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ORIGINAL ARTICLE

Dignity at the end of life: from philosophy to health care practice - Lithuanian case

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Abstract

Regulation and clinical practices regarding end of human life care differ among the nations and countries. These differences reflect the history of the development of state health systems, different societal values, and different understandings of dignity and what it means to protect or respect dignity. The result is variation in the ethical, legal, and practical approaches to end-of-life issues. The article analyzes the diversity of strategies to strengthen dignity at the end of life of terminally ill patients and to highlight the legal preconditions and limitations for implementing these strategies in independent Lithuania, as a former state of the Soviet Union. It is based on the critical analysis of philosophical literature, legal national and international documents and scientific evidence related to the issue. The author argues that the legal system in Lithuania is not sufficient to ensure the patient's dignity at the end of life and remains far behind other Western European countries. Legal regulations in Lithuania do not guarantee the right of the patient to express his or her will regarding the future treatment, including the refusal of resuscitation, do not regulate the termination of burdensome, non-viable and meaningless treatment that is undesired by the patient, and limit the accessibility of palliative care with its necessary quality and comfort.

Keywords Dignity · End of life · Human rights · Palliative care · Advance directives · Terminally ill patient · Lithuania, soviet

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1 Introduction

Dying with dignity has been reported as being important by patients and health professionals alike. Dignity is a term that is multifaceted and not easily defined (Guo and Jacelon 2014). It is both intrinsic and extrinsic, being influenced by culture, personal values, family and community influences and governmental power structures (Periyakoil et al., 2010). According to Periyakoil et al., (2010), everyone is born with intrinsic dignity based on a person's autonomy, self-respect, and spirituality. Extrinsic dignity is maintained when others around the person afford respect through meeting the needs (physical and emotional) of the person. According to the World Health Organization dignity is a human right and is central to palliative care, which should be made available to anyone with a life-threatening condition (Östlund et al. 2012). However, ensuring human dignity at the end of life remains one of the key challenges for the 21st century healthcare, despite increasing knowledge of the personal right to choose how to die. This is because dignity is both a moral and legal concept that is constructed differently according to the context within which it is being applied (Johnson & Eliot, 2003; Horn and Kerasidou 2016). Despite being a fundamental human right the protection of human dignity is especially sensitive when it comes to terminally ill patients where medical decisions are made at the last stage of their lives. Heywood and Mullock (2016) argue that death with dignity is often not acknowledged as sacred in these cases.

This tension between dignity as a legal element and a fundamental human right can often be seen in intensive care or emergency departments where the philosophy of saving or restoring life at all costs overrides any acceptance of a dignified death (Mercadante et al. 2018). Dignity in fact, comes from the Latin word "dignitas" which means worthy, or with merit (Street, 2001). Some authors argue that dignity is a useless concept having no meaning beyond the present (Macklin 2003). Others note that it is merely a fashionable new term for existing values, such as autonomy, compassion, privacy, respect, voluntary consent, safety, and also linked to personal identity, where values, cultural beliefs and personal experiences shape how dignity is perceived and embraced (Viftrup et al. 2021). The tension between active medical intervention and acceptance of death as a quality of life is therefore evident. Heywood and Mullock note that,

> "We sit on a 'perilous perch' regarding the endless battles about the intrinsic value of life. Religious doctrines enshrining the 'sanctity' of life invoke connotations that do not reflect the concerns of a pluralistic and predominantly secular society" (p. 681).

Additional to the tension between medical intervention and respect for a dignified death is further complicated by ideologies and directives of countries. In some countries, the autonomy of the individual is traditionally emphasized, allowing the individual the right to choose how to die. In other countries, human life has a fundamental value to the society, which then means that the individual is not granted the right to reject one's life. However, in many western countries where a comprehensive law concerning advance directives in medical treatments is applied, it is now acknowledged that providing a person with an informed choice about how to die is important if human rights and the Declaration of Geneva are to be upheld (Cilieberti et al., 2018). These countries differ, however, in how far this choice extends. For example, some prohibit all forms of medical aid in dying (including euthanasia and physician-assisted suicide) while others are more permissive (Penney & Black, 2012; Verbakel and Jaspers 2010).

Lithuania is tackling change in relation dying with dignity. Although there is a growing awareness of the need to acknowledge dignity at end of life, there has been little debate in relation to models of care where dignity at end of life is upheld, nor is there sufficient clinical competence or a full understanding of the concept. Medical professionals work in isolation intuitively dealing with the issues of dignity in their everyday practice; and lawyers see no need for solutions until a precedent emerges. The Christian church reflects on the divine origin and the innate dignity of human life that should be a priority despite any circumstances (Powers 2013), although the integration of church into health care decisions and policy making in Lithuania is still very weak. Without a consensus on fundamental ethical principles and important guidelines, the most vulnerable group, end-of-life patients, are affected.

In Lithuania during the sparse debates on human rights, attempts have been made to prove the existence of one ‘fair’ concept or description of dignity, while, in the field of lawmaking, there is a tendency to occupy a neutral position, implying a very limited possibility of securing dignity at the end of life. As a transitional country, Lithuania has experienced a radical change of values in a short period of time since its independence in the early 1990s and, therefore, it is still exposed to more severe and more prominent ethical issues such as end of life choices. It will probably take some time for new values and approaches to be fully integrated into healthcare law and practice.

