

Palliative care as a human right after 2020 pandemic

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Abstract

The right to life is at the very top of the hierarchy of fundamental human rights. Following the Coronavirus pandemic 2020, this right will be even more important in the future. At the same time, it is to be hoped that it will not be exposed to even greater problems at the same time: political, institutional, medical - and legal/constitutional/conventional. An integral and inseparable part of this right is palliative care. The ECtHR also decided on this in 2002. The author discusses the social, political and legal aspects of palliative care and places it at the center of future short-term priorities of Slovenia and other EU Member States. He strongly emphasizes that the right to a dignified life, the right to a decent living, to live in and with dignity, especially in the last days of life, and thus the right to an effective and high-quality palliative care system need to be significantly better protected as it has been protected before the 2020 pandemic. Also, but not only because during the official pandemic, it became clear how fragile this right is and that the palliative care system is not (medically, ethically and legally) properly regulated. In this area and in this context, including the proper care for the elderly, disabled people and terminally ill, author sees a good opportunity for professionals in physiology and physiotherapy: for their active participation in the establishment of a high-quality and effective palliative care system and in the systemic (in the sense of legal policies, legal regulations, organization, functioning, funding and employment) care of the elderly, disabled people and terminally ill. Keywords: Right to Life; Palliative Care; Human Dignity; Euthanasia; Right to Live in Dignity; Right to Die in Dignity; Positive Obligations of the State; Quality Public Healthcare System.

Paliativna nega kot človekova pravica po pandemiji 2020

Povzetek

Paliativna nega kot temeljna človekova pravica bi morala biti po pandemiji 2020 bolj zaščiten. *Pravica do življenja je v hierarhiji temeljnih človekovih pravic na samem vrhu. Po Koronavirus COVID-19 pandemiji 2020 bo ta pravica še bolj pomembna. Ob tem pa je upati, da ne bo hkrati izpostavljena še večjim problemom: političnim, institucionalnim in pravnim. Sestavni in neločljivi del te pravice je paliativna nega. O tem je že leta 2002 odločilo tudi ESČP. Avtor spregovori o socialnih, političnih in pravnih vidikih paliativne nege in jo postavi v središče prihodnjih kratkoročnih prioritet Slovenije in drugih držav članic EU. Odločno poudari, da je treba pravico do dostojnega življenja, pravico do življenja s socialnim in zdravstvenim dostojanstvom, predvsem pa pravico do dostojnega preživljanja zadnjih dni življenja in s tem pravico do učinkovitega in kakovostnega sistema paliativne nege znatno bolj zaščititi, ko je bila zaščiten pred pandemijo. Tudi, a ne le zato, ker se je med uradno pandemijo nazorno pokazalo, kako krhka je ta pravica in da sistem paliativne nege ni (medicinsko, etično in pravno) ustrezno urejen. Na tem področju in v tem kontekstu vidi dobro priložnost za strokovnjake s področja fiziologije in fizioterapije: za njihovo aktivno soudeležbo pri vzpostavljanju kakovostnega sistema paliativne nege in pri skrbi za ostarele, neozdravljivo bolne in umirajoče ljudi. Ključne besede: pravica do življenja; človekovo osebno dostojanstvo; evtanazija; dostojanstvena smrt; paliativna nega; pozitivne pravne obveznosti države; kakovost sistema javnega zdravstva.*

1. INTRODUCTION¹

It is true, I am a lawyer, by education, and a university professor of law by profession. Especially constitutional law, modern constitutionalism and the law of fundamental human rights and freedoms.² But since I am also interested in other areas of human activity, in education, in finding answers to interesting questions and in getting to know myself (especially in the fields of psychology and psychoanalysis), I am naturally also interested in questions, challenges and problems of modern medicine. One of these problems is that all too often people are treated as *things*, as naked *objects*. Even when they are treated as patients. Too often it seems and happens that a person enters a medical facility and leaves it with the feeling that he or she has been to a car mechanic, for example. In the sense that too many of the representative of medical profession act as they would prefer a human, a patient to bring a sick body part in a sack, leave it at the reception desk and search for it when asked. The easiest way is by text message. This is the strength of the unpleasant feeling. It forces a person into a diminished trust, into doubt, into insecurity, sometimes into fear and sometimes even into despair or a feeling of hopelessness.

