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POST-PANDEMIC COPING WITH SOCIAL INEQUALITIES: PALLIATIVE CARE IN THE AGE OF COVID-19 PANDEMIC¹

Abstract: Palliative patients (patients suffering from an incurable disease that significantly shortens life expectancy) represent one of the most vulnerable social groups among users of the healthcare system. Due to certain poor life prognoses, comorbidities and the severity of the overall clinical picture, the care of this type of patient requires an interdisciplinary approach and the expertise of several specialists at the same time. In this sense, palliative care includes, on the one hand, medical services aimed at alleviating the suffering of palliative patients and improving their quality of life, and on the other hand, psychological support for their families in order to strengthen their resilience. Unfortunately, in periods of instability of the health system, such as the one marked by the COVID-19 pandemic, palliative care services are among those that become subject to systemic restrictions in the field of health services. The paper examines the social position of palliative care patients during the COVID-19 pandemic and the challenges they and their families have encountered.

Keywords MesH: COVID-19, palliative care, Serbia

Non MeSH: health system, resilience

Surviving natural disasters and establishing control over them has always been an integral part of the dynamics of human communities: «For several million years the human race has been improving its control over what is, in many respects, a hostile environment. Mother Earth protects and nurtures us, but also brutally kills and maims many of us. One of the ways we reduce these aberrations of our planet is through the application of science. In the case of earthquakes, this includes seismic prediction, geological analysis, econometric forecasts, projections and institutional policy evalua-

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tion, among others. These procedures are included in what economists call risk analysis and hazard mitigation planning.” [1 p299]

However, natural catastrophes, as Kelman notes, «rarely exist, because disasters are (always, author’s note) social. They arise from a combination of hazard and vulnerability, with vulnerability as a causal factor. ... the disaster occurs on several levels simultaneously, and ... responses to the danger expose problems of vulnerability as much as the original danger...” [2 p296] Indeed, many studies examining the consequences of disasters and social responses to the challenges they impose show that different social groups bear unequally the burden of social system instability produced by a disaster: «Inequalities in income and education, residential segregation and discrimination ... are ‘translated’ into different strategies for coping with the crisis, which themselves are unequal and provide uneven chances, since the resources embodied in them are socially stratified.» [3 p106] The strategies themselves and their choice are not a matter of the free choice of individuals, but the result of the structural circumstances in which specific individuals live. They are a «reflection of long-term fissures in the social structure» [3 p106] that the disaster only makes apparent.

Although «none of this knowledge is new» and most of it was «available long before the virus (corona: author’s note) appeared at the end of 2019, we are again witnessing the failure to use what we know to prevent disasters» [2 p297] and create protocols that would be able to protect the most vulnerable members of the community as well.

Post-pandemic coping with social inequalities

The coronavirus entered the Republic of Serbia on March 6, 2020, when the first officially reported case of the disease was diagnosed. Not long after, on March 15, 2020, the President of the Republic, the President of the Assembly and the Prime Minister signed the Decision on declaring a state of emergency as a response to the pandemic challenge. With the declaration of an «epidemic of major epidemiological importance» on the territory of the Republic of Serbia on March 20, 2020, the health system switches to a special mode of operation, in which the main priority becomes bringing the epidemic under control. The already overstretched² healthcare system in new circumstances tries to organize work with «restructured» and «rationalized» personnel re-

² In the years preceding the outbreak of the coronavirus pandemic, the health system, as well as other systems within the public sector (such as education, the social protection system, etc.), was subjected to “savings measures” introduced by the Government of Serbia for the purpose of restructuring the public sector and consolidation of the financial system of Serbia. The Government of Serbia initiated these reform measures by adopting two documents entitled: (a) Program of Measures for Public Sector Reform, dated June 28, 2013, [4] and (b) National Program of Economic Reforms for the period from 2015 to 2017, [5] which was adopted by the Government of Serbia in March 2015. These documents were intended to implement:

“As part of the fiscal consolidation ... the rationalization of the health system primarily through the reduction of the number of non-medical personnel, the rationalization of the number of hospital beds, the improvement of mechanisms for selecting priorities regarding the acquisition of new equipment and better control of expenditures for medical services (underlined by the author). This will increase the efficiency of health institutions, ensure the evaluation of their actual performance

sources, which produces numerous problems, both within the healthcare system³ itself and in its communication with other social subsystems. Thus, the «sudden» pandemic exposed various «contradictions and vulnerabilities of insufficiently articulated mutual connection» [6 p1] of various social subsystems that, most certainly in the years to come, will face various «cascading» consequences of the pandemic on the social and economic level. Experiences related to the work of the health system in Serbia, which our informants testify about, could show, among other things, how the applied models of austerity measures additionally destabilized various social subsystems and problematized the current strategies of socio-economic development [6 p2] that the Republic of Serbia also applies, sacrificing the interests and well-being of the most vulnerable parts of the population, including palliative patients and their family members.

According to estimates by the World Health Organization, around 40 million people in the world need palliative care every year. It is estimated that 78% of that number live in low- and middle-income countries. Unfortunately, only about 14% of people in the world who need this type of care have the privilege of receiving it. At this moment, it could be said that the global need for palliative care is continuously growing as a result of the global aging of the population and the increase in the number of people suffering from chronic non-communicable diseases and a certain number of infectious diseases. In this sense, the situation in the Republic of Serbia is not significantly different.

The coronavirus pandemic has made the already difficult situation of palliative care patients and their family members in the Republic of Serbia⁴ even more difficult, further limiting their access to various palliative care services. The timely inclusion and continuous availability of palliative care services in the treatment and relief of suffering of palliative patients, on the one hand, relieves the health system due to the reduction of unnecessary admissions to hospitals and the number of different types of health services that patients require, and on the other hand, it affects the improvement of the quality of life and everyday life of palliative patients and their family members. For this reason, any articulated response to the «disaster» would have to take into account the needs of this socially extremely vulnerable group, to whom the denial of any type of service increases suffering and pain at the end of life. The research we present aimed to try to reconstruct what happened to palliative care patients during the first year of the coronavirus pandemic.

Research method and sample

The research was carried out on the basis of data collected as part of two field surveys⁵ conducted in 2021 and 2022. For the purposes of this work, the collected data

and increase the quality of health care. On this basis, significant savings (underlined by the author) and reduction of corruption in healthcare are expected.” [5 p68-9]

³ Related to the lack of medical personnel of certain profiles, lack of medical equipment, etc.

⁴ See more about it in [7 p83-122]

⁵ Empirical research conducted within the framework of the Palliative Care – My Care, My Right project (BELhospice, Serbia), whose field part of the research was carried out during April and May

were additionally filtered in terms of the subsequent selection of the sample. The statements of those informants who do not refer to palliative care in the period of the coronavirus pandemic were excluded from the analysis sample. With additional filtering, the sample was reduced to the statements of 33 informants who at different points within their narratives thematized problems related to the availability and quality of palliative care services during the coronavirus pandemic.

Although the analyzed empirical material was collected during two different researches, the thematic affinity of the research focus⁶ (perceptions of respondents related to health system services) and the research method (focus group interviews) enabled the coherent use of subsequently selected material for the needs of secondary research. The research sample included informants who can be conditionally divided into two groups: (a) *providers* of palliative care services (doctors, nurses, caregivers, social workers, psychologists, activists, volunteers and members of various civil society organizations engaged in providing palliative care services), and (b) *users* of palliative care services (palliative patients and their family members). **Table 1** provides an overview of the sample structure.

