeless resuscitation", which provides that the resuscitation of a patient in a critical condition "for whom the treatment of the disease does not exist or has already been exhausted and there are objective signs of irreversible damage to one or more organ systems, for which there is no medically justifiable chance of improving or restoring the patient's vital functions prior to critical condition,"[26] is considered hopeless (or futile).

The legal debate raises questions about the lack of coherence between the legislation governing possible actions/omissions in the implementation of patients' end-of-life decisions and the legal responsibility for such actions.[27] However, the current legal regulation is comprehensively defining the situations in which the patient with decision capacity, or his relatives may decide that resuscitation procedures should not be applied in the critical condition. The essential conditions for the implementation of this decision are the hopeless state of health of the patient and the decision of the doctors' Concilium that the patient's resuscitation would be hopeless (futile). The executive documents supporting the implementation of the law provide the forms of advance directives that can be signed either by the patient, or his relatives.

[22] Roberto Andorno, David M. Shaw, and Bernice Elger, "Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues," *Medicine, health care and philosophy* 18(1) (2015).
[23] Eimantas Peicius, Aurelija Blazeviciene, and Raimondas Kaminskas, *supra* note 14.
[24] *Republic of Lithuania Law on the Establishment of Death of a Human Being, and on Critical Conditions* (25 March 1997, No. VIII-157).
[25] *Republic of Lithuania Minister of Health Order on the Establishment of the Standards of Resuscitation* (31 August 2011, No. V-822).
[26] *Ibid*., Art. 2
[27] Kristina Astromskė, *et al*., "Sunkiomis ir nepagydomomis ligomis sergančių asmenų orumo apsaugos reikalavimas – tarptautinės ir nacionalinės teisės normos bei praktiniai jų taikymo aspektai," *Law Review* 23, No. 1 (2021) // https://doi.org/10.7220/2029-4239.23.1.

As the decisions of the ECHR emphasize the need to establish an accessible complaint procedure, in Lithuania decisions regarding implementation of advance directives not to resuscitate can be appealed in accordance with the procedures established by the Law on Patients' Rights and Compensation for Health Damage of the Republic of Lithuania[28]. However, the time limitations provided for therein (e.g., 20 working days for the examination of the complaint) raise reasonable doubts about the effectiveness of this procedure in cases of sometimes urgent decisions regarding the end of life of a seriously ill patient. Even more uncertainty about ensuring the implementation of end-of-life decisions is caused by the active involvement of relatives in decision-making according to the laws establishing patients' rights. Relatives in Lithuania may give informed consent or disagreement not only when the patient is legally declared incapacitated by the court, but also in cases where the healthcare professionals regard the patient as unable to make the necessary and, although not urgent, but still immediately necessary decisions due to his/her state of health. In sensitive situations involving the death of a family member, misunderstandings and contradictions between health care professionals and relatives often arise, and the possibility that relatives may disregard the autonomously expressed will of the patient is not excluded.[29] Thus, although the political decision implemented in Lithuania is to allow the advance directives on non-resuscitation, it is necessary to find out what reasons may prevent their proper implementation.

Therefore, the questions are: who exactly is responsible and based on what criteria should there be responsibility for the final decision on further (non-) treatment or procedures. It is not uncommon that participants of the end-of-life decision making depart from reason and emotion dividing medico-legal perspectives, calling into question the previously made advanced directives‘ power to act on behalf of dying patients.[30] There is no doubt that in a sensitive and fragile situation such as end-of-life healthcare, a change in relationships between patients, their families and healthcare professionals is not created solely by legal decisions approved by the authorities. Interviews with caregivers from previously mentioned study also revealed the problem of the acknowledgement by caregiver’s role as surrogate decision makers. In the study, informants addressed these aspects in the following

[28] *Republic of Lithuania Law on the Rights of Patients and Compensation for the Damage to Their Health* (3 October 1996, No. I-1562).
[29] David Kuhl, Matthew B. Stanbrook, and Paul C. Hébert, “What people want at the end of life,” *CMAJ* 182 (16) (November 2010): 1707; Ruth Horn, “Why Should I Question a Patient’s Wish?” A Comparative Study on Physicians’ Perspectives on Their Duties to Respect Advance Directives,” *European Journal of Health Law* 24(5) (2017).
[30] Tanya Zivkovic, “Forecasting and Foreclosing Futures: The Temporal Dissonance of Advance Care Directives,” *Social Science & Medicine* 215 (October 2018) // https://doi.org/10.1016/j.socscimed.2018.08.035.

statements: "In relationship with my beloved one, I think the most important not to impose my understanding, my vision or my desires on behalf of him"; and, similarly, "'Being heard' means that those who are next to the patient are listening to their wishes, trying to consider and fulfil the patient's will, not imposing the proposed division of role." Such a situation according to M. Foucault[31] and G. Agamben[32] could be regarded as particularly tempting for the establishing bio-power and ruling the boundaries between life and death according to institutional, but not an autonomous patient's life view and values.