2 Aim

This paper explores the influences at play in Lithuania, regarding the establishment of end-of-life choices and the concept of dying with dignity in Lithuania. It explores how health professionals interpret, act, and embed the discourses of death and dying into the everyday practice and how this is influenced by those who drive the agenda. It also considers relevant policies and institutional directives that are informed by government ideology.

The article is based on the critical analysis of philosophical literature, legal national and international documents and scientific evidence related to the issue. We also want to identify key ideological and social changes that have influenced end of life care and examine the current literature emerging from Lithuania in relation to current health practice regarding end-of-life care. We hope that this discourse may assist the health services in moving forward on a policy for practice that supports social, cultural, and individual values in end-of-life choices.

3 The concept of dignity from the philosophic perspective

Before discussing Lithuanian framework of end-of-life care and identifying the main ethical issues, it is appropriate to return to the philosophical reflection on the concept of dignity and related topics. We do not pretend to offer a thorough philosophical discourse on the concept of dignity. Instead, we have limited discussion to two dominant philosophical orientations in our country - Christian and liberal positions - defending and upholding dignity at the end of life.

Dignity is considered as both a human construct, linked to personal identity which is subjective, and a social construct. As a social construct, the properties that constitute dignity can be studied empirically and compared across different contexts. It also has four aspects to it, described as, dignity as a merit, which relies upon social status of a person within a community context; dignity as moral stature, which emerges out of respect for self and others; dignity of identity meaning that which is internal, personal, and experiential; and dignity of humanity as a sense of belonging (Hemati et al. 2016, p. 1219). Dignity therefore as a construct in health care is closely aligned to the social norms of the community and the person. In life, dignity is respectful and intertwined with humanity. In death, dignity requires respect for autonomy, which can be described as respecting the human right to self-determination and decision making about what is done to us, including whether to accept treatment. As a moral construct, dignity guides how people should be treated within a given social and cultural context and is embedded in the Charter of the United Nations, both in life and in death (George P. Smith, II, 2018).

Barclay discussed multiple understandings of 'dignity' and noticed that philosophers have historically provided rather abstract and distinct meaning of dignity with limited practical implications to the concrete health care setting (Barclay 2016).

The concept of human dignity (in Latin, *dignitas humana*) was introduced by Cicero in 44 BC. He used it in two distinct but interdependent meanings: as the notion of *general (equal) dignity*, related to human's biological nature and the notion of *differentiated dignity*, associated with human performance or his position. The two concepts should not be attributed as equivalent as the differentiated concept of dignity is subordinated to the general concept of human dignity (Vaišvila 2005).

It should be noted that The Dictionary of Contemporary Lithuanian (Keinys 2012, p. 463) does not provide a definition of the word "dignity"; instead, it describes the word "dignified" as "having self-respect, feeling one's own worth". In this context, dignity should be comprehended as the inner quality of the self and an understanding of one's worth in comparison to others. Similarly, in the Oxford English dictionary (2010) the dignity is defined and means the quality of being worthy of honor or respect.

In Greek philosophy, the issues of dignity were analyzed together with the concept of human freedom. For example, to Plato freedom is the freedom of a human soul from slavery and low desires; it is associated with the self-control and self-government, subordination of lower inclinations to the noble intentions and finally seeking the ultimate goal, the 'Form of the Good' (Degutis 2013).

Aristotle thought similarly. For him liberty is the ability to follow such goals, whose objective value is recognized by the mind, and which has as much value as it helps the human nature to acquire the perfect moral virtue (in Greek, *aretē*). The pursuit of fulfillment is good not because we choose it; on the contrary, our choices are good if they help us to realize that fulfillment (ibid.).

Christianity enriched the Classical Antiquity concept of freedom and dignity by emphasizing the uniqueness of a man as a person. It treats a single person not only as a specimen of a human race but also as a unique and indispensable work of God, made in the image of God and called for the mission of eternity. Therefore, each person acquires the absolute spiritual value, far superior to any economic or political interest. The halo of almost divine dignity and immunity arises, in which Christianity shields a person as an individual.

The transition from the theocentric approach toward the anthropocentric paradigm in philosophy specifically raised the question of who is human and what is personal dignity. Dignity had begun to be treated as the value of a person, arising from his ability to live right in society and to perform certain duties significant to the public. Dignity was viewed in a very instrumental way, not as individual's quality or innate ability, but as a relation to the interests of the state or society in terms of the implementation of those interests. In his book 'Leviathan', Thomas Hobbes, writing about the agreement between the individual and public interest, states that an individual is totally involved in the process of nature and his will is not free - it is primarily determined by the self-preservation. This fundamental instinct explains the ongoing 'war of all against all', which can only be ended by securing a 'social contract'. The Hobbesian approach to dignity, based on the social suitability of a person, opened the door to the concept of the so-called active dignity (Vaišvila 2005, 52).

A little later, emerging liberalism rejected the idea of common or objective good and proposed to follow the assumption that all final values are subjective and depend on the individual wishes, evaluations, and preferences. An ideological change brought by liberalism had significantly transformed the concept of dignity: Dignity was identified as individual's right of self-determination and individual choice. While a liberal approach has supported self-determination in a dignified death, constraints in health professions' workloads have meant that these critical conversations are not always fully explored between a person and their medical adviser (Parsa-Parsi 2017).

At first glance, the position of liberalism satisfies all, as it elevates the autonomy of each individual and promises to everyone the freedom to choose his own life. However, based on the assumption that an individual is the measure and expression of his own values, if there is no higher measure that allows us to assess the value of different goals, conflicts of different goals do not have a rational solution. It is proposed that:

'A liberal does not follow and cannot follow his own thesis about the subjectivity of the ultimate values. After all, if no goals have an objective or intrinsic value, but would have no intrinsic value and would blurs completely' (Degutis 2010, 60).