Table 1. – Sample structure⁷

Identity/Gender		Women	Men	Total
Palliative care providers	Employee in healthcare institution	4	2	6
	Employee in social care institution	3	0	3
	Employee/activist in CSO	9	2	11
Palliative care receivers	Palliative patients	6	3	9
	Family members	4	0	4
Total		26	7	33

2021, and the research Access to health care for people who are not directly affected by the emergency situation – Lessons from the Kovid 19 crisis in Serbia (Association of Lawyers for Health and Medical Law of Serbia SUPRAM, Serbia) within which the field part of the research was carried out in the period March-April 2022.

⁶ In the case of the first research (Palliative Care – My Care, My Right), the research task was aimed at *identifying the offer, needs and obstacles* through participatory research with key actors involved in the process of palliative care - those who provide different palliative care services (different professionals employed in health and social care institutions, but also employees and activists of various civil society organizations) and/or those who use them (palliative patients and their family members) and analysis of their perception of the researched problems. In the case of the second research (*Access to health care for people not directly affected by the emergency situation – Lessons from the Covid-19 crisis in Serbia*), the focus was on the experiences of patients suffering from various chronic non-communicable diseases, who, according to some estimates, make up almost half of the population of Serbia, related to the availability of health care during the coronavirus pandemic. Both surveys were conducted on the territory of Serbia without Kosovo.

⁷ Source: author's research

Collected empirical data were analyzed with the help of discursive analysis. Like any discursive analysis, ours was focused on language and the meanings produced by language through speech (testimonies/narratives of respondents). It was done because language is not a neutral medium through which information is «only» communicated and exchanged. Language is a social field within which our knowledge of the world around us is actively shaped. In this sense, the discursive analysis used in this research tried to treat the language used by the respondents not as a mere reflection of reality, but as a medium that constructs and organizes that reality for us. [8 p246] The narrative of each individual respondent as a place within which social meanings are articulated and reproduced, and certain (personal and social) identities are formed.

The discursive analysis of the empirical material was focused on two central themes:

a) interpretative context [8 p249] (in our specific case it is constituted within the social reality shaped by the needs of patients at the end of life within and in relation to which the narrative(s) arise, and:

b) rhetorical organization of the narrative. [8 p250]

Interpretive context refers to the social circumstances within which certain narratives are created, because each narrative is constructed in a specific social context to which its authors (consciously or unconsciously) always adapt in a certain way. In this sense, the research of the interpretive context implies a kind of search for meanings that can be found and understood only if the analysis goes «behind the narrative itself» [8 p249] and looks for an interpretation that stems from the specific context within which the narrative of the interviewee was created. On the other hand, the analysis of the rhetorical organization of the narrative implies the search for a specific matrix of arguments, which originates on the one hand from a certain chosen interpretative strategy, and on the other from a certain value discourse (which can be externally induced as part of a wider strategy of adapting to the context of hegemonic culture or subculture). Understanding the position of different actors within this specific interpretive context and the structure of argumentation within the narrative is of particular importance for illuminating the problems that induce specific contextual, institutional and actor positions in relation to the researched topic.

Research results

Although few, research in our country shows that palliative care services are not sufficiently developed (in terms of their availability and diversity). [7 p100-9] The first steps towards a better articulation of the system's response to the growing needs for this type of care were taken back in 2009 with the adoption of the already expired *Strategy for palliative care* [9] and then the adoption of the *Action Plan for the implementation of the Strategy for the period 2009-2015*. [10] The *Strategy* was adopted, on the one hand, «in accordance with the Recommendations of the Committee of Ministers of the Council of Europe REC 24 (2003) which refer to the organization of palliative care, as well as in accordance with the Recommendations of the European Conference, held in Belgrade in 2005, that palliative care should become an integral part of

the health care system and an inseparable element of citizens' right to health care», [9] and on the other hand, taking into account the reasons that mark the reality of modern Serbian society and refer to: (a) the progressive aging of the Serbian population, and (b) the increase in the number of people suffering from diseases that have a progressive course (cardiovascular diseases, malignant diseases, diabetes, neuromuscular, cerebrovascular diseases), HIV/AIDS, traffic trauma, etc.). [9] Even from the explanation contained in the *Strategy* of the context in which this document was created, the legislator's clear intention to make a step forward from the existing relationship of society and its institutions towards palliative care and accordingly reorganize the existing health care system is visible.

