

Editorial / Uvodnik

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

Paliativna oskrba naj ne bo zanemarjena ali celo potisnjena na stranski tir: paliativna oskrba kot sestavni del pravice do življenja in dostenjanstvenega konca življenja

Andraž Teršek^{1, 2, 3,*}

There is one health only. Human health should be understood holistically: psyche (mentality) plus physiology (physicality), as two parts of a whole. And it seems reasonable to conclude that there is only one *death with dignity*. This is the main purpose and central message of my editorial (although I do not oppose the idea of legalising voluntary euthanasia as a "last resort" in cases of unbearable suffering and lack of 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, only to suffer and deteriorate until natural death (Teršek, 2012)).

Or as my friend and outstanding psychiatrist and scientist wrote before cancer ended his precious life:

"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 this short editorial essay, 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 home country, the Republic of Slovenia, an European Union

(EU) Member State, I have been repeating publicly for several years, as a warning and an appeal to the state and the general public, that the *right to life* as such is still not adequately, legally correctly and effectively protected. What I am pointing to is the right to LIFE, the right FOR LIFE, the right to "live a life" until it ends in – its natural – death, and in DIGNITY.

At the time when the coronavirus outbreak was officially declared a pandemic in 2020, this problem was exactly what it seemed: 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, possibly chronic in nature, represented the most vulnerable group: the *elderly* and *terminally ill* (Preskorn, 2020). As can be seen from the reports of EU commissions and committees, from the Slovene National Institute of Public Health (NIJZ) and related institutes in other EU Member States and across the Atlantic, many of these people were not provided with the best nursing care or high-quality and optimal medical and psychological care (RTVSLO, 2020; Sancin, 2020; Siolnet, 2020).

There were many substantial and noticeable differences between EU Member States in this regard. For example, according to media reports and interviews with doctors and other medical professionals conducted by Slovenia's public television, in Slovenia patients aged 75 years or more accounted for 80 % of deaths presumably resulting from the COVID-19 virus, whereas in neighbouring Austria this population accounted for only 20 % of deaths. Quite a difference, one would argue? While we may have some doubts about this information and cannot regard it as categorically reliable (besides, such data varies between individual EU Member States), we may

¹ University of Primorska, Faculty of Education, Cankarjeva 5, 6000 Koper, Slovenia

² University of Primorska, Faculty of Humanities, Titov trg 5, 6000 Koper, Slovenia

³ European Faculty of Law, New University, Mestni trg 23, 1000 Ljubljana, Slovenia

* Corresponding author / Korespondenčni avtor: andraz.tersek@gmail.com

Received / Prejeto: 15. 7. 2020

Accepted / Sprejeto: 1. 11. 2020



nevertheless tentatively conclude – by browsing the internet and combining the publicly offered reports by nursing homes (Krajnc, 2020) and official government statistics – that the elderly and terminally ill presented the most vulnerable population (National Institute of Public Health of the RS [NIJZ], 2020. I am referring to the people whose lives were quickly slipping away due to terminal illness even before the actual *state of emergency* (even if only *de facto* and not *de iure*) was declared at the time of the pandemic, addressed as (merely) "extraordinary circumstances" (for the constitutional-law analysis of the restrictions on constitutional rights and freedoms by the government decree during the official pandemic, see Dragan and Teršek (2020)). Many of these people unfortunately lost their lives during the pandemic. Should we be concerned about this fact? I maintain that we should and must be very concerned (Mekina, 2020).

Palliative care as a fundamental human right

In its most important final decision on voluntarily euthanasia and physician-assisted suicide, the European Court of Human Rights (ECtHR) explicitly stated: "Other research indicated that many people who requested physician-assisted suicide 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" (Pretty v. the United Kingdom, 2002; Valentinčič, 2015). This statement has only reaffirmed and intensified my firm conviction of the need to raise awareness, as objectively and reasonably as possible, of the importance of palliative care which is to be organised systemically and with the highest possible quality and effectiveness.