I admit that I do not tolerate such an attitude of some doctors. And I resolutely oppose it when it happens: with choice of words and tone of voice. But I am lucky that I did not have to do this often. And I never bend down, I do not bend my spine when the lady who works in the reception office of the hospital or health centre cannot hear me well enough, when I stand behind a glass wall and ask and answer in a moderate tone - in that circle in the middle of the glass or plastic partition. People who bend down and start talking through a small opening at waist height, directly above the counter, I understand with indulgence. I try to understand them. But when I notice or observe it, I approach those people and straighten them up. To give them back a part of... but an important part of their personal dignity.³ As a lawyer, I also pay special attention to the irritating signing of the same "*official forms*" that patients know as a reference to "*awareness of the possibility of a treatment error or during the medical intervention*". In principle, this is a friendly form, the completion of which also includes a polite offer to "*indicate whether the patient suffers from chronic diseases and allergies*". But if I put cynicism aside, even if I can afford it, I must point out that these "leaflets" are first and foremost just that: a piece of paper officially intended for the "*informed consent*" of a patient before a medical intervention. Although the signature on this piece of paper is the patient's consent, it is not "*informed consent*". This is because in most cases the doctor would need at least a few minutes, sometimes an hour or more, to explain the reasons for the procedure, its technical manner, anticipated result and statistically possible side effects or consequential damages - in a detailed and understandable way.

Usually these slips of paper are then put into drawers, thrown away, in one or more stacks of the same or similar slips of paper. And that too is a legal question. *Such a paper has no legal value*. It does not release the doctor from his subjective legal responsibility if he has made a mistake. It does not release the medical institution from its objective legal liability if an error in the procedure occurred through no fault of the physician. In other words, medical institution is still objectively legally liable to the extent that the realized statistical possibilities of the occurrence of errors are recognized.

However, this piece of paper has a psychological effect: less intellectually sovereign and more anxious people may be too anxious and get scared. And this in itself has a negative effect on the psycho-physical condition of the patient before the medical intervention. Perhaps it is this piece of paper that even discourages him from a medical procedure that would otherwise be harmless and routine.

That is why I respect and appreciate those representatives of the medical profession who look at the patient and talk to the patient, deal with the patient as a person, as a human being. And has the right to be treated in such a way, with acknowledging and protecting his DIGNITY. And who know very well that a patient's trust in a doctor is essential for successful treatment. Therefore, a doctor must be a

¹ The article is a partially revised, supplemented and expanded version of the article entitled *Let us not neglect or even put it aside: palliative care as an integral part of the right to life and dignified end of life*, published by the author in *Obzornik zdravstvene nege*, 54(4), pp. 272–278, Editorial.

² I kindly invite readers to see my webpage: <https://andraz-tersek.si/home/>

³ For the constitutional interpretation of the right to personal dignity and security see Kleindienst, 2019.

person who loves people, who is aware of the different psychological effects that different rhetorical and psychological approaches have on the patient. And those doctors who are well aware of this are the best doctors. Therefore, it often happens that they "cure" the patient, so to speak, before they touch him or her and before they give him or her medication or perform a medical procedure. Such doctors can treat with words, with touch, with the tone of the spoken words, with the language of the face and body. It is not miracles they are producing, it is the nature of man, the way how human brain works. Such doctors are an exemplary example of the medical profession and medical activity. Virtuosos in their professional conduct. And in my life, I have had the good fortune to meet some such doctors. Even a few such physiotherapists.

Let me expose just one example. For 40 years I was convinced that with my knees and my tendons I could not run more than five kilometers. The physiotherapist dr. Mojca Amon solved my problem, due to which I unsuccessfully and in vain visited a large number of other, otherwise serious and recognized and accredited physiotherapists, in one hour. She looked at me correctly, her face had the right expression, her words were right and her touch was right. She told me this: "*Andraž, even if it hurts, I do not see any medical reason for it to hurt, run - because it will stop hurting you.*" In two weeks, I effortlessly ran a small marathon and next year a full marathon. No pain, no negative consequences. Pure joy.

For me, this is a real, human, intelligent approach to medicine and the patient as a person, as a human being. In addition, the doctor must tell the patient the truth, and the patient must be approached in the gentlest and most reassuring way.⁴ And if this is the case, such an approach can in itself have effective placebo effects. And that is a good thing also.⁵

2. METHODS

A short methodological excursion

I began to write the article from four aspects. The first aspect is my knowledge of the constitutional foundations and its substantive interpretation when it comes to the issue of fundamental human rights, such as the right to health, life, personal dignity, privacy, a healthy living environment etc. And of course, my knowledge of the "rights of patients". The other aspect is represented by my own experience when, as a legal assistant and consultant, I was actively involved in some cases of conflicts between patients and doctors. The third aspect presents my many years of public debate and legal study on palliative care. I collected information about it, read documents, specialist literature and wrote some short professional articles. The fourth aspect, however, presents my daily collection of information on the title topic in daily communication with people who wrote to me during the official Coronavirus COVID - 19 Pandemic 2020 – orientating on the palliative care and care for the elderly in homes for the elderly and terminally ill people. I have used the findings in writing this article. But not all of them, because I had to limit myself to the content and the intended scope of the article.