On that track, the *Strategy* recognized palliative care as: «an approach that improves the quality of life of the patient and the family, facing the problems that accompany life-threatening diseases through the prevention and elimination of suffering through early detection and unerring assessment and treatment of pain and other problems: physical, psychosocial and spiritual (World Health Organization 2002)», where the term «life-threatening disease» refers to «patients with active, progressive, advanced disease for whom the prognosis is limited.» [9]

The *Strategy* focused attention on four priorities that the state should respond to in order to integrate palliative care into the existing health care system. Those priorities relate to: (a) changes to existing regulations governing the health care system in the Republic of Serbia, (b) integration of palliative care services into the health care system in the Republic of Serbia, (c) provision of drugs (painkillers – opioids and other medicines for palliative care of patients) and their availability «in accordance with the development of the list of essential medicines for palliative care of patients», as well as (d) education of health workers and health associates, patients, families and the public about palliative care. Based on these priorities, two main strategic goals were defined:

«6.1.1. The inclusion of palliative care in the healthcare system of the Republic of Serbia in order to make it an inalienable element of citizens' right to healthcare.

6.1.2. Improving and achieving the best possible quality of life for the patient and his family.» [9]

As well as the «main messages» of the *Strategy*:

«(a) Illness, loss and death are an integral and inevitable part of life.

(b) The goal of palliative care is less suffering, more dignity and a better quality of life.

(c) Quality, not quantity, of life is at the heart of palliative care.

(d) Palliative care is an interdisciplinary and multiprofessional approach and involves teamwork. Palliative care promotes a philosophy of team and teamwork.

(e) Palliative care should become an integral part of the health care system and an inalienable element of the citizen's right to health care.

(f) It is necessary to define a national health policy on palliative care in cooperation with health workers and associates, associations, patients and families.

(g) Palliative care should be available and free of charge to all patients who need it, regardless of disease type, geographic location, or socioeconomic status.

(h) Palliative care requires comprehensive and continuous care for the patient and family and implies a branched network of services that ensure that continuity.» [9]

Although on the legislative level, the Republic of Serbia recognizes, on the one hand, the need to organize palliative care services for this extremely vulnerable category of patients, and on the other hand, the right of patients to receive palliative care if they suffer from incurable diseases,⁸ in reality, at least according to the claims of our respondents, this the right is not always easy to realize. In the reality of the existing health and social system, this right often remains only a possibility that most patients and their family members fail to consume.

Patients' lack of information related to the geographical location of these centers is not a random or accidental problem, but a structural one. In the *Regulation on the plan of the network of health institutions*, which was last amended in 2018, palliative patient care is mentioned in only a few places. Article 4 of this document states:

“Health care at the primary level is carried out by the health center, pharmacy and institute (Institute for Students' Health Protection, Institute for Workers' Health Protection, Institute for Emergency Medical Assistance, *Institute for Gerontology and Palliative Care* (pointed out by I.J.), Institute for Dentistry, Institute for Pulmonary diseases and tuberculosis and the Institute for skin-venereal diseases).” [11]

From this we can conclude that the legislator explicitly provided that palliative care of patients takes place exclusively in *gerontology and palliative care institutes*. Although palliative care is undoubtedly an important part of the everyday life of these institutions, above all the specific «group of the population» for which the services of these institutions are intended – the elderly, there are also various other «groups» that need this type of health services – oncology patients in the terminal stages of the disease, HIV patients, patients with rare diseases with an extremely severe clinical picture and numerous other patients with incurable diseases that significantly shorten life expectancy. Palliative care of all other patients, who do not fall under the category of old,