By perceiving the problem of personal freedom Jean-Jacques Rousseau proposed a radical decision 'to collect all the freedoms of individuals, and only then, following the common will, to grant everyone a fitting share of freedom' (as quoted in Degutis 2010, 59).

Immanuel Kant pursued further the idea about the inevitability of limiting the free will of the individual. According to him, the 'social contract' leads human away from the condition of natural law. Only the state that obeys it can guarantee its citizens' freedom and equality. Kant's categorical imperative of law states: 'Act in such a way that by freely exercising your will you would always be able to match it to everyone's freedom based on the universal principle' (as quoted in Minotaite 1988, 138). He emphasizes the moral quality of freedom of choice and argues that the value of an action must not be measured for the purpose.

According to Kant, the moral quality of action is determined by the will of mind. The mind, by obeying the duty, obeys its own laws. It is autonomous and gives orders to itself. Kant notes that the core of dignity consists of all means respected each person's self-purposive and intelligent moral decision as an individual. The most important quality of the intelligent human being's will be his autonomy, manifested through freedom. Kant succeeded in showing that a person through duty 'obeys only his own established, and yet universal, principles. Moral freedom is the ability to choose only what the mind recognizes as good; the free will and the will that obeys the principles of morality are the same' (as quoted in Minotaite 1988, 138). Or, as Georg Wilhelm Friedrich Hegel put it, freedom is the cognized necessity or deliberate self-limitation to do what is right and good. From here, two definitions of dignity arise: the subjective (the person has a free will to make valuable decisions) and the objective one (the precedence of the public opinion over the person's point of view) (as quoted in Minotaite 1988).

Kant's titanic efforts to make the will of the free man noble as the main source of morality did not have the expected practical effect on human moral development. Subjective morality, liberated from God's care, was enabled to conflict with social or objective morality. To prevent the 'war of all against all', the problem of managing subjective morality, which under a social contract can only be solved by the state, must be resolved constantly. Therefore, philosophy returned to the idea of an external authority, although not at the moral level, but at the level of power. At the same time the discussion about the legitimacy of the restriction of the free will of an individual, which complicates the understanding of human dignity, continues.

The brief review of the concept of dignity in philosophy can be summarized in a few statements. There is no unanimity in philosophic approaches and in social theory about the concept of human dignity. A distinction between the two concepts of dignity is highlighted. The first concept considers dignity as an innate human characteristic, while the second proposes that human dignity and the right to it derives from a social relation, i.e., the social recognition and the assessment of person's performance. The latter approach links dignity with the individual's autonomy, as a freedom of choice based on moral determination, and often provokes a debate about the limits of the individual free will, especially when discussing human right to die with dignity.

The philosophical context set out shows that neither the Greek theoretical foundation (the concept of freedom) nor the Kantian ideas (the exaltation of autonomy and the decision-making based on it for the patient, the professional and other participants in the debate), the liberal approach (emphasis on individual rights) and the traditional Christian position does not provide unambiguous universal solutions. These views are merely a philosophical discourse that does not enshrine guarantees of dignity and remain beyond medical practice and health policy. Nevertheless, these philosophical truths are fundamental, they resonate in the Lithuanian debate on human dignity and the end-of-life care, and show the positions of society, health care professionals and politicians. As Hill (2014) noted in the analysis of Kant's work,

"human dignity is an innate worth or status that we did not earn and cannot forfeit…We must act as if we were both law-makers and subjects in an ideal moral commonwealth in which the members, as ends in themselves, have dignity rather than mere price" (p. 221).

4 The Lithuanian health system and palliative care service

Lithuania is a Northern European country with a resident population of just under three million people (First population estimates, 2020). Health care spending totals 6.6% of gross domestic product, or 1 061 EUR per inhabitant (Healthcare expenditure across the EU: 10% of GDP). Lithuania was the first country to break away from the Soviet Union and in 1991, the country regain independence, stimulating societal, ideological, spiritual and economic change, especially health and education (Riklikienė et al. 2019a).

Lithuania was part of the United Soviet States of Russia from 1944 to 1990. During this period, Lithuania operated under the Russian Semashko model of primary care, which was a national health system, with facilities owned and managed by the state, and health personnel were government employees (Padaiga et al. 2006). Although health care was free to all under this model, it was grossly underfunded and under-resourced, and thus, after independence, the decision was made to decentralize health care services into primary, secondary and tertiary services alongside a change to a market-driven economy.

Health care funding after the restoration of Lithuania's independence essentially changed the Lithuanian health system, when the old integrated model of state-funded health care financing was replaced by the mandatory system of health insurance in 1997, establishing a split between providers and purchasers of health services. The national Health Insurance fund, accountable to the Ministry of Health, is now responsible for the allocation and distribution of resources related to health care. The health insurance system is financed by a combination of insurance contributions and, predominantly, tax revenues. The Ministry of Health oversees the overall regulation and organization of the health system. Over the last three decades the main developments in the health care system in Lithuania has included: a reformation of fiscal policy from a centralized service model towards a system of mandatory health insurance; ownership of health care institutions transferred into public and private sectors; and the provision of health services geared towards accessibility and primary care services with further focus and support for expanded home nursing services (Riklikienė et al. 2019a). As religious and spiritual beliefs of individuals were historically restricted and suppressed over 50 years, after independence, the restoration of a more comprehensive approach to patient and care, i.e. holistic paradigm, was restored (Riklikienė et al. 2020).