3. RESULTS

Starting point

There is *one health only*. Human health should be understood holistically: psyche (mentality) plus physiology / physicality, as a part of one whole. And, the conclusion seems in place, there is one *death with dignity* only. This is the main purpose, the central message of my essay.⁶

Or as my friend and an outstanding psychiatrist and scientist has written, before the cancer ended his precious life:

⁴ Comp. Lukman, 2010, pp.11-24.

⁵ Therefore, in this regard, I attribute and acknowledge, I express my praise to my doctors: dr. Mojca Amon, dr. Sanela Banović, Denis Baš, dr. med., Sašo Rebolj, dr. med., and surgeons Robert Juvan, dr. med., and Primož Sever, dr. med..

⁶ Even though I do not oppose the idea that voluntarily euthanasia should be legalized as a "final resort" in cases of unbearable suffering and the absence of the possibility of healing or prolonging life, which at the same time means a dignified and quality life for the individual as a person, without unbearable suffering and the desire to continue living in medically conditioned agony and despair just to suffer and torment until natural death. See Teršek, 2012, pp. 541-556.

“It might be a good time for public health experts to move from the mental health as one of the health determinants to the mental health as the main health indicator of the interplay between the unpleasant life circumstances or events on one side and the quality of health care on the other. Life events and circumstances are known to have a considerable effect on our health in general with the mental health being the most acutely responsive and as such the most sensitive one. As such, the mental health should be developed into a most sensitive health indicator indicating some possible effects of a different quality of health care on one hand or life events and changed life circumstances on the other” (Marušič, 2009, p. 93, in Teršek, ed., 2009).

The right to life includes the dignified death

In this article, I will not directly address the human and constitutional right to “dignity” and legal protection of a “decent life”; of any *individual-as-person*, in a social sense (Barak, 2015). In my homeland, The Republic of Slovenia, an EU Member State, I have been publicly repeating for many years, as a warning and as an appeal to the State and the general public, the *right to life* as such is still not appropriately, legally correct and effectively protected. Having expressed that I was and still am thinking directly of this: the right to LIVE with dignity, the right FOR a dignified LIFE, the right to “live a life” until it ends in – its natural – death in DIGNITY. To die in and with dignity.⁷

At the time of the officially declared 2020 Coronavirus pandemic, this problem was exactly what it was: the life itself was placed at the core of the issue, of the events. Nationally and globally. Especially the lives of people who, due to their age or previous illnesses, possible the chronic ones, represented the most endangered group of people; the *elderly* and *terminally ill*. Many of those people, as can be seen from the reports of EU Commissions and Committees, from the *Slovenian National Institute of Public Health* and related institutes in other EU Member States, also across the Atlantic, weren’t given and secured the optimal nursing, a quality and optimal medical and psychological care.⁸

There were many substantial and notifiable differences among EU Member States in this regard. For example, while in Slovenia 80% of deaths which were presumably the direct consequence of the COVID-19 virus included the elderly over 75 years old or more, in a neighbouring Austria this population represented only 20% of the deaths – according to the media reports and interviews with doctors or other medical professionals done by the Slovenian public television. Quite a difference, one would argue? We may have some doubts about this information and it cannot be taken so easily as categorically reliable. And data on this vary from one EU Member State to another. Yet we timidly come to a conclusion – by searching through the internet and combining the publicly offered messages from management in nursing homes and from official state statistics – the elderly and terminally ill were the most endangered population.⁹ I have in mind the people whose lives were running out quickly, due to terminal illness, even before the actual *state of emergency* (even though – only - *de facto* and not *de iure*), addressed as (merely) “extraordinary circumstances,” came into force at the time of the pandemic.¹⁰ Many lives of those people - unfortunately - were lost during the pandemic. Should we be concerned about this fact? I claim we should and must be very concerned.¹¹

The media, in Slovenia and other European countries, reported on the situation in homes for the elderly and (mostly terminally) sick as being hard to bear, especially difficult, risky and problematic.¹² In

⁷ Eleven years ago I edited a collection of scientific papers in this regard, in memory of prof. dr. Andrej Marušič. See Teršek, ed., 2009. It was not a coincidence that DIGNITAS – Human Rights Journal was established in late 1999, by prof. dr. Peter Jambreč. In the first years I had a privilege to be the assistant editor. See Brennan, 2007; Radbruch et al., 2013.