⁸ As evidenced by the following documents: (1) Strategy for palliative care (“Official Gazette of the RS”, No. 17/09), [9] then (2) Regulation on the plan of the network of health institutions (“Official Gazette of the RS”, No. 42/06, 119/07, 84/08, 71/09, 85/09, 24/10, 6/12, 37/12, 8/14, 92/15, 111/17, 114/17 - corr., 13/18 and 15/18 - corr.), [11] (3) Rulebook on the content and scope of the right to health care from compulsory health insurance and on participation for the year 2019 (“Official Gazette of the RS”, No. 7/19 of February 6, 2019, which entered into force on February 14, 2019, and the provisions of Article 14, paragraphs 2-6 of this rulebook shall be applied until February 28, 2019), [12] which explicitly or implicitly refer to the palliative care of patients, as well as the new (4) Draft strategy of social protection in the Republic of Serbia for the period from 2019 to 2025: the initial version, which was prepared within the project “Support for the development of regulatory mechanisms of social protection”, which was financed by the European Union through the IPA 2013, within which he made this draft was published on March 27, 2019.

including patients who belong to this category, is regulated by Article 22, paragraph 5 of the same document, which states:

«The capacities of hospital institutions for care and treatment of acute diseases, conditions and injuries at the secondary level, with an average length of stay of those treated at the institution level up to 8.5, are expressed by the number of beds by area of hospital care per 1,000 inhabitants of the administrative district and the city of Belgrade (hereinafter: hospital bed provision rate) as follows:

5. Prolonged treatment and care (geriatrics, *palliative care* (highlighted by I.J.), chemotherapy, physical medicine and rehabilitation)

The stay of patients in the unit for prolonged treatment and care, including the period of acute treatment in another department, can last *up to 30 days* (pointed out by I.J.)» [11]

Therefore, within the various institutions of secondary health care, a certain number of hospital beds (0.20 beds for every 1,000 inhabitants of the administrative district or city) is provided for the needs of prolonged treatment and care, which includes, among other things, palliative care. This means that patients who need this type of care can turn to local secondary and tertiary health care institutions where they should receive “palliative care” for “up to 30 days”.

Unfortunately, in practice, even before the outbreak of the coronavirus pandemic, it was shown that, on the one hand, these accommodation facilities are insufficient to meet the needs of all those who need this type of support and care, and on the other hand, that the competences of doctors, who are delegated the obligation to provide this type of care is often insufficient and that due to the specifics of caring for palliative patients, which are not studied separately within the curriculum of basic integrated medical studies,⁹ they should be additionally educated so that they can competently respond to the needs of palliative patients:

“Accommodation for palliative patients is something that is sorely lacking, everyone agrees on that.” Hospitals are not a practical place for that, especially tertiary care is not the place to take care of these patients [...] they are for acute conditions, they are for day hospitals [...] for long-term accommodation, no. Since we have enough capacity for long-term accommodation of these patients, they are often accommodated where there is room. What my experience from abroad has shown is that palliative care is quite well covered in the world, in terms of home treatment, which is also lacking in our country, and it all boils down to the examples of good practice, i.e. the home treatment and care services that worked in the education of doctors, but that is not the standard.” (doctor, specialist in palliative medicine).

In everyday reality, the need for palliative medical support for dying patients is most often compensated by home treatment departments within health centers at the primary level of health care, especially in the stages when patients are no longer able to move.