The legal and moral responsibility to empower the patient's autonomy in cases where the patient is unable to express his or her will, remains open. Who should take a charge to represent the patient's will and best interests - family members, health professionals or maybe other surrogate decision makers? These issues will be discussed in the next section. Even given the fundamental right to life of every human being, it is not necessarily self-evident that decisions should be made by health professionals, as they are not necessarily better representatives of the patient's interests. Similarly, family members may disagree, and their decisions may not be medically justified, especially when it comes to sensitive issues of life or death, e.g., deciding on artificial feeding in a permanent vegetative state, in cases of permanent coma et cetera. So, the ethical and legal imperative to respect patient's rights and consequently respect for patient's will meet the dilemma of how severely or terminally ill patients could be involved in end-of-life decision making so that their autonomy and their best interests were balanced and secured. In this respect, one of the most controversial and intensively debated issues of the surrogate decision making will be discussed.

2. SURROGATE DECISION MAKING

Lithuanian law on Human Death and Critical Conditions of the Person allows advance directives to be implemented only when there are clinical findings that at least one organ system is failing and there is no evidence-based prognosis for the recovery. It must be decided by at least three medical doctors before the advance directive not to resuscitate can be implemented in case of emergency. This scenario is in line with the ethical and legal principle of a person's autonomy, while assuring that the patient's advance directive will be implemented on certain conditions and not revoked by anyone else but the patient himself. But the additional condition of the same law allows healthcare practitioners to ask for the decision of family

[31] Michel Foucault, *The History of Sexuality* (London: Penguin, 1990), 136-138.
[32] Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford: Stanford University Press, 1995), 165-166.

members (relatives determined by the Lithuanian Civil Code if certain person is not appointed as a proxy) if the patient did not sign an advance directive prior the terminal condition when personal decision becomes impossible. Such situation becomes much more uncertain because of few conditions: first, the decision is suggested by the health professionals, and this suggestion may be influenced by certain attitudes towards the possibly futile treatment or further outcomes of resuscitation.[33] Second, the prior will of the patient is uncertain, and there is probability that patient consciously was against signing an advance directive with the purpose of being resuscitated in any condition and third, when the surrogate decision is suggested, especially not by appointed proxy, but by standard line of relatives – the selfish reasoning for the final decision may not be avoided.

We believe that the requirement of respect for human dignity and autonomy in the provision of health care is not feasible without the establishment of the primacy of the human will, in whatever form. Whatever model and scope of expression of will is chosen in a country, the Council of Europe notes that prior declarations of will can be seen as essential tools in a general stakeholder debate. Although the changed legal regulation in Lithuania provided an opportunity to express the will regarding the non-application of certain healthcare services (resuscitation) at the end of life, it should be noted that such a decision is possible only regarding the measures applied when the person is in critical condition described by the law. The possibility of any other advance planning on termination life-support measures, which may be applied both before and immediately after resuscitation from a critical condition, has not yet been clearly established. According to the Law on Patients' Rights and Compensation for Health Damage of the Republic of Lithuania[34], any healthcare service provision requires the consent by the patient or his/her proxy; accordingly, in the absence of consent, no health care services may be applied except for emergency care (including resuscitation). Since the forms for the patient's informed consent that meet the requirements approved by the Ministry of Health of the Republic of Lithuania are routinely used, it is unclear in what form and according to what procedure the disagreement to continue life support of the patient by himself or his family should be expressed, especially because this decision may accelerate the death of the patient. Moreover, the end of life decisions are not always logical, and not linear, but

[33] Samuel M. Brown, "Whose Advance Directives Are They, after All?" *The Lancet Respiratory Medicine* 5, No. 6 (June 2017) // https://doi.org/10.1016/S2213-2600(17)30176-5.
[34] *Republic of Lithuania Law on the Rights of Patients and Compensation for the Damage to Their Health*, *supra* note 28.