For several years, I have been publicly warning in Slovenia that the state – or any EU member state – is legally obliged by its Constitution and international law to provide high-quality, effective, systemically and institutionally regulated care for the elderly and terminally ill (Secretariat of the Commission of the European Community, 2016), especially for people who are naturally approaching the end of their lives (voluntary euthanasia and physician-assisted suicide still being excluded and prohibited under criminal law). This is also an explicit requirement or rather a demand of the ECtHR case law (Pretty v. the United Kingdom, 2002; Valentinčič, 2015). The right to life as such also includes in itself the legal duty of the state to provide adequate care for the terminally ill and dying via its legal policies and legislation, and through systemic mechanisms and appropriate institutions, which are to function effectively and without financial obstacles. This is an essential part of the so-called constitutional *doctrine of positive obligations of the State* (Mowbray, 2004). According to this doctrine, which forms an integral part of the common European

law, the state must do everything reasonable within its power to optimally regulate the life situation of the terminally ill and dying. It must provide them with an effective institutional care and thus ensure that they spend their pain- and suffering-filled final days in as dignified, peaceful and humane a manner as possible. The state must ensure this due to the existing and confirmed human right to a dignified life, so as to fulfil its legal obligation to protect the *right to a dignified life* - which includes *dignified natural death*. In other words, this right also includes the right to a dignified and as painless as possible "waiting" for natural death (World Health Organisation [WHO], 2020).

As I have publicly repeated for several years, the state must therefore either establish and operate a system of hospices and other palliative care facilities, or provide privately established hospices and palliative care providers with legal, financial and systemic assistance of the highest possible (objective and reasonable) degree. Above all, the state must not allow these institutions to become fewer and fewer in number, or to have less and less professional staff available, not to say less and less funds. In its policies and financing, the state must not allow or even cause these institutions to close their doors or to stop functioning due to a lack of professional staff and funding. Should the state administration allow this to happen, it would not only act immorally and in an ethically unacceptable manner, but it would also be in violation of its legal duty under the Slovene Constitution and the common European law, the legal order of the EU as such and the ECtHR case law.

If the state fails to do so, or fails to do so in an efficient and persuasive manner, not only politically, but also legally 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 fails to provide financial assistance to those who provide such services, thus making their work significantly more difficult or even impossible.

Palliative care before euthanasia

There are many citizens, members of academia, medical scientists and in particular ethical philosophers in Slovenia who accept and strongly support the idea of legalising voluntarily euthanasia and medical physician-assisted suicide. This question has already been publicly addressed and repeated: Are there convincing reasons to reconsider our position on the *right to die* and to 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 such issues of life and death. Our concern with issues of death should in fact imply the highest possible concern for an effective, persuasive and responsible protection of the quality

of life *per se*. In constitutional terms, this means the strongest and most effective protection of the right to human dignity, the dignity of each individual-as-person, which seems, at least to me personally, to be an absolute, convincing and coercive necessity. This concern and responsibility must be strengthened. This had already been obvious before, it became obvious during the COVID-19 pandemic, and it is becoming even more obvious now, after the official end (let us hope not only the end of the first "wave") of the epidemic in Slovenia.

At the same time, there are several fair, reasonable and convincing arguments which support the view that the right to active voluntary euthanasia and physician-assisted suicide should be legally allowed, at least in some cases. Society could (or would) thus necessarily, responsibly and persuasively also demonstrate its respect for other fundamental human rights and specific issues, such as (the most obvious) liberty interest and the right to an effective protection of human dignity and to life in dignity. This is an argument which is most strongly emphasised by publicly active supporters of the proposal.

However, before the Republic of Slovenia recognises the right to voluntary euthanasia and physician-assisted suicide by law, which I consider to be a legitimate proposal of secondary importance, a goal of primary importance must be achieved: to secure and establish a much more efficient and high-quality systemic and institutional responsibility regarding the right to life and human dignity (Teršek, 2014). First, a high-quality and effective system of palliative care is needed. Second, a high-quality and effective systemic protection of mental health, for each individual and the Nation as a whole. Third, a quality and effective system of suicide prevention.