⁸ Media reports. Available at: <https://www.primorski.eu/trzaska/domovi-za-ostarele-protest-sindikatoxH548202> (2.6.2020); <https://www.rtvlo.si/svet/s-in-j-amerika/oskrbovanci-domov-za-starejse-oblezali-v-amazanih-plenicah/525212> (27.5.2020); <https://siol.net/novice/svet/v-kanadskih-domovih-za-starejse-grozljive-razmere-526348> (27.5.2020); <https://www.24ur.com/novice/tujina/v-zda-pricakujejo-vec-kot-100-000-smrti-zaradi-pandemije-trump-pripravite-se-na-dva-huda-tedna.html> (1.4.2020).

⁹ For daily data on COVID-19 infections see Slovenian Institute for Public Health webpage. (<https://www.nijz.si/en>)

¹⁰ For the constitution-law analysis of the restrictions on constitutional rights and freedoms by the government Decree during the official pandemic see Teršek & Dragan, 2020.

¹¹ Comp. INSAIDER.com, 2020. Left to die in an “intimate home”: The elderly are discriminated against, and the government “lipstick” the terrible truth.

¹² Comp. Zdurove strani. Homes for the elderly at the time of the epidemic, 2020: “The management of the Association of Pensioners’ Associations of Slovenia supports the demands of the Community of Social Institutions of Slovenia to improve work and life in homes for the

Slovenia, some homes for the elderly and terminally ill were particularly exposed: as particularly risky, understaffed and overcrowded. The medical profession community and daily politics have tried to comment on the situation in these homes. Some of them have denied the existence of “special concern and dire straits,” some of them have confirmed it. The media and investigative journalists are trying to figure out what was really going on and what were the actual consequences of the situation during the pandemic in these homes. There are indications that not everything was as it should be. The media and the public demand and wait to final findings.¹³

At first only politicians were addressing the public about what is happening in general and about what is happening in these institutions.¹⁴ Over time, representatives of medicine, psychology, psychiatry and psychotherapy began to appear in the media in greater numbers and with more media attention. They tried to explain the general conditions and feelings of the elderly as the most endangered population, their mental and physical sensations, with explicit emphasis on the increase of such health problems which directly affected this population in pandemic times: how to medically and psychologically treat those people, how to alleviate their suffering, how to calm them down etc. And they also warned that this problem will not end after the official announcement of the end of the pandemic (which came first in Slovenia, Austria and Hungary being second).

On the contrary, it is very likely that this particular problem will intensify after the pandemic (or even, as the WHO and so many doctors and medical scientists across the Europe say, after its “first wave”) (PSYCHIATRIC TIMES, 2019). But there is also reason to ease the concern: due to the latest medical evaluations and predictions the impression is, and this can fill us with optimism, that the effort to address the public encouragingly is also intensifying. In Slovenia and elsewhere in Europe.

The people's testimonies of the facts and circumstances

During the pandemic, I received many letters and messages addressing this topic. People wrote to me about the care given to the elderly. The relatives of the elderly living in nursing homes and similar institutions expressed concern, based on their experience during the pandemic, that they were not being cared in the best way possible. In a medical and psychological sense. I made a promise, at their request, that I would write to the minister responsible for the health department and the president of the Slovenian parliamentary party, which puts the care of pensioners and the elderly in the first place of its daily policy. I kept my promise. And both, the minister and the president of this party responded: quickly, especially to the difficulty and diversity of their work during the pandemic, politely and kindly. With a commitment that they will do their best in this direction as well: in the direction reflected by the letters I have received. The people wanted the two of them to address the public more, frequently and with some optimism, also with the special emphasis on the urgency to act and on the legal, not only political duty of the State Administration and State's institutions in order to optimally take care of this most vulnerable group of people.

4. DISCUSSION

The quality and availability of the palliative care

In its most important final decision on voluntarily euthanasia and physician assisted suicide the ECtHR explicitly stated: “Other research indicated that many people who requested physician-assisted suicide

elderly. Among these is the requirement to develop a unified professional strategy for home management during the epidemic, as the vast majority of coronavirus victims were home residents.”

¹³ Officially (according to the statistics provided by the Slovenian National Institute for Public Health, June 2020) 108 people have died from Coronavirus. The vast majority of deaths included population of elders over 85 y. o.: 61 people. Within the population of those between 75 and 84 y. o. there were 28 cases of death, between 65 and 74 y. o. the number is 15, two cases of death between 55 and 64 and one death in the group of 45 to 54 y. o. More women than men died. The number of people infected by Coronavirus is – to the date – 1500. This includes 306 doctors or other medical staff, 323 care recipients living in nursing homes for elders and 137 members of staff in those nursing homes. Conclusion: old people living in nursing homes for elders (most of them with chronic diseases or other disabilities) were the most endangered population in Slovenia.