rather "complex, uncertain, emotionally laden, and can change rapidly in clinical conditions "[35] and, so, need to be developed in accordance to practice.[36]

In Lithuania, the issues of surrogate decision making and advance care planning related to the end-of-life care just started to be analysed empirically. Two recent qualitative studies were conducted by a multidisciplinary team of researchers between November 2020 and May 2021.[37] The samples consisted of 33 family caregivers and 26 health professionals were recruited by using purposeful and snowball sampling techniques. Comparative thematic analysis was conducted to evaluate dignity-related topics from the viewpoints of family members (who played caregiver's role)–and healthcare professionals who were directly involved in care of terminally ill patients. In the context of surrogate decision making for terminally ill patients, at least 3 important issues were identified within the interviews with health professionals and caregivers. The study results revealed that patients, the (non) acknowledgement of caregivers as proxy decision makers role, institutional staff members, and professionals all are subject to the taboo around discussions of death and the effects of "deliberately avoiding death-related topics in communication can be reflected."[38]

The 2014 Council of Europe Recommendations on Medical Treatment Decision-Making in End-of-Life Situations emphasize that respect for individual dignity and autonomy must be at the heart of medical treatment. The guidelines suggested that patients with severe and incurable diseases should be able to express their will when planning healthcare, including at the stage when the patient loses any ability to express their will.[39] Currently, there is no consensus among Council of Europe member states on the possibility of not applying or terminating life support measures, although most states legitimize this practice in one form or another, recognizing that the patient's will must play a decisive role in the decision-making process. It should be noted that any substituted judgment decision should be based primarily on the patient's values. However, many years of clinical experience show that patients in the end-of-life period are vulnerable and may find it difficult to express their views. There are also situations where decisions are made when the patient is no longer able to express his or her will on his or her own. Moreover, in some cases, patients can explicitly express a legitimate desire not to make decisions about their treatment. These recommendations are primarily aimed at healthcare professionals, but at the

[35] R. Sean Morrison, *supra* note 11.
[36] *Europos Tarybos rekomendacijos dėl medicininio gydymo sprendimų priėmimo proceso gyvenimo pabaigos situacijose* (Guide on the decision-making process regarding medical treatment in end-of-life situations (CE (2015) // https://edoc.coe.int/en/bioethics/6530-rekomendacijos-del-medicininio-gydymo-sprendimu-priemimo-proceso-gyvenimo-pabaigos-situacijose.html.
[37] Research studies were funded by Lithuanian Research Council, grant no. S-GEV- 20-2.
[38] Rūta Butkevičienė, *supra* note 5: 1318.
[39] *Europos Tarybos rekomendacijos*, *supra* note 36.

same time they are a source of information for patients, their families, and close friends and all those who face decision-making in end-of-life situations and seek to help develop practice.[40] Therefore, the protection of dignity at the end of life identifies not only the inner, unconditional quality of human value, but also the external qualities of physical comfort, independence, meaningfulness, usefulness, readiness, and interpersonal communication.[41]

So, surrogate decision making on behalf of a terminally ill patient is always a complex and demanding process implying enormous responsibility on the family members or caregivers (as legal representatives). It is argued that the best interests of the patient should be also considered if the patient's own preferences are unknown or are unclear.[42] It presupposes that "the surrogate's decision must promote the individual's welfare" and consequently, "making those choices about relief of suffering, preservation or restoration of function, and the extent and sustained quality of life that reasonable persons in similar circumstances would be likely to choose."[43] In this respect, the so-called "substituted interests' model" was introduced by American experts of clinical ethics. Importantly, it emphasizes individualized decision making which entails cover not only deliberation of patients' values, believes, preferences but also emphasize shared decision making "in light of interpersonal relationships and cultural, religious, and other commitments."[44] It implies the idea that "encouraging discussions with loved ones about the process of decision making becomes central to advance care planning. The studies showed that surrogates are very limited while realizing preferences and interests and as a rule they consider their it from their own preferences, interests, emotions, experiences and religious beliefs, factors which are not traditionally included in ethical models of surrogate decision making."[45] Accordingly, to participate in advance care planning they need more information, consultation, or even expertized support for complex surrogate end of life decision making.