Direct focus should be directed towards fulfilling the *primary goal*: effective protection of mental health, suicide prevention and ensuring high-quality palliative care. The latter is also a positive obligation of the state according to the case law of the ECtHR (Pretty v. the United Kingdom, 2002), an obligation to place this vital and responsible task within the framework of improving the public health system and improving the systemic care for the terminally ill and the elderly, as well as for children, especially those who are terminally ill and those with special needs. This includes empowering their parents, guardians, educators and teachers with knowledge, sufficient funds and employment possibilities. I firmly believe that this is a reasonable component of the positive obligations of the state. However, before this task is completed in a systemic and institutional manner that is convincing, effective and of the highest quality, any genuine attempt to defend the right to die as a fundamental right, any attempt to hold a serious and credible discussion on a general "right to die" will seem no more than inappropriate (Teršek, 2020b).

Increased awareness and strengthened positive obligations

It is necessary to increase and strengthen the awareness of the legally existing positive obligation of the state to secure, through its day-to-day politics, the general public and the legal community, high-quality and effective legal policies, adequate institutional environment and legal mechanisms for providing high-quality and effective palliative care — of course and above all by doctors and other healthcare professionals.

»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).

The state must assist them, through a high-quality public healthcare system, by providing the necessary financial resources and 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, as well as through an adequate salary, personnel and employment policies in the health sector.

Institutions such as hospices and nursing homes should not be regarded as second- or third- class institutions or even be pushed aside and overlooked. The same applies to the professional staff needed for a high-quality operation of these institutions, their employment opportunities and the level of their personal income (Teršek, 2020a). After all, this is not only a legal issue (and problem). It is a matter of ethics, a matter of humanity.

Slovenian translation / Prevod v slovenščino

Zdravje je eno samo. Človekovo zdravje je treba razumeti celostno: psiha (miselnost) ter fiziologija (telesnost) namreč tvorita neločljivo celoto. Iz tega sledi, da je dostojanstvena smrt prav tako ena sama. To je poglavitni namen in osrednje sporočilo mojega uvodnika, čeprav ne nasprotujem zamisli o legalizaciji prostovoljne evtanazije v smislu »skrajnega ukrepa« v primerih neznosnega trpljenja in nezmožnosti

ozdravitve ali podaljšanja življenja. Obenem to pomeni posamezniku kot človeku omogočiti dostojno in kakovostno življenje brez neznosnega trpljenja in želje po nadaljevanju življenja v medicinsko pogojeni agoniji in obupu samo z namenom podaljšanja trpljenja in mučenja do naravne smrti (Teršek, 2012).

Ali kot je zapisal moj prijatelj ter izjemen psihiater in znanstvenik, preden je rak končal njegovo dragoceno življenje:

Morda je sedaj čas, da strokovnjaki za javno zdravje preidejo z razumevanja duševnega zdravja kot enega od dejavnikov zdravja na duševno zdravje kot poglavitni zdravstveni kazalnik prepletanja tako neprijetnih življenjskih okoliščin ali dogodkov kot tudi kakovosti zdravstvene oskrbe. Vemo, da življenjski dogodki in okoliščine pomembno vplivajo na splošno zdravje človeka, pri čemer je duševno zdravje zaradi svoje visoko akutne odzivnosti tudi najbolj občutljivo. Posledično bi bilo duševno zdravje potrebno upoštevati kot najobčutljivejši zdravstveni kazalnik, ki po eni strani odseva možne učinke različnih stopenj kakovosti zdravstvene oskrbe, po drugi strani pa življenjske dogodke in spremenjene življenjske okoliščine (Marušič, 2009, str. 93).

