

---

## Rethinking the Protection of Vulnerable Groups in the Pandemic Situation (SARS-COVID 19): The Necessity to Implement the HRA and Human Security Framework into the Healthcare Professionals and Caregivers

---

Submitted 20/09/20, 1st revision 12/10/20, 2nd revision 30/10/20, accepted 14/11/20

Daria Bieńkowska<sup>1</sup>, Ryszard Kozłowski<sup>2</sup>, Mikołaj Jacek Łuczak<sup>3</sup>

### **Abstract:**

**Purpose:** Changes caused by the COVID-19 pandemic in the organisation of medical care and medical social work provided to patients as part of end-of-life care, make it necessary to re-evaluate the ethical and legal obligations for the protection of this particularly vulnerable groups.

**Design/Methodology/Approach:** This article draws attention to palliative care, a specific form of medical care, and in particular to end-of-life care. Changes in medical practice and medical social work caused by the pandemic, while epidemiologically justified, in many cases lead to violations of the selected European and global standards of care, including end-of-life care. The COVID-19 pandemic has clearly demonstrated, also in Europe, how difficult it is to meet social, medical, and legal standards of care for terminal patients while limiting the possibility of virus transmission.

**Findings:** Patients and their relatives suffer great mental discomfort caused by violations of certain standards of care resulting from an elevated sanitary regime in medical facilities. Such violations can be regarded as violations of patients' rights and of human rights in broader terms.

**Practical implications:** We recommend standardising and popularising the following three parallel solutions to facilitate their funding: 1/ preparing and implementing technical infrastructure to make possible for patients to meet in person with their family and relatives, while preventing physical contact; 2/ extending the use of video chat technologies in hospitals and hospices; 3/ implementing educational activities addressed to patients, their families, and medical staff. These standards positively influence patients' quality of life and, at the same time, make it possible to meet the ethical and legal requirements of medical care.

**Originality/value:** This article included in our depth legal and axiological analyses, and will contribute to the overall strengthening of the value-based health policy of vulnerable groups as the implementation of HRA and human security framework for physician and social workers (caregivers) developed in response to the current pandemic crisis are now becoming an urgent global need.

**Keywords:** Human rights, human security, social workers (caregivers), medical care.

**JEL classification:** I1, I3, K38.

**Paper Type:** Research study.

---

<sup>1</sup>Pomeranian University, ORCID ID: 0000-0002-5659-4819, [tittke@wp.pl](mailto:tittke@wp.pl);

<sup>2</sup>Pomeranian University, ORCID ID: 0000-0001-6789-3438, [ryszard.kozlowski@apsl.edu.pl](mailto:ryszard.kozlowski@apsl.edu.pl);

<sup>3</sup>Pomeranian University, ORCID ID: 0000-0003-3651-3150, [mikolaj.luczak@apsl.edu.pl](mailto:mikolaj.luczak@apsl.edu.pl);

## **1. Introduction**

Terminal patients are a particularly vulnerable social group and require enhanced care and social protection along with their families and relatives. Such services are provided under end-of-life care which forms part of palliative and hospice care. 'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. (WHO, 2002). Also, the International Association for Hospice & Palliative Care indicates that a holistic approach to patients and relief of physical, mental, and spiritual suffering to improve quality of life, as well as mental and social care for the patient's family and relatives, is of crucial importance to palliative care (Doyle, Woodruff, 2013). The specificity of palliative care stems from the fact that its holistic approach to the problems faced by patients and their families is the most complete method of putting into practice the current biopsychosocial model of health.

## **2. Health Policy – (Non)Quaranteed Benefits**

The SARS-COVID 19 pandemic has demonstrated the limitations of the health systems. This is particularly evident in the Polish public health system. It is worth noting that inappropriate health policy is applied in the domain in question, both in terms of respect for fundamental rights and safeguarding patients' rights through the right to receive guaranteed benefits (Regulation of the Minister of Health of 29 October 2013 on guaranteed benefits in palliative and hospice care, Journal of Laws of 2013, item 1347). One may point out that services in palliative medicine are clearly undervalued. The President of the Polish Association for Palliative Care (PTMP) points to many errors and procedural shortcomings in terms of policy and efficiency in the redistribution of guaranteed benefits to palliative care patients. Benefits provided in this specific sector of health care were priced in 2015 based on cost data for 2014. It is also worth noting that the Polish Ministry of Health, on the basis of an arrangement of April 2019 between the Management Board of PTMP and the national consultant, has committed itself to re-pricing palliative and hospice care services. Nevertheless, these issues have never left the level of arrangements and, to date, health policy on the provision of guaranteed benefits has not been of interest to the Ministry of Health when it comes to the financing of primary activities in the fields of palliative and hospice care.

End-of-life care is a special sphere of palliative care since it is provided when the patient faces their imminent and inevitable death. It is then necessary to intensify certain supporting (medical and non-medical) activities, as the approaching death may increase the intensity of the patient's physical, mental, existential, spiritual, and family-related problems. This type of care should make it easier for the patient to

make the right decisions about the place of a dignified passing as preferred by the patient themselves and their family. This may be a hospital or a hospice, but many patients want to spend their final moments at home (Steinhauser and Tulsky, 2015).

The overarching objective of palliative and hospice care, i.e., to improve quality of life, remains unchanged for end-of-life care, but the goals of specific activities and their psychosocial context change with the dynamics of the disease and the approaching end of life. The important role of social workers and the necessity of having them involved in end-of-life care was underlined by, among others, Jean C. Munn and Sheryl Zimmerman (2006). Palliative care, including end-of-life care, aims at increasing patients' awareness that the end of life is part of the natural course of the disease and, at the same time, at giving them a sense of human dignity in the face of death. This approach implements the postulates of contemporary tanatopedagogy as a discipline which has originated from the hospice movement, traditional medical ethics, and ethical personalism, enriched by so-called ethics of care. 'Many patients imagine that death comes suddenly, but for many, the knowledge that one's death is imminent comes first.