Advance directives for the end-of-life care are different decision-making tools in comparison with other advanced care planning, which is more like informed consent – the appointment of proxy decision making person is usually necessary.[46]

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[40] *Ibid*.
[41] Zeinab Hemati, *et al*., "Dying with dignity: a concept analysis," *Journal of clinical nursing* 25.9-10 (2016): 1218-1228.
[42] Albert R. Jonsen, Mark Siegler, and William J. Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 8th ed. (NY: McGraw-Hill, 2015).
[43] *Ibid*.
[44] Daniel P. Sulmasy, and Snyder Lois. "Substituted interests and best judgments: an integrated model of surrogate decision making." *JAMA* 304.17 (2010): 1946-1947. doi:10.1001/jama.2010.1595.
[45] Jenna Fritch, *et al*., "Making decisions for hospitalized older adults: ethical factors considered by family surrogates," *The Journal of clinical ethics* 24.2 (2013): 125-134; Sarah Barnes, *et al*., "Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature," *Journal of pain and symptom management* 44.6 (2012): 866-879.
[46] Gianluca Montanari Vergallo, "Advance Healthcare Directives: Binding or Informational Value?" *Cambridge Quarterly of Healthcare Ethics* 29, 1 (2020): 98-109 //

As advance decisions are made prior to the actual terminal stage of the illness, they cannot be precise without any information about the actual situation; therefore meticulous regulation on the form and contents of such decisions must be implemented, often requiring supportive clinical decisions on necessary conditions for the application of advance directives.

For instance, in our qualitative study the end of life is frequently regarded as taboo topic, and discussion about death are to be avoided: "We do not speak about death… We try to deny it and we say you will be better tomorrow, … doctor will come and prescribe drugs. Even when patient speak to their grandchildren... they say, my baby, I am going to die, … they reply, what are talking about, no you don't... However, patients they want to speak about it and most of terminally ill they understand their situation. But it is not acceptable in our culture" [nursing administrator]. In addition: "Speaking about death is a big problem. Nobody knows how to talk and what to do. We are not competent, family member too" [nurse].

Is there a difference in the quality of the process of signing advance directive, when the person is still healthy, and when the person already knows he is terminally ill? The matter of timing (proximity of the end-of -life moment) as well as the vulnerability and ability to express genuine attitudes and wishes, as Andorno puts in the context of prisoners:

> The three most important elements to consider are the quality and relevance of the information provided, the mental competence of the prisoner, and his or her freedom from any form of coercion or deception at the time the directive was made. While advance directives can play a positive role in enabling prisoners to continue exercising their autonomy once they lose decision-making capacity, they can also provide an opportunity for abuse of the most vulnerable inmates. Great care must be exercised to guarantee that prisoners are mentally competent at the time they give their instructions, and that they are free to express their genuine wishes.[47]

Consequently, the challenge for the legal regulation of advance directives "starts from the premise that not only can the patient determine medical treatment here and now, but the right to self-determination extends to future situations when the patient is unconscious and incompetent."[48] As the future is not foreseeable in detail, advance directive documents are deemed to be vague and sometimes, there may be situations where family, and health care professionals will not agree on the applicability of advance directives. In Lithuania patients' representatives are the

https://doi.org/10.1017/S0963180119000823.

[47] Roberto Andorno, David M. Shaw, and Bernice Elger, *supra* note 22.

[48] Alfred Simon, "Historical Review of Advance Directives": 3–16; in: Peter Lack, Nikola Biller-Andorno, and Susanne Brauer, eds., *Advance Directives*, Vol. 54 (Dordrecht: Springer Netherlands, 2014) // https://doi.org/10.1007/978-94-007-7377-6_1.

closest family members by law if the power of attorney is not expressly given to another certain person. That is why there is clear necessity to customize the forms and to go into detail of advance directives as much as is necessary in every case. Also, education on how to discuss these matters in family, or how to assist patients and their families to reach and implement certain advance decisions on health care, is paramount to make existing legal regulation really work.