¹⁴ From the very start of the pandemic I was addressing the Slovenian media and tried to motivate the journalists to give more media coverage, space and time to doctors, other medical staff and professional staff in nursing homes nad homes for the elderly. With some success, I can say with moderate satisfaction. See, for example, one of my public addresses on the issue; Teršek, 2020a.

withdrew that request if their depression and pain were treated. In their experience, palliative care could in virtually every case succeed in substantially relieving a patient of physical and psychosomatic suffering” (ECtHR, case of *Pretty v. UK*, 2002, para. 30). So, my strong conviction to raise awareness of the importance of the palliative care, organized systemically and with the most quality and effectiveness as objectively and reasonably possible remained and intensified.

For several years now, I have been publicly warning in Slovenia that the State – or any of the EU Member States - is legally obliged, by the Constitution and international law, to provide quality and effective, systemic and institutionally regulated care for the elderly and terminally ill people (PALLIATIVE CARE IN THE EUROPEAN UNION, 2020; Gwyther, Brennan and Harding, 2009). Especially for those people rapidly approaching the moment of the end of life in a natural way (voluntary euthanasia and physician assisted suicide still being excluded and prohibited by the criminal law). And that this is also an explicit request, or rather demand of the ECtHR case-law. The right to life as such, in itself, also includes the legal duty of the state to take appropriate care of the terminally ill and dying people; through legal policies and legislation, and through the systemic mechanisms and appropriate institutions, functioning effectively and without financial obstacles. It is an integral part of the s. c. constitutional *doctrine of positive obligations of the State*; Mowbray, 2004). According to this doctrine, which is an integral part of common European law, the State must do everything that can be reasonably expected of it to optimally regulate the living situation of terminally ill and dying people. To regulate effective institutional care for them and thus ensure that they spend as dignified, peaceful and as humane time as possible in their torments, suffering and spending of the last days in this world. The State must do this because of the existing and confirmed human right to a dignified life; because of its legal obligation regarding the *right to dignified life* - which includes *the dignified natural death*. By other words, this right also includes the right to a dignified and as painless as possible “waiting” for the natural death (WHO. Palliative care, 2020).

For so many years, I have been publicly repeating in Slovenia, over and over again, that the state must therefore either establish and run a system of hospices and other palliative care facilities or help privately established hospices and palliative care providers as much as it possible (objectively and reasonably) can; legally, financially and systemically. Above all, the state must not allow these institutions to be less and less in numbers, or to have less and less professional staff available, not to say less and less funds... The state must not allow, or even cause – due to its policies and financing - for these institutions to close their doors and to fail, to cease to function - due to lack of the professional staff available and funding. For the State Administration to allow this to happen would not only be to act immorally and ethically unacceptable, but it would also be a violation of the state's legal duty: both, under the Slovenian Constitution and under the common European law, the legal order of the EU as such and the ECtHR case-law.

If the state doesn't do this, or if it doesn't do so in efficient and persuasive manner, it is legally, not just politically, responsible for failing to fulfil its positive legal obligations and for violating the right to life *as such*- of these people and their loved ones. This also applies in any case where the state does not provide financial assistance to those who carry out such an activity, thus making their work significantly more difficult or even impossible.

The waiver of this duty of the state in such a case allows (or calls for) the initiation of legal proceedings - against the state. The victims - the sick, the dying and those closest to them - can sue the state before national courts for damages, and, if doing so unsuccessfully, later also before the ECtHR; if for nothing more than at least for just satisfaction, materially based on an indirect violation of the right to life. I believe that such legal actions (lawsuits) against the state should also be allowed before the Court of Justice of the EU.

As a constitutional lawyer and a citizen, I therefore propose that individuals who have a legitimate legal interest bring legal actions (lawsuits) for damages against their country in the national courts. In EU Member States where the law (statutes) allows the filing of the so-called *class actions*, this legally institutionalised mechanism should be used also. Even if national courts are not able to deal professionally and ethically with these cases and resolve this issue in a judicial manner, the way to the ECtHR must be open in all such cases. In such cases, lawsuits could amount to tens or even hundreds of

thousands of Euros. After all, it is THE *right to life*, combined with a *right to human dignity*, a *right to live and die in dignity* (Brennan, Gwyther, and Harding, 2008), a right for *living a dignified life*. A right that is above all other fundamental human rights.¹⁵ In such cases, the legal action, the lawsuit, can be brought to the courts with a description of the facts, with a convincing explanation of the reasons for claiming that the state has not fulfilled its positive obligations regarding the right to life, as well as with a flat financial assessment of the damage caused: for material and non-pecuniary damage (Teršek, 2014, pp. 312-322). The lawsuit can be filed by legal representatives of hospices, other similar palliative care facilities, relatives or other persons who are intimately closest to the dead or terminally ill, or by the latest themselves; generally, by the directly affected people / patients / terminally ill / dying.¹⁶