In 2007 the decree issued by the Minister of Health described the requirements for the palliative care services for adult and paediatric patients. To provide palliative care service hospitals would have specifically trained personnel on palliative care and would have a multi-professional team. However, it was soon realized that ingrained institutional ways of treating people in hospital meant that primary care services, such as outpatient departments and community nursing models of care were not developed (Jakušovaitė et al. 2005). Palliative care, therefore, has lagged progress made across Europe, even though Lithuania has a deep-seated spirituality going back to the 13th Century. Whilst many international palliative care models of care utilise nursing roles to co-ordinate end of life care, Blaževičienė et al. (2017) found the major impediments to establishing a palliative care nursing service in Lithuania was the lack of autonomy that nurses have and the inherent disrespect of nurses' decision-making in such care, arising from an enduring paternalistic health service structure. Additionally, the authors found that internationally, there was no one standard end of life care model from which to draw on for the Lithuanian context.

Lithuania now has one inpatient hospice (standalone facility) for adults, 48 home and hospital programs offering inpatient and home nursing service, and 3 day-care services for adult palliative patients (Arias-Casais et al. 2020). In 2019 the average number of palliative care beds in a country was 284. In total, 953 adult palliative patients were admitted and 879 died in 2019 (Institute of Hygiene, 2019). During last decade numbers of palliative care patients' admission as well as total number of beds is expanding with the average hospital stay of a palliative care patient being dependant on whether their stay is in a public or private facility. The duration of stay in palliative care units of public hospitals is unlimited and funded by the national health insurance fund.

Further work by Blaževičienė et al. (2020) identified that palliative care is undertaken in hospitals and other community and home settings outside of the dedicated palliative care facilities. The authors surveyed nurses across seven hospitals and found that the main points about palliative care was the importance of meeting patients' spiritual needs in a safe and effective way. They also found that the negative attitude towards nurses' capability in managing end of life care was still an impediment to the delivery of palliative care. Yet there is significant evidence to suggest that nurses are the main carers at end-of-life, working alongside a team of clinical and spiritual professionals (O'Brian et al. 2019).

Throughout the economic and political reforms in post-communist countries, significant changes have also occurred in public morality. In retrospect, the health care systems of Western European countries have developed in the paradigm of democracy and free thinking for many past decades. After regaining independence, Lithuania, on the contrary, first had to restore the former moral values and worldview that were, until Soviet occupations deeply spiritual. It was important to return to what had long been forbidden - the two distinct paradigms of thinking: the Christian and the liberal views.

The transition period was complicated, and some issues that relate to implementation of ethical principles in care (autonomy, informed consent, respect for the person, justice) or economic limitations (shortage of financial, material, and human resources, accessibility, and continuity of services) still need more effective resolution. One of the tasks of the present Lithuanian health policy still is to create mechanisms for strengthening the significance of ethical considerations in the decision-making processes concerning end of life care at health settings.

5 Ensuring patient's dignity at the end-of-life care: legal means and their implication into the real-world practice of care

When safeguarding of death with dignity in medical practice in terms of human rights, several aspects of this problem are discussed. By default, it is accepted that one aspect of this right should be the right to receive patient-centered holistic end of life care. The reality is that not each country in Central and Eastern Europe has adequately developed palliative and end of life care service and when it is established, the accessibility to the service or to the reliable and well-structured information is limited (Lynch et al. 2009; Jünger et al. 2015; Hawley 2017).

Another aspect being debated is the so-called need to avoid "extraordinary," "disproportionate," or treatment with no prospect of meaningful recovery for the patient, extending the suffering of a dying person. For this purpose, Tamayo-Velazquez et al. (2012) propose three main strategies that help to ensure death with dignity that is: (1) refusal of treatment, (2) termination of treatment, and (3) palliative care. Further, we will discuss these three strategies relying on international real-world practice of care at end-of-life stage and the case of Lithuania.

5.1 The right to refuse treatment: is the principle of dignity and autonomy respected?

The right of an active patient to refuse treatment is ensured by international documents and the national legislation of many European Union countries. This right is based on the principle of dignity and freedom of the individual to make decisions related to his or her own life. This value-based determination of personal wishes helps individuals to protect their independence and self-sufficiency. However, this is not always upheld in individual countries. In the case of Lambert and Others v. France, the right to die by withdrawing treatment of a person living in a permanent vegetative state was challenged because French law does not authorize euthanasia or assisted suicide. This landmark case recognised the right of the person to die with dignity over arguments brought to bear from religious, community and family beliefs, making the argument that a judge-made law was not the answer to matters related to a dignified death, thus calling for further discussion on the matter (Kishore 2016). In questioning how a person's right to die with dignity can be honored, Allmark (2002) argued that "health care professionals cannot confer on patients either dignity or death with dignity. They can, however, attempt to ensure that the patient dies without indignity" (p. 255). This raises the tenson again, between personal autonomy and what that means, and the role that law and medical ethics play in choosing how to die. The Oviedo Convention on human rights and biomedicine (ratified in Lithuania and entered into force in 2002) already embodies not only ethical (declaratory) norms, but legal and binding rules for states that have ratified the Convention (Council of Europe, 1997). This Convention aims to protect the dignity and identity of all human beings with regard to the application of biology and medicine, and sets out fundamental principles applicable to daily medical practice. Article 5 states that intervention in the field of health requires freely given and informed consent and Article 9 highlights the respect for previously expressed personal wishes for medical intervention (European Union, 2010).