V svojem kratkem uredniškem eseju ne bom neposredno obravnaval človekove in ustavne pravice do »dostojanstva« ali pravnega varstva »dostojnega življenja« vsakega posameznika kot osebe v družbenem smislu (Barak, 2015). V svoji domovini, Republiki Sloveniji, državi članici Evropske unije (EU), že vrsto let javno opozarjam državo ter širšo javnost, da pravica do življenja kot tako še vedno ni primerno, pravno ustrezno in učinkovito zaščitena. V tem kontekstu ciljam neposredno na pravico DO ŽIVLJENJA, pravico ZA ŽIVLJENJE, pravico »živeti življenje«, dokler se to ne zaključi z naravno smrtno, DOSTOJANSTVENO.

V času uradno razglašene pandemije koronavirusna 2020 je bil problem natanko ta: življenje samo je bilo postavljeno v jedro problematike in dogodkov na nacionalni in svetovni ravni. Zlasti življenje oseb, ki so zaradi starosti ali predhodnih (morda kroničnih) bolezni predstavljalni najbolj ogroženo populacijo: starejših in neozdravljivo bolnih (Preskorn, 2020). Kot je razvidno iz poročil komisij in svetov Evropske unije, slovenskega Nacionalnega inštituta za javno zdravje (NIJZ) in sorodnih inštitutov v drugih državah članicah EU ter onkraj Atlantika, mnogim od teh posameznikov ni bila zagotovljena optimalna zdravstvena nega ali kakovostna in optimalna zdravstvena ter psihološka oskrba (RTVSLO, 2020; Sancin, 2020; Siolnet, 2020).

V tem smislu so bile med državami članicami EU bistvene in opazne razlike. Medtem ko je bilo v Sloveniji, sodeč po medijskih poročilih in intervjujih z zdravniki in drugimi zdravstvenimi delavci, ki jih je opravila slovenska javna televizija, med smrtnimi primeri, ki so bili najverjetnejše neposredna posledica virusa COVID-19, kar 80 % starejših od 75 let, je v

sosednji Avstriji ta populacija predstavlja le 20 % smrti. Najbrž je upravičeno trditi, da je razlika precejšnja. Glede teh podatkov imamo lahko določene zadružke, saj jih ni mogoče enostavno sprejeti kot kategorično zanesljive. Prav tako se tovrstni podatki razlikujejo med državami članicami EU. Pa vendarle lahko izpeljemo previden zaključek: glede na spletnne podatke in pregled javno dostopnih sporočil vodstev domov za starejše (Krajnc, 2020) ter glede na uradne državne statistike v najbolj ogroženo populacijo sodijo ostarele in neozdravljivo bolne osebe (National Institute of Public Health of the RS, 2020). V mislih imam ljudi, katerih življenje se je zaradi neozdravljive bolezni hitro bližalo koncu, še preden je prišlo do dejanskega izrednega stanja (čeprav le *de facto*, ne pa tudi *de iure*), ki se ga je obravnavalo kot (zgolj) »izredne okoliščine« v času pandemije (za ustavnopravno analizo omejitev ustavnih pravic in svoboščin z vladno uredbo med uradno pandemijo glej Dragan in Teršek (2020)). Mnoge od teh oseb so med pandemijo žal izgubile življenje. Bi nas to dejstvo moralo skrbeti? Trdim, da bi nas moralno in nas mora zelo skrbeti (Mekina, 2020).

Paliativna oskrba kot temeljna človekova pravica

Evropsko sodišče za človekove pravice (ESČP) v svoji najpomembnejši končni odločitvi o prostovoljni evtanaziji in samomoru z zdravniško pomočjo izrecno navaja, da nekatere raziskave kažejo, da številni ljudje, ki zaprosijo za samomor z zdravniško pomočjo, to prošnjo umaknejo po zdravljenju depresije in bolečin. Sodeč po njihovih izkušnjah, bi lahko paliativna oskrba v skoraj vsakem primeru bistveno razbremenila pacienta njegovega fizičnega in psihosomatskega trpljenja (Pretty v. the United Kingdom, 2002; Valentincič, 2015). To samo še potrjuje in krepi moje prepričanje o nujnosti ozaveščanja o pomenu sistemsko organizirane ter karseda kakovostne in učinkovite paliativne oskrbe.