The success of implementation of the surrogate decision-making model depends on how it is going to be organized and managed. In the context of surrogate end of life decisions, the concept of advance care planning is usually employed. First introduced in bioethics discourses, advance care planning was regarded as the process involving patients, their family members and healthcare professionals and other potential stakeholders into consultation the future medical treatment decisions.[49] It should entail discussions about goals of care, resuscitation and life support, palliative care options, role of surrogates in medical decision making, completion of advance directives and the occurrence of discussions about end-of-life care preferences, and the concordance between patient's preferences and end-of-life care received in different adult populations.[50] Advance care planning can play an important role in supporting surrogate decision making process especially when cognitive functions of patients are very limited like in cases on dementia.[51] Previous empirical studies have also showed the positive effect of advance care planning interventions which are likely to improve quality of communication between patients and their family members or caregivers as well as better understanding of patient's cultural and religious perspective and other positive effects which were recommended to be implemented into regular clinical practice.[52] Among other implications of advance care decisions, quality of communication between family members of patient and health professionals, better knowledge of advance care planning, end-of-life care preferences, satisfaction with healthcare, decisional conflict, confidence of healthcare services and their providers were reported.[53]

Therefore, in the US and several other countries the surrogate decision-making process and advance care planning is followed by ethical consultations (by involving ethics consultants) to avoid any potential violation of patient's rights such as convincing patient or, enforcement, misleading interpretations of patient will. The

[49] Peter A. Singer , Geral Robertson, and David J. Roy, "Bioethics for clinicians: 6. Advance care planning," *CMAJ* 155.12 (1996): 1689-1692.
[50] Carmen H. Houben, *et al*., "Efficacy of advance care planning: a systematic review and meta-analysis," *Journal of the American Medical Directors Association* 15(7) (2014).
[51] Deirdre Fetherstonhaugh, *et al*., "Decision-making on behalf of people living with dementia: how do surrogate decision-makers decide?" *Journal of Medical Ethics* 43(1) (2017).
[52] Andre J. Billings, "The need for safeguards in advance care planning," *Journal of general internal medicine* 27(5) (2012): 595-600; Urška Lunder, Branka Červ, and Hana Kodba-Čeh, "Impact of advance care planning on end-of-life management," *Current opinion in supportive and palliative care* 11(4) (2017).
[53] Carmen H. Houben, *et al*., *supra* note 50.

purposive discussions about end of life should enhance proxies as well as health professionals for better understand their options and the benefits of when a palliative approach may be appropriate. Decision aids which provide information on the decision and the options available have shown promise to support family carers as well. [54] Even in the pandemic period, when current circumstances limited communication between all end-of-life decision makers, the technologies "may offer alternative forms for communicating where social distancing is in place, but these options may be challenging or not possible for many frail older people and people with moderate to advanced dementia."[55]

The aforementioned studies reflecting the experience of surrogate decision making suggest the importance of a patient-centered approach for further improvement of the end-of-life care policy in Lithuania. A majority of caregivers and health professionals recognized the importance of surrogate decision making for the protection of dignity and rights of patients in the end-of-life situations. They also suggest extending the scope of institutional care as an appropriate option for the terminally ill patient and elaborate a sort of responsibility sharing model for best patient and society interests. Such situations are potential reasons why the demand of the nursing services at home are on high demand and not always adequately met: patients or their official representatives (caregivers) used to express their desire to "die at home" or refuse further hospitalization in cases of clear prognosis of the terminal stage of disease. [56] Maintaining health does not become the sole responsibility of the doctor, because even if he wants and is able to help his patient, he cannot do so for "objective" reasons such as lack of necessary medicines, nursing facilities, staff or refusal of treatment, statutory situations solutions. Although in some areas of medicine (such as intensive care) paternalistic relationships are seen as unavoidable and necessary to save the patient's life, the model of paternalistic doctor-patient relationships no longer satisfies both healthcare professionals and patients and runs counter to the values of today's changing society.[57]

Overall, ethical implications regarding the respect of individual autonomy should be always open for the discussion until they are not clearly conceptualized in legal system. Therefore, the first step in ensuring the dignity of a person suffering from a serious or incurable disease is the perspectives, values and priorities of that

[54] Michael W. Rabow, Joshua M. Hauser, amd Jocella Adams, "Supporting family caregivers at the end of life: They don't know what they don't know," *Jama* 291(4) (2004) // DOI:10.1001/jama.291.4.483.
[55] K. J. Moore, E. L. Sampson, N. Kupeli, and N. Davies, "Supporting families in end-of-life care and bereavement in the COVID-19 era," *International psychogeriatrics* 32(10) (2020) // DOI:10.1017/S1041610220000745
[56] Renata Kudukytė-Gasperė, Danguolė Jankauskienė, and Kęstutis Štaras. "Assessment of nursing and social policy changes in Centro out-patient clinics." *Sveikatos Politika ir Valdymas (Health Policy and Management)* 1.4 (2012): 127–146.
[57] Shigeko Izumi, *et al*., "Defining end-of-life care from perspectives of nursing ethics," *Nursing ethics* 19.5 (2012).