The right to autonomy for each patient is protected by international legal instruments, such as the UNESCO universal declaration on bioethics and human rights (2005) (Article 7), which emphasizes the importance of a living will (Universal Declaration on Bioethics and Human Rights, 2019b). The European Convention on human rights and biomedicine (Article 9) also foster the regulatory process of living will implementation in a number of European countries (European Convention on Human Rights, 1997). However, since all the aforementioned documents do not indicate the way for the terminal patient to waive treatment in advance, every country chooses a different path. Central to most views though, is about the implementation of patient rights in a national regulation and a clear statement about what legal power must be granted to the documents overseeing this right.

For example, End of life care strategy that was adopted in England in 2008 emphasizes the importance of treating every patient as an individual with the right to make a choice and have individual preferences. The document proves that the self-determination right based on the principle of individual autonomy predominates in the country. It gives the right for terminally ill patient to control his or her own life and make autonomous decisions until the end of life. In such a way, individual rights are perceived higher than the public interest. The national laws, guaranteeing patients' rights based on the principle of autonomy, give the patient the right to refuse treatment without naming the reasons for such decision.

However, it is much more difficult to safeguard the right to refuse treatment for terminally ill patients who cannot decide for themselves on further treatment or its termination because of their serious medical condition. The mean for safeguarding the patient's will is the legalization of the advance directives (Living will) (Horn and Kerasidou 2016). Advance directives are legally recognized in Austria, Belgium, the United Kingdom, Finland, Germany, the Netherlands, Spain and Switzerland. More recently, law on informed consent and advance directives was introduced in Italy (Ciliberti et al. 2018). Yet, advance directives (AD) remain relatively new practice in Eastern and Central Europe. Lithuania introduced ADs cautiously and remains almost the only state in the European Union without regulation on ADs (Peičius et al. 2017). The reason for the delay is the lack of information and initiatives from authorities that left the public unaware of the potential advantages and possibilities of AD. In addition to this, a study on the role of health professionals when applying advance directives to manage the decision-making process at the end-of-life care revealed a low level of knowledge on ADs among health professionals. Moreover, physicians more than nurses preferred the formalisation of ADs to support their decision making in end-of-life situations (Peičius et al. 2017). However, only 15 EU countries out of 28 signed the rules for implementing advance directives practically, and only Spain and Portugal opened the registries related to the recording of ADs. In regard to the rest of the countries, regulation regarding the practical implementation of ADs / Living will differs by both content and form (Rodado et al. 2021). The possibility of granting a decision to another person when a patient is unable to do so, is legitimized and binding in an increasing number of countries, for example, Austria, Belgium, Germany, Hungary, the Netherlands, Serbia, Spain, Switzerland, and Lithuania. Such practice assures the fundamental principle of autonomy by involving alternatives (family members, authorized representatives) in decision-making when the person, due to his health condition, is not able to make a personal decision.

Other European countries have taken a different path in ensuring the patient's right to refuse treatment. In France, dignity is understood as the intrinsic and innate human characteristic, such as respect for human life and humanity, and for every human being's that forms a group dignity, and not as a right to act individually (Horn and Kerasidou 2016). Such perception is the highest value to be defended, even if it restricts the freedom of the individual. Despite many attempts to strengthen patients' rights in recent years, in France a strong commitment to protecting the vulnerable and delegating responsibility to the doctor remain a key element in regulating medical decisions at the end of patient's life.

Although the Patients' Rights Act adopted in France provides citizens with the possibility of advance directives, the Public Health code states that the doctor should consider the AD. Similarly, in France, the law permits the patient to refuse treatment but, unlike England, it requires the doctor to do his or her utmost to persuade the patient to continue the treatment. However, as the doctor himself / herself decides on the continuation or termination of treatment (Horn and Kerasidou 2016), he / she performs their professional duty by preserving social values rather than a personal choice of the patient.

The rather limited legal possibilities of death with dignity in Lithuania (this speaks of not effective protection of patients' right to refuse medical treatment) are regulated by few legal documents. The chapter II on 'Human being and State' of the Constitution of the Republic of Lithuania has several articles on human dignity (Lithuania 1992, rev. 2006). Article 18 is related to human rights and states that 'Human rights and freedoms shall be innate'. Articles 21 and 22 articulate the term of dignity in a sense of a legal protection, i.e. 'The dignity of the human being shall be protected by law' and that 'It shall be prohibited to <…> degrade his [person's] dignity, <…>' and 'The law and the court shall protect everyone from <…> encroachment upon his honour and dignity'. Moreover, Article 25 relates to dignity in the light of freedom for the own convictions and self-expression: 'Freedom to express convictions, to receive and impart information may not be limited otherwise than by law, if this is necessary to protect the health, honour and dignity, private life, and morals of a human being, or to defend the constitutional order' (Lithuania 1992, rev. 2006).

Next to these constitutional statements on dignity, another contradiction appears regarding the person's right to death. The Article 19 of the Constitution of the Republic of Lithuania proposes that 'The right to life of a human being shall be protected by law'.

Safeguarding the person's 'right to life', any national legal document does not support person's right to refuse unwanted treatment even if that refusal might and often will result in death (Lithuania 1992, rev. 2006). A person cannot indirectly (through the termination of the unwanted life support), terminate his life because in that case he would not comply with the obligation arising from the subjective side of the 'right to life'. Complying with such obligation / duty turns the 'right to life' into a privilege (Bobinaite 2014).