V Sloveniji že vrsto let javno opozarjam, da je država – ali katera koli država članica EU – po ustavi in mednarodnem pravu zakonsko obvezana k zagotavljanju kakovostne in učinkovite, sistemskih in institucionalno urejene oskrbe starejših in neozdravljivo bolnih (Secretariat of the Commission of the European Community, 2016). To velja predvsem za tiste osebe, ki se hitro približujejo naravnemu koncu življenja (kazenska zakonodaja še vedno izključuje in prepoveduje prostovoljno evtanazijo in samomor z zdravniško pomočjo). To je tudi izrecna zahteva ustaljene sodne prakse ESČP (Pretty v. the United Kingdom, 2002; Valentincič, 2015). Pravica do življenja sama po sebi vključuje tudi zakonsko dolžnost države, da neozdravljivo bolnim in umirajočim nudi ustrezno nego s pomočjo pravnih politik, zakonodaje ter sistemskih mehanizmov in ustreznih institucij, ki morajo delovati učinkovito in brez finančnih ovir. To je sestavni del tako imenovane ustavne *doktrine*

o pozitivnih obveznostih države (Mowbray, 2004). V skladu s to doktrino, ki je sestavni del skupnega evropskega prava, mora država storiti vse, kar je od nje upravičeno pričakovati, da optimalno uredi življenjsko situacijo neozdravljivo bolnih in umirajočih. Z zagotovitvijo učinkovite institucionalne oskrbe mora tem osebam omogočiti, da muke in trpljenje ob koncu življenja preživijo čim bolj dostojanstveno, mirno in humano. Država mora to zagotoviti zaradi svoje pravne obveznosti glede uresničevanja obstoječe in potrjene človekove pravice do dostojnega življenja, ki vključuje dostojanstveno naravno smrt. Z drugimi besedami, ta pravica vključuje tudi pravico do dostojanstvenega in čim bolj nebolečega »čakanja« na naravno smrt (World Health Organisation [WHO], 2020).

V Sloveniji že dolga leta javno ponavljam, da mora država zato bodisi vzpostaviti in voditi sistem hospicev in drugih objektov paliativne oskrbe bodisi zagotoviti pomoč zasebno ustanovljenim hospicem in izvajalcem paliativne oskrbe, če je to (objektivno in razumno) mogoče v pravnem, finančnem in sistemskem smislu. Predvsem pa država ne sme dopustiti znižanja števila tovrstnih ustanov ali njihovega strokovnega osebja (in sredstev). V kontekstu državnih politik in sistema financiranja država ne sme dopustiti ali celo povzročiti zapiranja, propada ali prenehanja delovanja tovrstnih ustanov zaradi pomanjkanja razpoložljivega strokovnega osebja in financiranja, saj bi takšno ravnanje državne uprave bilo ne le nemoralno in etično nesprejemljivo, ampak bi s tem kršila pravno dolžnost države – tako po slovenski ustavi kot po skupnem evropskem zakonodajnem pravnem redu EU ter sodni praksi ESČP.

Če država tega ne zagotovi oziroma tega ne zagotovi dovolj učinkovito in prepričljivo, je ne le politično, ampak tudi pravno odgovorna za neizpolnjevanje pozitivnih zakonskih obveznosti in tako posameznikom kot njihovim svojcem za kršitev pravice do življenja. To velja tudi v vsakem primeru, ko država z nezagotavljanjem finančne pomoči tistim, ki tovrstno dejavnost opravlja, znatno oteži ali celo onemogoči njihovo delovanje.