person, i.e., what is important to that person in this situation.[58] Some scholars believe that this should lead to a better understanding of dignity and patient autonomy, explain its content and present ways, and provide a means of ensuring dignity, based on both values and human rights, as well as scientific (i.e., empirical) data.[59]

We believe that in addition to legal regulations, a team of health professionals (including social workers, spiritual assistants, ethics consultants, psychologists) should be involved in the decision-making process, assessing the patient's condition, and having the discretion to identify the condition when the patient's recovery is considered hopeless. The improvement of a culture of mutual collaboration and shared decision making, even in the absence of practice of advanced car planning, is a key issue for empowering health professionals to the right to contact the family members (caregivers) regarding patient preferences, especially in obscure and legally unclear situations.

CONCLUSIONS

The analysis of legal and ethical arguments related to advance directives lead us to the assumption that the specific question of respect of dignity in the end of life is not just the problem of health care management or the quality of health care services, but rather a fundamental challenge to human rights that should be discussed and applied in accordance with the case-law of EHRC, ideals of welfare society and other national laws as well as public interests. Despite the existing legal regulations on end-of-life decisions, including patient right to refuse resuscitation or other lifesaving interventions, the implementation of these legal provisions in practice seems to be relevant for several reasons. One of them is that neither public nor health professionals are ready to use such instruments as advance directives or proxy decision making adequately because of unclear sharing of responsibilities between health professionals and patient's representative – for example, with the patient's caregivers in the cases of terminally ill patients. The qualitative indicators from recent empirical studies suggest that the patient-centred approach that can provide the hints for harmonization of national legal system including supportive decision-making culture, raise public awareness and confidence, provide more effective professional communication and broader public involvement in end-of-life deliberations.

Patient-oriented healthcare undoubtedly includes the respect for a patient‘s autonomy and a patient‘s family or other caregivers, working together with the

[58] David Kuhl, *supra* note 29.
[59] Ruth Horn, *supra* note 29.

healthcare professionals while caring for the patient. That is why the legal framework must be arranged in a way that facilitates effective decision making, which does not overburden or create additional distress in difficult times. Such is the first necessary step of creating and introducing the system and culture of advance or surrogate decision making. The other one, in our opinion even more difficult, is to inform and educate people, especially healthcare professionals, as to how to overcome different backgrounds and attitudes while working with unified regulations in practice. Information and education are essential for the patients for getting a good quality service and to participate in public life as regulatory actors, as it certainly can be pointed out, that poorly informed patients experience lower-quality and less safe health care[60], we assert that in the end-of-life care and decision-making context the same applies to the family and healthcare professionals.

We assume that morally and legally correct management of end of life should be based on more comprehensive analysis of empirical data and future studies are needed. Thus, to reduce the physical and mental suffering of a person with a serious and incurable disease and to improve the health care of the current or future patient so that he or she does not feel sick at that special time, considering the views of all stakeholders, also the necessary means and financial resources, but not limited to these only. To respond to these aspirations, we suggest overcoming the limitations of the classical liberalism approach to the concept of individual autonomy and right to choose. Empirical analysis of the Lithuanian context showed that the implementation of advance directives is rather occasional or usually not followed by the supportive (for proxy decision makers) end of life decision making measures, which most probably prevent its application in practical situations. Among many of them, the issues of collaborative health and patient communication, accessibility of advance directives related documents, and case management and supportive consultations from various professionals, consultations with lawyers and other measures, were indicated as the main challenges at the end-of-life care institutions. Given the ever-changing value and social context and the differences in attitudes between the generations, we recommend outlining the clear roles and responsibilities of family members or legal representatives of terminally ill patients while defining the values, preferences and priorities of terminally ill persons in the last stages of their life. Finally, harmonization of health care policy and social support systems should work for the best interests of terminally ill patients and their caregivers (family members).

[60] Peter Drahos and Martin Krygier, "Regulation, institutions and networks"; in: Peter Drahos, ed., *Regulatory theory: foundations and applications* (Acton: ANU Press, 2017) // http://hdl.handle.net/1814/50511.

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