Palliative Care vs. Euthanasia

There are many citizens, members of the academia, medical scientists and especially philosophers of ethics in Slovenia who not only think, but strongly support the idea of legalizing voluntarily euthanasia and medical physician assisted suicide. In the past the question was publicly asked and repeated: are there persuasive reasons to once again rethink our position on *the right to die* and justify its recognition as a constitutional right? Many well-founded reasons seem to argue in favour of a constitutional and medical re-evaluation of certain approaches to matters of life and death. Our concern with matters of death should in fact imply the highest possible concern for effective, persuasive and responsible protection of the quality of life *per se*. This meaning, in constitutional terms, the strongest and the most effective protection of the right to human dignity, the dignity of each individual as-a-person. It seems, at least for me, to be an absolute, persuasive and coercive necessity. This concern and responsibility must be strengthened. It was obvious before, it became obvious during the Coronavirus COVID-19 pandemic and it is becoming ever more obvious now, after the official end (let us hope not just the end of the first “wave”) of the pandemic in Slovenia.

At the same time, there are several fair, reasonable and convincing arguments in favour of the view that the right to active voluntary euthanasia and physician-assisted suicide should, at least in some cases, be legally allowed. In doing so, the society could (or would) necessarily, responsibly and persuasively show the respect for other fundamental human rights and special issues, such as (the most obvious) liberty interest and the right to the effective protection of human dignity. To the life IN dignity. This is the most emphasized argument of the publicly most active supporters of this proposal.

But, before the Republic of Slovenia recognizes the right to voluntarily euthanasia and physician assisted suicide by law, which I consider to be the legitimate proposal of the secondary importance, the goal with primary importance must be achieved: assuring and establishing much more efficient and quality systemic and institutional responsibility regarding the right to life and human dignity. First, the quality and effective system of palliative care is needed. Second, the quality and effective systemic protection of mental health, of each individual and of the Nation as a whole. Third, the quality and effective system

¹⁵ E. B. Moltara, 2014, p. 1: »Palliative care (PAL) is an important, indispensable component of the health care of patients with incurable disease and is provided at all levels of the health system. The comprehensive care of palliative patients is provided by a multi-professional team that provides solutions to the physical, mental, social and spiritual problems faced by palliative patients and their relatives. The main goal is to take care of the best possible quality of life. Palliative care recognizes life and dying as a natural process.»

¹⁶ Univerzitetna klinika Golnik: »The terminally ill are often treated unsatisfactorily in the advanced stage of the disease, as both healthcare professionals and relatives want to prolong their lives at all costs. We cannot usually enable them to do so, but we can reduce or eliminate their suffering and improve the quality of the rest of our lives. We try to alleviate patients' pain and other disturbing symptoms as much as possible, but we also take care of their mental and spiritual needs and the needs of their relatives. We help them live as well as possible (to the best of their ability) and, as far as possible, actively until death, and we offer help to the patient's family both during the illness and after the patient's death, during mourning. We do not accelerate or delay death, we accept it as a natural process. Through our work, we try to develop compassion and hope.

A condition for good palliative care is good communication between staff, patients and their relatives. The patient and his / her relatives should entrust their problems, wishes and expectations to the experts participating in the palliative care team. It is also important that they actively participate in planning treatment procedures for the time when they will not be able to actively decide for themselves (refusal of hospital treatment in the last period of illness, refusal of resuscitation and other procedures of hopeless attempts to prolong life). Thus, the patient and his relatives become equal members of the team and actively participate in the treatment.” Available at: <https://www.klinika-golnik.si/dejavnost-klinike/paliativna-dejavnost> (1.8.2020).

for preventing suicides. Before this is done, that's my strong claim, the proposal for legalizing voluntarily euthanasia and physician assisted suicide must step aside as the concern of secondary importance.¹⁷ So, I claim: direct focus should be on fulfilling the *primary goal*: the effective protection of mental health, preventing suicide and assuring the quality palliative care. The latter being the positive obligation of the state even according to the ECtHR case-law. Putting this necessary and responsible task inside the frame of improving the system of public health and improving the systemic care for terminally ill patients and for the elderly. And for children, especially for terminally ill children and children with special needs. Which includes the empowerment of their parents, guardians, educator and teachers with knowledge, sufficient funds and employment possibilities. I strongly consider this to be a reasonable component of the positive obligations of the state. Before this task will be done convincingly, effectively and with the most quality, in the systemic and institutional manner, any real effort to defend the right to die as a fundamental right, any attempt for serious and credible discussion on general "right to die" will seem more than just inappropriate (Teršek, 2020b).¹⁸