Paliativna oskrba pred evtanazijo

V Sloveniji številni državljeni, člani akademskih krogov, raziskovalci s področja medicine, predvsem pa etični filozofi ne le pozdravljajo, ampak močno podpirajo zamisel o legalizaciji prostovoljne evtanazije in samomora z zdravniško pomočjo. Vprašanje, ki je že bilo javno zastavljeno in ponovljeno, se glasi: Ali obstajajo prepričljivi razlogi za ponovno opredelitev stališča do pravice do smrti in za upravičenje njenega priznanja v smislu ustavne pravice? Zdi se, da v prid ponovni ustavni in zdravstveni presoji nekaterih pristopov k vprašanjem življenja in smrti govorijo številni utemeljeni razlogi. Osredotočanje na vprašanja, povezana s smrto, naj bi vendarle odsevalo največjo

možno skrb za učinkovito, prepričljivo in odgovorno varovanje kakovosti življenja. Ta namreč v ustavnem smislu pomeni najmočnejšo in najučinkovitejšo zaščito pravice do človekovega dostojanstva, torej dostojanstva vsakega posameznika, kar pa vsaj jaz osebno vidim kot absolutno, prepričljivo in nujno potrebo. To skrb in odgovornost je treba okrepliti. Kar je bilo očitno že prej in je postalo očitno med pandemijo koronavirusa COVID-19, postaja vse bolj očitno zdaj, po uradnem koncu (upajmo ne le koncu prvega »vala«) epidemije v Sloveniji.

Obenem obstaja nemalo tehtnih, racionalnih in prepričljivih argumentov, ki podpirajo stališče, da bi bilo pravico do aktivne prostovoljne evtanazije in samomora z zdravniško pomočjo vsaj v nekaterih primerih treba zakonsko dovoliti. Družba bi s tem (lahko) nedvoumno, odgovorno in prepričljivo izkazala spoštovanje do drugih temeljnih človekovih pravic in posebnih vprašanj, kot so (najbolj očitno) osebne svoboščine ter pravica do učinkovite zaščite človekovega dostojanstva in dostojanstvenega življenja. Javno najaktivnejši zagovorniki tega predloga najbolj poudarjajo ravno ta argument.

Preden pa Republika Slovenija zakonsko prizna pravico do prostovoljne evtanazije in samomora z zdravniško pomočjo, kar vidim kot legitimen predlog sekundarnega pomena, je treba doseči cilj primarnega pomena: zagotoviti in vzpostaviti mnogo učinkovitejšo in kakovostnejšo sistemsko in institucionalno odgovornost glede pravice do življenja in človeškega dostojanstva (Teršek, 2014). Najprej je torej treba zagotoviti kakovosten in učinkovit sistem paliativne oskrbe, nato kakovostno ter učinkovito sistemsko varovanje duševnega zdravja vsakega posameznika in naroda kot celote, nenazadnje pa tudi kakovosten in učinkovit sistem preprečevanja samomorov.

Neposreden poudarek bi moral biti na doseganju *primarnega cilja*, ki je zagotavljanje učinkovitega varovanja duševnega zdravja, preprečevanje samomorov ter zagotavljanje kakovostne paliativne oskrbe. Slednje je pozitivna obveznost države tudi v skladu s sodno praksjo ESČP (Pretty v. the United Kingdom, 2002). To nujno in odgovorno nalogu bi bilo treba postaviti v kontekst izboljšanja sistema javnega zdravja ter izboljšanja sistemске nege neozdravljivo bolnih in starejših, prav tako tudi nege otrok, zlasti neozdravljivo bolnih in otrok s posebnimi potrebami, kar pa vključuje tudi opolnomočenje njihovih staršev, skrbnikov, vzgojiteljev in učiteljev z znanjem, zadostnimi sredstvi in možnostmi zaposlitve. Odločno menim, da je to smiseln sestavni del pozitivnih obveznosti države. Dokler ta naloga ne bo prepričljivo, učinkovito in karseda kakovostno opravljena na sistemski in institucionalni ravni, bosta vsakršno prizadevanje v smeri zagovarjanja pravice do smrti kot temeljne pravice ter vsak poskus resne in verodostojne razprave o splošni »pravici do smrti« vse prej kot primerna (Teršek, 2020b).