The patient's right to care and dignified death is guaranteed by Article 3, paragraph 3 of the Law on the patients' rights and compensation for the damage to their health of the Republic of Lithuania (Republic of Lithuania Law on the Rights of Patients and Compensation of the Damage to Their Health, 1997). Paragraphs 5 and 6 of Article 12 of this Law provide the patient with the right to accept or reject the proposed treatment and to be informed on the consequences of refusing it. The patient may also refuse the resuscitation, which often becomes a disproportionate measure of treatment at the end of the life of terminally ill patients (Article. 10, paragraph 2 and Article. 11, paragraph 3). This statement of the law came into force only on 1 January 2020. Until then, the situation of incurably ill patients in Lithuania was such that even if the patient had expressed a desire not to be resuscitated in accordance with the procedure established by law, this decision needed the approval of the doctors' joint judgment (in Latin, *consilium*). In clinical practice, this meant that a seriously ill person, although granted the right for autonomy to make a will in advance, did not legally oblige health service providers to carry it out, since there were no implementation procedures in place supporting patient's refusal of resuscitation. This situation meant that: 'we cannot help, but we will not allow you to die'.

Traditional Christian moral and spiritual norms often conflict with and oppose the pragmatic and utilitarian goals and motives of human life, where benefit and universal happiness is prevalent, i.e., as many people as possible will die without suffering and pain, and termination of treatment is a pragmatic solution. An example of this case may be the treatment of a patient with a terminal illness (Jakušovaitė & Bankauskaite 2007). Lithuanian physicians faced a real challenge to provide medical interventions to patients that are humane and helpful at the same time (Niemeyer-Guimarães and Schramm 2017). The discussion that was initiated by physician anaestesiologist-reanimatologists, the Association of junior doctors, Lithuanian cancer patient coalition – POLA, and bioethicists from academic and clinical settings with the media moved to a wider publicity and reached the legislators. Representatives of the Catholic Church also took part in the debate and expressed their position. Seeking the change, the proposal for the amendment of the law was submitted to the Parliament of the Republic of Lithuania (in Lithuanian, Seimas) in 2017. The proposal consolidated both liberal and Christian values (freedom of choose non-application of treatment with no prospect of meaningful recovery for the patient) and fundamental principles of medical and professional ethics (innocuousness, respect for the person and preservation of his / her dignity). Here it can be assumed that a new generation of doctors grew up, who had already been taught ethics, anthropology, philosophy of medicine, i.e., the subjects of medical humanities that stimulate the development of the personal and social competence. Such competence helps young health professionals in gaining a practical wisdom that relates to moral efforts identifying and evaluating the situation (Jakušovaitė et al. 2014). Therefore, faced with practice during their residency and observing conflicting situation of incurably sick people those young professionals did not come to terms with the moral dilemma. They began to seek change and consolidate both moral values and the goals / ideals of professional ethics. They began to raise the issue in public, to discuss, to seek the support of bioethicists, the public, church representatives and politicians.

It was suggested that a legal guidance for physicians be developed in the case of not resuscitating terminally ill patients if treatment was not meaningful and would only prolong their suffering. The health professionals declared that present regulation made them feel morally obliged in relation to both life and death: it would be more humane to not resuscitate (principle of do no harm, mercifulness, and autonomy) even though the law requires opposite.

In 2019 the Law on The Determination of death and critical conditions of a person of the Republic of Lithuania was amended, and a new edition came into force on 1 January 2020 (Law on the Establishment of Death of a Human Being, and on Critical Conditions of the Republic of Lithuania, 1997). Finally, a legal background for physicians to not resuscitate the terminally ill patients if this is unwanted or ineffective treatment was created. Thus, a practical step has been taken to help health professionals fulfil their duties of providing medical services to incurable patients, consolidating the principles of medical and professional ethics, and giving those patients hope of not being resuscitated when all medical devices have been exhausted and the continuation of life has become a *technical procedure* for prolonging suffering. As Niemeyer-Guimarães and Schramm (2017) proposed, the conscious use of scientific knowledge and methods finally met the desired ethical principles of beneficence, nonmaleficence, equity, precaution, responsibility, justice, and protection. Following the scientific progress 'it is imperative to take into account the best interests of the person, with particular emphasis on human dignity' (Niemeyer-Guimarães and Schramm 2017).

5.2 'To do everything possible': dignity ends where medical futility begins

Discontinuing life-sustaining treatment on the grounds of medical futility, that was traditionally taboo in many European countries with strong conservative views, such as Lithuania, is increasingly being discussed. As with other countries, Lithuania considers the fact that as the populations age, it is necessary to balance growing but limited public funding of health care (financial, material and human) with existing demand (Jox et al. 2013; Hawley 2017).

It is difficult to define and interpret the concept of dignity in medicine, but it is also difficult to describe, and agree upon, the concept of medical futility and valid criterion for its determination. According to Aghabarary & Nayeri (2016), medical futility is 'a complex, ambiguous, subjective, situation-specific, value-laden, and goal-dependent concept that is almost always surrounded by some degrees of uncertainty'. In Lithuania, the withdrawal of ineffective treatment to the patient is not regulated by law either. Any law or subordinate legislation foresees the right of a doctor or a medical institution to terminate an artificially maintained life.