5. CONCLUSION

Last but not least

The awareness of the legally existing positive obligation of the state to secure quality and effective legal policies, institutional environment and legal mechanisms for a successful effort towards a quality and effective palliative care system must be increased and strengthened. In the daily politics realm, general public and legal community. And, of course and above all, by doctors and other professional staff in the healthcare system.¹⁹

¹⁷ Slovensko združenje paliativne oskrbe: »Palliative care is the active holistic treatment of patients with incurable disease and the support of their loved ones. The main elements of palliative care are: individual (patient) tailored management of problems (physical, psychological, spiritual, social) during the treatment of an incurable disease, professional care in the last period of life and during death, support for the family during illness and during mourning. Treatment should be ongoing regardless of when and where the patient is cared for. Basic palliative care can be excellently provided by a selected family doctor together with a community doctor, only 20% require procedures that require treatment within the hospital.

The basic purpose of palliative care is to improve the quality of life of the patient and their loved ones through procedures and measures to ensure the appropriate identification, assessment and treatment of the problems of terminally ill patients. The palliative approach in the treatment of the patient should start early after the diagnosis of an incurable disease and should initially be intertwined with treatment aimed at slowing down the underlying disease. As the underlying disease progresses, however, palliative care usually prevails in treatment and continues to be treated in the process of dying, death, and mourning. The care of a dying patient is merely part of comprehensive palliative care.

Palliative care is not only appropriate for patients with an incurable stage of cancer, but is an integral part of the health care of patients with chronic cardiovascular diseases (lung, lung, neurological diseases (e.g. chronic heart failure, chronic obstructive pulmonary disease, dementia, and also in the elderly with geriatric syndromes).

Palliative care ensures respect for applicable ethical and legal norms: human rights, the rights of the sick and the dying. A well-trained team of experts is needed to deal with more complex problems during the period of palliative care. The basic specialist team consists of a doctor, nurse and coordinator with additional knowledge of palliative care, and if necessary also includes a social worker, clinical psychologist, occupational therapist, physiotherapist, dietitian, spiritual care provider and volunteers. The extent of their care depends on the needs of the patient and his loved ones and escalates from the onset of the disease to death. In the implementation of palliative care, a good mastery of communication skills is essential.

In palliative care, an equal and active relationship with the patient and his relatives is very important, which ensures that the patient's values and desires guide clinical decisions.

The positive effects of palliative care have been scientifically proven, making palliative care an indispensable component of healthcare in many more developed countries. Palliative medicine is a profession that has been rapidly evolving and advancing in recent years. Every year, more and more new, evidence-based approaches and options for managing symptoms become available. The knowledge and skills of palliative medicine are highly valued as they are an integral part of the daily work of many healthcare professionals. With the increase in the number of cancer patients and other chronic diseases and the increase in life expectancy, the need for palliative care is growing. Palliative care is an integral part of the health and social care system at all levels and thus an inalienable element of the human right to health and social care."

¹⁸ Vita: » Despite great technological developments and the success of modern medicine, there is often no cure. If the disease spreads and affects vital organs, the disease is no longer manageable. In such cases, intensive care procedures (used too often) do not stop the disease, burden the patient, and do not alleviate the problems caused by the advanced disease. Palliative care eliminates and alleviates the symptoms of the disease in such patients for the remaining months of life." Available at: https://www.revija-vita.com/vita/57/Ko_ni_ozdravitve_tegobe_bla%C5%BEi_paliativa (2.8.2020).

¹⁹ The Institute of Oncology Ljubljana. Palliative care: Palliative care (PAL) is a comprehensive treatment of patients with incurable disease and assistance to their loved ones. It covers the management of physical symptoms of illness, care, alleviation of mental, social and spiritual problems. The purpose of palliative care is to maintain an optimal quality of life, taking into account all the patient's needs, to help relatives during illness, death and mourning. Available at: https://www.onko-i.si/dejavnosti/zdravstvena_dejavnost/skupne_zdravstvene_dejavnosti/paliativna_oskrba (1.8.2020).