Večja ozaveščenost in okrepljene pozitivne obveznosti

Povečati in okrepliti moramo zavedanje o pravno obstoječi pozitivni obveznosti države, da zagotavlja kakovostne in učinkovite pravne politike, institucionalno okolje ter pravne mehanizme, ki bi na področju dnevne politike, splošne javnosti in pravne skupnosti podprtli prizadevanja za vzpostavitev kakovostnega in učinkovitega sistema paliativne oskrbe, seveda predvsem s strani zdravnikov in drugega strokovnega zdravstvenega osebja.

Od zdravnikov, medicinskih sester in sorodnih profilov zdravstvenega osebja v bolnišnicah se vse bolj zahteva skrb za zadovoljevanje kompleksnih potreb starejših oseb, ki so morda na koncu življenja. Zmožnost zdravljenja neozdravljinjivih kroničnih zapletenih bolezni končnih stadijev ter prepoznavanja konca življenja in priprava na smrt sta kompetenci, ki sta pri mnogih zdravstvenih delavcih premalo razviti. Bolnišnični sistemi in zdravniki so namreč za zdravljenje kroničnih zapletenih bolezni in podaljšanje življenja usposobljeni tako vrhunsko, da se odpiranje razprave o neizogibnem koncu življenja ali umiranju morda zdi odveč. Vendar bomo vsi umrli. Za zaposlene v zdravstvu so poleg učinkovitega timskega dela, prepoznavanja in odzivanja na trpljenje ter sočutne oskrbe, ko je smrt neizogibna, ključnega pomena tudi spremnosti in znanja, povezana s tem, kako načeti pogovor o prihodnjih potrebah pacienta po oskrbi in verjetni prognozi (Devery, 2020).

Država mora s kakovostnim javnim zdravstvenim sistemom ter ustrezno plačno politiko, kadrovsko politiko in politiko zaposlovanja v zdravstvenem sektorju zdravstvenim delavcem zagotoviti potrebna finančna sredstva, prav tako pa tudi sredstva za kakovost in razvoj izobraževalnega sistema bodočih zdravnikov, znanstvenikov ter strokovnega osebja na področju medicine, zdravstvene nege in paliativne oskrbe. Institucij, kot so hospici in domovi za ostarele, ne bi smeli prištevati med drugo- ali tretjerazedne, niti jih ne bi smeli spregledati ali potisniti na stranski tir. Enako velja za strokovno osebje, ki je nujno potrebno za kakovostno delovanje teh ustanov, za njihove zaposlitvene možnosti ter višino njihovih osebnih dohodkov (Teršek, 2020a). Navsezadnje to ni samo pravno vprašanje (in problem). To je stvar etike, stvar človečnosti.

Conflict of interest / Nasprotje interesov

Avtor izjavlja, da ni nasprotja interesov. / The author declares that there is no conflict of interest.

Literature

Barak, A., 2015. *Human dignity: the constitutional value and the constitutional right*. Cambridge: Cambridge University Press.

Devery, A., 2020. End-of-life essentials: increasing professionals' skills and confidence in end-of-life care. *The Blog of the European Association for Palliative Care*, 27. 5. 2020. Available at: <https://eapcnet.wordpress.com/2020/05/27/end-of-life-essentials-increasing-professionals-skills-and-confidence-in-end-of-life-care/> [30. 5. 2020].

Dragan, J. & Teršek, A., 2020. Constitutional-law analysis on constitutional rights and freedoms restrictions in time of 2020 pandemic. *Javna uprava*, 56(1/2), pp. 85–102.

Krajnc, M., 2020. Zdusove strani: domovi za starejše v času epidemije. *Vzajemnost*, 10. Available at: <https://www.vzajemnost.si/clanek/184730/domovi-za-starejse-v-casu-epidemije/> [15. 6. 2020].

Mekina, I., 2020. Prepuščeni smrti v »intimnem domu«: starostnike diskriminirali, vlada pa »šminka« grozno resnico. *Insajder*. Available at: <https://insajder.com/slovenija/prepusceni-smrti-v-intimnem-domu-starostnike-diskriminirali-vlada-pa-sminka-grozno-resnico> [28. 5. 2020].