«[...] theoretically speaking [...] the ideal is for palliative patients to be cared for at home as much as possible. When there are objective complications due to the disease itself,

⁹ See more about it in [7 p51-82]

progression, etc., then he should be moved for a certain period to a specialized unit, such as a palliative care unit, which exists in developed countries, or a hospice [...] But they are not residential-type institutions, where this patient stays, but he stabilizes there, the family rests a bit, and the patient returns to home conditions again [...] Systemically speaking, when the consilium makes a decision, after which the palliative patient is released home, mostly he is told – contact your doctor at the health center for symptomatic therapy. Unfortunately, most patients do not understand what to do next. [...] the path to palliation, it seems to me, is not very clear. Does the patient even know what now, what awaits him? [...] who takes care of him, who leads him, who takes care of that family, what set of services should be available to those family members who take over most of the care, in principle, about that patient [...] the problem is also, let's say, the fact that health centers, for example in Belgrade, are organized in different ways, you understand - Savski venac, Palilula and Voždovac or Vračar are three or four different stories...» (doctor, palliative medicine specialist)

Those «different stories» refer to the different types of services that specific home treatment teams are able to offer in the field:

«Unfortunately, we only have a doctor and a technician in the team. Unfortunately, we don't have a psychologist, a social worker, or a priest. For a short period, we also had a physiotherapist, who went out with us to the field, as needed, but now, unfortunately, due to the lack of staff, that is no longer the case» (doctor employed in the Home Treatment service).

Although, according to the definition of the World Health Organization (WHO), the basic principles of palliative care include: providing relief from pain, affirming life and death as natural processes, integrating psychological, social and spiritual aspects into the clinical aspect of patient care and an interdisciplinary approach in assessing the patient's health condition in order to respond in a timely manner to the various (sometimes atypical) medical, psychological, social and spiritual needs of palliative patients and their family members, in the everyday reality of the Serbian health-care system, this is often not the case, as evidenced by the previous quote. Therefore, on the ground, this type of need is often compensated by various civil society organizations in the geographical locations where they exist:

“Health care and social support are equally important for people suffering from serious and incurable diseases. Regular contact with members of our teams at the Home Help Service, keeping the living space tidy, maintaining personal hygiene at a certain level, ‘fulfilling wishes’ through small purchases are services that improve the quality of life for the users and change the attitude towards the disease itself as much as possible. . We're trying to encourage that.” (activist of Caritas)

The outbreak of the coronavirus pandemic has made the already complicated position of palliative patients even more anxious. The uncertainty and fear that marked the first months of the outbreak of the coronavirus pandemic and the imposition of a state of emergency were additional unsettling for patients at the end of life and those who care for them. The introduction of the lockdown overnight introduced new restrictions into the already limited reality of palliative patients, in which the existing services were put on hold without clear information until when:

«When the state of emergency was declared, we were completely cut off, as if in a vacuum. Doctors (from the Home Treatment Service, author's note) were no longer visiting us, the hospitals were closed [...] we didn't know what to do. I remember that fear and uncertainty [...] what if mom's situation worsens [...] new symptoms appear [...] who should I call? What should I do? How long will this situation last?» (daughter)

This anxious vacuum was experienced by many palliative patients and their family members as a painful reminder of the social blindness they face anyway:

«Covid has made our whole situation even more difficult, but our situation has not changed significantly because of Covid compared to what our situation is otherwise.» (wife)

«In general, everything just came to the fore [...] all our problems, which were there even without the pandemic. All of them additionally came to the fore in the pandemic itself, simply, we, somehow out of fear, because we have an obligation to protect ourselves and our children who have some of the rare diseases [...] we take extra care and protect ourselves, the only difference is that in Covid regime, we don't have the option to go for that regular control and [...] I think that [...] everyone here, we are absolutely talking about some things that have nothing to do with Covid. It's just that with Covid it became [...] as I would say, more pronounced. [...] we have all these problems even without Covid. Now it's just a little more pronounced... « (mother)

The coronavirus pandemic has only made the multiple vulnerabilities of this group of patients and their formal and informal caregivers more apparent. Feelings of isolation, systemic rejection (in the sense of institutional neglect for patients whose diseases «have no cure») and abandonment in the narratives of palliative patients and their relatives intensify when they talk about this period. The respondents link the first step out of this narrative matrix to the initiatives of patient associations that broke this psychologically disturbing pandemic silence:

«I am the mother of a child with a rare disease. After the initial shock due to the lockdown, we parents of children suffering from rare diseases realized that if our children do not have access to health facilities, many of them will face worsening of the clinical picture and some may not survive. That's why the Association launched an initiative and sent [...] an opinion to the Ministry [...] The Ministry then reacted and sent a letter to health institutions that additionally, regardless of Covid, patients with rare diseases should [...] be additionally protected and go to their regular examinations as regularly as possible [...] Unfortunately, [...] It is solved only on paper. So the competent authorities said that they have good will [...] determined that all hospitals and primary institutions must have a special entrance for people with rare diseases [...] They defined it all very finely for us on paper, but not in practice [...] So, we initiated and that solution exists on paper, which is very nice. But the problem is that it is not realized in practice. For many reasons. Some hospitals did not have the capacity, they did not have the personnel, they did not have the opportunities. No one other than the authorities dealt with it... because such solutions are not implemented in practice. ...» (mother)

Conclusion

In the years ahead, similar situations will most certainly be repeated. The World Health Organization predicts that in the future humanity will face similar pandemics, and possibly “catastrophes” that we are unable to conceptualize at this time. Understanding the position of socially vulnerable groups and the limitations that arise from them, as well as the consequences that certain institutional protocols produce in the personal lives of members of these groups must be incorporated into the design of any such protocol. Existing mechanisms based on: (a) “the routinization of responses by emergency-oriented groups so as to prevent emergencies from escalating into disasters or crises.” and (b) “the development of specific organizations to deal first with wartime crises and then with peacetime disasters. Civilian emergency management agencies have evolved from roots in civil defense groups created for air raid situations” [13 p20], obviously require additional adaptation to the values and achievements of civil society with full respect for the human rights of all members of society, no matter how exotic their needs may be for the majority. Of course, if as a society we want to strengthen their resilience.

Rezime

Palijativni pacijenti (pacijenti oboleli od neizlečive bolesti koja značajno skraćuje životni vek) predstavljaju jednu od najranjivijih socijalnih grupa među korisnicima zdravstvenog sistema. Zbog izvesno loših životnih prognoza, komorbiditeta i težine sveukupne kliničke slike zbrinjavanje ove vrste pacijenata zahteva interdisciplinarni pristup i ekspertizu, često istovremeno više specijalista. U tom smislu, palijativno zbrinjavanje podrazumeva s jedne strane medicinske usluge koje imaju za cilj da ublaže patnje palijativnih pacijenata i unaprede kvalitet njihovog života, a s druge strane psihološku podršku njihovim porodicama kako bi se osnažila njihova rezilijentnost. Nažalost, u periodima nestabilnosti zdravstvenog sistema, poput ovog koji je obeležila COVID-19 pandemija, usluge palijativnog zbrinjavanja su među onima koje postaju predmet sistemskih restrikcija u polju zdravstvenih usluga. U godinama koje su pred nama slične situacije će se sasvim sigurno ponavljati. Svetska zdravstvena organizacija predviđa da će se u budućnosti čovečanstvo suočavati sa sličnim pandemijama, a verovatno i sa „katastrofama“ koje u ovom trenutku nismo u stanju da konceptualizujemo. Razumevanje pozicije socijalno vulnerabilnih grupa i ograničenja koja iz njih proističu, kao i posledica koje određeni institucionalni protokoli proizvode u ličnim životima pripadnika ovih grupa mora biti inkorporirano u dizajniranje svakog takvog protokola. Dosadašnji mehanizmi očigledno zahtevaju dodatno prilagođavanje vrednostima i tekovinama civilnog društva uz puno uvažavanje ljudskih prava svih članova društva, ma kako njihove potrebe bile egzotične za većinu. Naravno, ukoliko kao društvo želimo da ojačamo njihovu rezilijentnost.

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