The Law on Medical Practice of the Republic of Lithuania states that a doctor has the right 'to refuse to provide health care services if it is contrary to the doctor's professional ethic principles or which may cause the actual risk to the patient life, except for the cases when the emergency medical aid is provided' (The Law on Medical Practice of the Republic of Lithuania, 1996). The long-term support of vital functions is not an urgent medical aid decision, and it seems that the doctor can discontinue such treatment regardless of financial or moral standpoints. However, doctors feeling insecure about deciding to terminate treatment based solely on principles of professional ethics and do not having strong and clear legal basis for that.

Lithuanian physicians are forced to take all possible measures of medical treatment, even though he or she is convinced of the futility of such treatment and artificial postponement of the patient's death. The family also tends to express the will for continuation of patient's life asking, 'to do everything possible'. Neither the world-view – liberalism, consensus, Christian philosophy (Lithuania is a Catholic country) nor the values and standards of professional and medical ethics make any difference to the need to continue life, even when there is no possibilities to it. When ethics has no legal status and the existing legal regulation is not sufficient, healthcare professionals are subject to shortcomings of the regulation lacking freedom of professional decision making and safety.

Around the world the proponents of the liberal approach to dying with dignity criticize the legal situation which, on the one hand, grants patients the right to refuse the resuscitation, and on the other hand, restricts it. They declare that the individual's freedom must include the right and possibility for the individual to make the decision, whether he or she wants his or her life maintained even if there is no hope of recovery and experiencing unbearable physical pain. The proponents of this approach often say that the value of a human life is inseparable from the quality of life, and the problem of disproportionate resuscitation becomes especially relevant in the face of progress of medical science and the emergence of the possibility of keeping patients in a vegetative state for prolonged periods (Yun et al. 2011).

The European Court of Human Rights in one of the most famous cases, the Case of Lambert, and others v. France, summed up the legislation on life-maintaining treatment in the Council of Europe member states and stressed that there is no consensus among the states on the issue of withdrawing of life-maintaining treatment (Case of Lambert and Others v. France, 2015). As stated in the Court's judgment, the legislation, or the medical code of ethics in most countries permits the withdrawal of such treatment based on a specific patient's situation. However, there are countries where the law prohibits it. Yet in other countries, there is no legal regulation, a practice of case law on this issue exists.

In finding solutions to provide dignified help to those who are severely ill, the good practice is to rely on the experience of other countries, more advanced in their developments. Unfortunately, even though situations and problems in dealing with the end-of-life care are similar, each country should find its own path. Often it takes years, as evidenced by the development of palliative care in Lithuania.

5.3 Palliative care as a relatively new strategic step in health policy

In Lithuania, the transition processes of values and ethical principles into care models took time and demanded decisive innovative solutions. Shortage of human resources with the necessary competence in health care, lack of modern equipment and material supply, politic and economic tension during the first decade of independence limited the development of health care towards holistic philosophy and Christian values. It took decades to change the strongly predominant biomedical approach to care by the holistic perspective that emphasizes and takes into consideration the overall health of the patients, including their physical, psychological, social and spiritual wellbeing. Unfortunately, the chosen path was first led toward medicalization and improvement of physical condition first.

Early in 2000s, the specialized nursing and supportive treatment hospitals were established aiming to provide treatment, nursing, restorative, other medical services to people with chronic diseases, disabled people, when rehabilitation in specialized departments was not appropriate. Nursing and supportive treatment service was available for patients with the main diagnostic categories as cardiovascular diseases, neurological diseases, cancer, other chronic diseases, traumas. Subsequently, it was these facilities that started providing palliative care service and end of life care.

Lithuania was the last European country to ratify the Order on the 'Description of Requirements to Provision of Palliative Care Services for Adults and Children' (Minister of Health, 2007), legitimizing palliative care in helping the terminal patients to live a good quality life before dying and to guarantee the preconditions for dying with dignity. Although palliative care was considered a new strategic step in Lithuanian health policy, these steps were limited to the management of physical condition and symptom control (pain, nausea, vomiting, etc.). The dominance of a medical approach in the practice of caring for a terminal patient may partly be explained by the doctors' notion about the factors that ensure dignity at the end of life. Most often health professionals consider physical and psychological dimensions of health as key outcomes, ignoring social and spiritual domain (Seale 2009; Antiel et al. 2012).

However, there are further problems related to the development of palliative care in Lithuania and its integration into healthcare. For example, in our country, palliative care is provided on the basis of the requirements to provision of palliative care services for adults and children (Minister of Health, 2007) which aims to reduce and/or prevent patient's physical pain; to accurately identify, control and reduce painful symptoms; to identify the psychological and social problems of the patient and his relatives, and to help them solve by strengthening their desire to live and thinking about death as a natural process; to improve the quality of life of the patient and his relatives; and to help during their loss. To receive palliative care in Lithuania, patients must have specific illnesses, i.e., medical diagnosis, listed in the Annex of the Order on Palliative health services for adults and children; besides, additional circumstances must be considered (for example, the compliance with the Karnofsky Index, etc.). Under such legal regulations, when precise indications have been established, palliative care is not available to anyone who needs it. Annually around 3.000 patients with incurable conditions receive palliative care services although the demand is not fully met. Another serious issue is that medical diagnosis is not suitable to be an absolute indicator for palliative care needs. For example, there are patients in constant pain, with total dependence and need for specific care interventions (dialysis, tracheostomy, or oxygen therapy) but their medical diagnosis is not valid for the palliative care. This degrades dignity of terminally ill patients and violates their right for equitable access to health care (Convention on Human Rights and Biomedicine, 1997, art. 3). Moreover, the failure to provide timely services of appropriate quality (in palliative care case - with the effective control of pain and suffering, and holistic approach to care) can be equated with cruel and degrading treatment. Due to the low rate of services, there is a shortage of multidisciplinary team specialists who provide outpatient palliative care in the institution or patient home Šeškevičius (2015).