Marušič, A., 2009. One health only. *Revus*, 10, p. 93. <https://doi.org/10.4000/revus.1060>

Mowbray, A., 2004. *The development of positive obligations under the European Convention on human rights by the European Court of Human Rights*. Oxford: Cambridge University Press.

Preskorn, S., 2020. Coronavirus Disease 2019: the first wave and beyond. *Psychiatric Times*. Available at: <https://www.psychiatrictimes.com/view/coronavirmediatus-disease-2019-first-wave-and-beyond> [25. 6. 2020].

Pretty v. the United Kingdom, 2002-I Eur. Ct. H.R., no. 2346/02.

RTVSLO, 2020. *Oskrovanci domov za starejše obležali v "umazanih plenicah"*. 1. 4. 2020. Available at: <https://www.rtvslo.si/svet/s-in-j-amerika/oskrbovanci-domov-za-starejse-oblezali-v-umazanih-plenicah/525212> [30. 5. 2020].

Sancin, V., 2020. Domovi za ostarele: protest sindikatov. *Primorski dnevnik*, 2. 7. 2020. Available at: <https://www.primorski.eu/trzaska/domovi-za-ostarele-protest-sindikatov-XH548202> [2. 8. 2020].

Secretariat of the Commission of the European Community, 2016. *Opinion of the working group on ethics in research and medicine on palliative care in the EU*. Brussel: COMECE. Available at: http://www.comece.eu/dl/uuomJKJKooNMJqx4KJK/PalliativeCARE_EN.pdf [2. 7. 2020].

Siolnet, 2020. *Grozljive razmere v kanadskih domovih za starejše*. 27. 5. 2020. Available at: <https://siol.net/novice/svet/v-kanadskih-domovih-za-starejse-grozljive-razmere-526348> [6. 6. 2020].

National Institute of Public Health of the RS (NIJZ), 2020. *Coronavirus disease COVID-19*. Available at: <https://www.nijz.si/en> [28. 10. 2020].

- Teršek, A., 2012. Pravica do smrti: vstop v razširjeno polje svobode. *Pravnik*, 67(129), pp. 541–556.
- Teršek, A., 2014. *Teorija legitimnosti in sodobno ustavništvo*. Koper: Univerzitetna založba Annales, Univerza na Primorskem, pp. 312–322.
- Teršek, A., 2020a. Kdo so junaki. *IUSINFO*, 3. 4. 2020. Available at: <https://www.iusinfo.si/medijsko-sredisce/kolumnne/261090> [29. 6. 2020].
- Teršek, A., 2020b. Reflection on legal and political deliberations regarding human life and dignity after the 2020 Coronavirus Pandemic. *ECHR case law*, 12. 6. 2020. Available at: <https://www.echrcaselaw.com/en/2020-pandemic/reflection-on-legal-and-political-deliberations-regarding-human-life-and-dignity-after-the-2020-coronavirus-pandemic/> [6. 7. 2020].
- Valentinčič, N., 2015. Pravica do odločitve o času in načinu lastne smrti. *Dignitas*, 65/66, pp. 37–38. Available at: <http://revije.nova-uni.si/index.php/dignitas/article/view/227> [15. 6. 2020].
- World Health Organization (WHO), 2020. *Palliative Care*. Available at: <https://www.who.int/home/search?query=palliative+care&page=1&pagesize=10&sortdir=desc&sort=relevant&default=AND&f.Countries.size=100&f.Lang.filter=en&f.RegionalSites.size=100&f.Topics.size=100&f.contenttype.size=100&fdoctype.size=101&facet.field=RegionalSites&facet.field=Topics&facet.field=doctype&facet.field=Countries&facet.field=contenttype&facet.field=Lang&tune=true&tune.0=3&tune.1=2&tune.2=2&tune.3=3&tune.4=180&tune.5=75> [5. 7. 2020].

Cite as / Citirajte kot:

Teršek, A., 2020. 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. *Obzornik zdravstvene nege*, 54(4), 272–278. <https://doi.org/10.14528/snr.2020.54.4.3054>