»Doctors, nurses and allied health professionals who work in hospitals are increasingly required to provide care and service to older people with complex needs who may be at the end of life. Balancing treatment of end-stage chronic complex conditions with identification of, and preparation for, the end of life are the skills in which many healthcare professionals are inadequately educated. Hospital systems and clinicians have become so wonderfully skilled at treating chronic complex illness and prolonging life, that entering into discussions about the inevitable end of life or dying may seem rather superfluous. However, we will all die. For professionals, learning how to begin conversations about future care needs and likely prognosis is key – along with effective teamwork, recognising and responding to suffering, and compassionate care when death is imminent« (Devery, 2020).

And the state must assist them, with quality public healthcare system, by providing the necessary financial resources, by providing funds for the quality and development of the education system of future doctors, scientists and professional staff in the field of medicine, nursing and palliative care, with an appropriate salary policy, personnel policy and employment policy in the health sector. Institutions such as hospices and nursing homes should not be considered second or third class, or even pushed aside and overlooked. The same applies to the professional staff needed for the quality operation of these institutions, for their employment opportunities and the amount of their personal income. After all, this is not only a legal question (and problem). It is a matter of ethics, a matter of humanity.²⁰

When we talk about the right to life and the right of every human being to (political, legal and medical) protection of his or her personal dignity, we are actually talking about the *fundamental human right to palliative care*: of the elderly, disabled people and terminally ill. In this area, the paths of responsible, caring, sensitive, solidarity-based, humanitarian and forgivingly loving CARE of the state, public administration, the legal order (as a system) and of the public healthcare system for each individual - as a person - cross. In the function of safeguarding everyone's personal dignity. And palliative care should be one of the absolute short-term priorities of legal policy and the organization of the public healthcare system in Slovenia and in all EU Member States.²¹

In this area and in this context, I see a good opportunity for professionals in physiology and physiotherapy: for their active participation in the establishment of a high-quality palliative care system and in the care of the elderly, disabled people, terminally ill and dying.

²⁰ Anton Trstenjak Institute. Palliative care: »Palliative care is active and comprehensive care, nursing and monitoring of the patient. In general, this term is used when talking about any form of care that alleviates symptoms, even if there is hope for a cure. The World Health Organization (WHO) defines palliative care as active assistance to terminally ill patients and their relatives. An incurable disease is not only cancer, but so are other chronic diseases. The life expectancy of patients with such diseases varies, and everyone needs the help of many professionals during the illness. The extent of this assistance escalates from the onset of the disease to death. Thus, palliative care encompasses a comprehensive treatment of the patient's psychological, social, spiritual, and existential needs, where needs related to the incurable disease are at the forefront. It focuses not only on the patient and his needs, but also on the care of the patient's family and, after the patient's death, also on the care of all the bereaved.« Available at: <http://www.inst-antonatrstenjaka.si/gerontologija/slovar/1040.html> (1.8.200).

»The term comes from the Latin word for cloak, "palla," and the verb "palliare" means "covered with a cloak, to cloak". In a figurative sense, we cover the patient with relief. Palliative means one that does not cure the disease, but only alleviates, alleviates its symptoms, usually associated with pain. The basic goal of palliative care is to achieve the best quality of life by alleviating suffering, managing and alleviating the symptoms of advanced disease, and restoring body functions according to individual feelings, nation culture, religious values, expectations, and practices in an environment. Palliative care should be available to patients where they are, most often at home, in nursing homes and in hospitals. Some patients need more complex care in specialized hospice facilities. Palliative care differs from palliative care provided only by a nurse and from palliative medicine provided by a physician (with methods aimed at relieving symptoms rather than treatment). The foundation of good and effective palliative care is a multidisciplinary team - a palliative team: a doctor, a nurse, a physiotherapist, an occupational therapist, a social worker, a psychologist, volunteers, a priest and relatives. The basic principles of palliative care, as enshrined in the World Health Organization, are: respects life and accepts dying as a natural occurrence, it neither delays nor accelerates death, takes care of relieving pain and other symptoms, gives the patient psychological, social and spiritual support, through various forms of assistance, it enables the patient to live a full and dignified life until death, helps the patient's family / loved ones during the illness and during mourning. In 1967, with the emergence of the first modern hospice (St. Christopher's Hospice) in the UK, modern palliative care began to develop. Its founder was Cicely Saunders, who was supposed to be the originator of the modern hospice movement. Palliative care as a comprehensive health care for patients and their relatives is not yet regulated in the Slovenian health care system, although the Social Welfare Strategy for the Elderly envisages that a national palliative care program will have to be prepared as an integral part of the public health service network. Since 1996, only the non-governmental organization Slovenian Hospice Association has been providing comprehensive palliative care.«

²¹ Comp. Teršek, 2020c.

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