A good spiritual care is part of good palliative care. In Lithuania, a country in which Christianity is largely practiced, there are efforts to expand pastoral care in palliative care wards and actualize the figure of the hospital chaplain by clarifying the role and duties in supporting patients and their families during moments of great emotional, spiritual, and psychosocial loss and grief (Riklikienė et al. 2019b). Now the professional spiritual care in palliative health care facilities is limited to clergy staff visits under requests and provision of the sacramental grace, those that undoubtedly helps 'to focus on the dignity of the dying person' (Powers 2013).

However, church representatives stand up to protect the rights of all sick people, and especially the incurably ill. By not only declaring their values and beliefs, but they also support the principles of dignity and respect for the person. According to Eisenberg and Evangelista (2008), Christian church considers palliative care as being an important instrument to restore or preserve the dignity of a person in the final stages of illness.

Catholic moral teaching holds at its foundation the human person's inherent dignity that cannot be diminished by any circumstances such as aging an illness (Powers 2013). During recent decades the Christian Church in Lithuania expands and increasingly returns to what in Soviet times was not only pushed back, but to completely isolated. It involves the training of spiritual advisors who are gradually getting involved in the health care system. Church representatives speak out very clearly against burdensome or disproportionate to the expected outcome treatment, support the prosthetic application of 'Doctrine of double effect'. Such doctrine is widely used in medicine in many cases and in end-of-life decisions when it is important to balance the benefits and risks of treatment. The application of this principle (formulated by the medieval theologian, philosopher Saint Thomas Aquinas) is also supported by the Catholic Church.

In summary, it can be said that the main challenge in palliative and end of life care provision remain the sufficient access to the service and the absence of holistic approach to care with the integration of a biopsychosocial-spiritual model to treat each patient as a 'whole'. Health care professionals are expected to work as multidisciplinary teams relying on competences of each member, while supporting not only 'primary' needs of a sick person but also addressing the person's existential and spiritual needs (Riklikienė et al. 2020). Integration of family members into palliative care process as well as individuality in care need to be strengthened as well. The professional collaboration, mutual understanding and support among staff and patient's family, the balanced resource allocation and team approach during every day work were recognised as the main facilitating behaviours to improve palliative and end of life care (Blaževičienė et al. 2017, 2020). Finally, faster practical integration of scientific evidence on different interdisciplinary care models for Lithuanian palliative care and end of life patients would make a progress, as research in palliative care is about making a difference in the lives of patients and families (Larkin et al. 2016).

Unfortunately, under the shortage of palliative care services and unmanaged suffering of terminally ill patients with the burden on relatives the issue of euthanasia has been exacerbated. This issue is dangerously escalated by politicians and other public figures, some with personal painful experience of caring the patient with serious illnesses, others declaring liberal values and defending the human right to decide, the rest only seeking visibility and popularity. We are confident that until palliative care is not ensured in Lithuania, the question of euthanasia should not be raised, as this violates the patient's primary right to receive treatment and care from the beginning of the illness to the end of life, reducing pain and suffering.

6 Conclusions

Dignity is having both moral and legal elements to making it a complex concept to define, explore and understand. Apart of existing controversy what dignity is and what it really means (or if the term itself has any meaning at all) we argue that in health care patient has dignity when he or she can live and die in accordance with his or her standards and values. In this sense, the legal system in Lithuania is not sufficient as it does not provide an effective legal framework for the implementation of key strategies for dying with dignity. The gaps of legal regulation in Lithuania when 'ethics and the law are conceptually and procedurally distinct' (ibid.), remain a serious obstacle to safeguarding of death with dignity.

The brief review of the philosophical concept of dignity from Christian and liberal perspectives highlighted the distinction between the two approaches of dignity during palliative care. The first approach considers dignity as an innate human characteristic, while the second proposes that human dignity and the right to it derives from a social relation, i.e., the social recognition and the assessment of individual's performance. The Christian posture treats and defends dignity in care as the non-application of burdensome treatment and the holism in palliative care. The liberal approach links dignity with the personal autonomy, as a freedom of choice based on moral determination, and often provokes a debate about the limits of the individual free will, especially when discussing human right to die with dignity.

Focusing exclusively on the disease and symptoms, the person disappears. The human existence, spiritual domain of care and dignity are pushed to the margins, where the most vulnerable incurably ill patients together with families and health professionals must wait for the appropriate political decisions and practical solutions to deal with the dignified end of life and guaranteeing a person free self-determination. Without appropriate palliative care services, the patient's primary right to receive treatment and care from the beginning of the illness to the end of life, reducing pain and suffering is violated.

And finally, to assure dignified end to the life for the incurably ill patients, philosophical ideas and theoretical foundations of medical and professional ethics remains as fundamental; unfortunately, they are significantly ruined or even ignored by historical and political collisions, and bio-technological progress of medicine. Relying on the best examples and practices of similar transition countries and western world, in Lithuania there is a need to integrate ethical, moral, and legal aspects of dignified death with the holistic approach by the cooperation of health professionals, academics, lawyers, bioethicists, religion and spiritual leaders, politicians, patient organizations and the public. The technological solutions, algorithms, therapeutic protocols turn the end of the patient's life into a purely 'technical process'.

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