Those with this awareness often must complete certain tasks to allow a peaceful death such as offering forgiveness, being forgiven, acknowledging regrets, finding closure in professional and community relationships, and saying goodbye to family and friends' (Rome, Luminais, Bourgeois, and Blais, 2011). This points to the role of communication in palliative and end-of-life care. One of its conditions is the personal contact and closeness between the patient and their family and relatives. Thus, attention to the social relations of the patient in the final moments of their life is being added to the list of professional obligations of care providers (physicians, nurses, psychologists, and social workers). This is also complemented by concern for mainly the emotional and social security of the families and relatives of terminal patients, as well as after their death, in difficult and often dramatic bereavement (Łuczak 2014; 2019).

Therefore, restrictions introduced due to the pandemic in hospitals and hospices around the world, while justified, may pose risks to end-of-life patients, their relatives, and the very idea of professional palliative care. Those restrictions can be also regarded as controversial in ethical and legal terms since they may endanger patients' fundamental rights.

### **3. Human Rights and Human Security Framework in Palliative Care**

It is worth quoting here Frank Brennan, Liz Gwyther and Richard Harding (2008) who stated that "*Overarching themes of dignity and non-discrimination are common to both palliative care and international human rights.*" Such a perception of the relationship between palliative care and human rights was explicitly supported and solidified in circles extending beyond physicians only by the declaration announced

at the 2013 World Congress of the European Association for Palliative Care in Prague, referred to as the Prague Charter – *“Palliative Care: a human right”*. Therefore, we are convinced that the idea of human rights should be the point of reference for assessing the rationality and effectiveness of organisational decisions taken in the health sector. This is also true in the face of a pandemic. A renewed sense is thus given to the following as noted by Stefan Elbe: *“Within human security framework, the premature loss of life caused by disease continues to represent one of the greatest threats to people around the world”* (Elbe, 2011). One also needs to remember that COVID-19 patients, for whom disease dynamics is particularly unfavourable and leads to death, also receive end-of-life care and, like other seriously ill patients, face at the end of their lives additional suffering caused by separation from their families and relatives.

End-of-life care of COVID-19 patients, in terms of medical care and pharmacotherapy, fits within the standards of palliative care (Jackson, Hobson, Clare, Weegmann, Moloughney, and McManus, 2020). In our opinion, legislative, economic, and educational initiatives should be implemented to make it possible to fully realise this model also in respect of psychological and spiritual care (Ferrell, Handzo, Picchi, Puchalski, and Rosa, 2020) and facilitate contact with families which would be as satisfying as possible. Medical facilities around the world, including in Europe, have introduced extensive restrictions to these contacts and are following the rules of increased social distancing, in accordance with the recommendations proposed by WHO, medical associations, and government regulations. It appears that currently the only way for palliative care and end-of-life care to preserve social relations between patients and their relatives is through forms of technologically mediated communication, such as video chats through instant messaging services.

A crucial coordinating role in this respect could be played by social workers as non-medical staff in hospices, while hospice volunteers could offer direct technological support. Such projects have been already implemented in Europe by leading hospices. In the United Kingdom, for example, a model solution in this field was introduced by Marie Curie Hospices, including its patients, families, and volunteers in a widespread educational incentive. Samuel S.Y. Wang, Wendy Z.W. Teo, Winnie Z.Y. Teo, and Yong Woon Chai, in their letter addressed to the publishers of *Journal of Palliative Medicine* published in May 2020, suggest the use of virtual reality to create more comfortable means of communication for end-of-life patients and their families. This would provide them with dignified dying conditions even in the event of an elevated sanitary regime when direct contact is restricted.

Undoubtedly, such solutions can only serve as an imperfect equivalent to personal relations. Furthermore, they also need to tackle organisational and financial obstacles, especially in countries characterised by medium and low-income values, therefore, low telecommunications saturation. Unfortunately, even in European

countries with a higher standard of palliative care, one can observe, during the pandemic, the absence of systemic guidelines, legal regulations, financial instruments, and properly trained non-medical staff to ensure the communication comfort of hospice patients. During a pandemic crisis, the inclusion of the communication context in the way the protection of vulnerable groups, including terminal patients, is perceived stems from a broad understanding of HRA postulates.

This implies a belief that their further implementation in healthcare systems, both in their medical and social dimensions, is necessary. At the same time, such an approach recognises the message of American physicians and nurses: 'For the duration of the COVID-19 pandemic, we, as palliative care advocates, whose aim is to role-model, teach, research, and advance awareness of the human condition in healthcare, must hold fast to our humanistic values through strategic personal and institutional action plans. This is the moment when our art must deliberately and consistently inform the broader science of the healthcare system' (Rosa, Ferrell, and Applebaum, 2020).

#### **4. Conclusion**

Palliative care engages various institutions and groups of people. The specificity of this type of care requires not only appropriate safeguards in the context of the correct redistribution of goods in respect of benefits guaranteed by the Ministry of Health, but also a holistic approach based on human rights standards, including individuals from non-medical environments. Law and medicine stripped from deeper analysis based on other fields of knowledge become defunct entities maladjusted to the dynamic reality and needs of those whom they are intended to serve. It takes extraordinary sensitivity and courage to face the suffering of a person who is battling the disease through the lens of their personal tragedy.

Physicians express the patient's wellbeing using conditions listed in legislative acts (e.g. hopeless, stable, and patients with limited prognosis), based on diagnosis focused primarily on the results of laboratory work and statistical data related to a given disease entity. In the vast majority of cases, physicians describe the disease as an anatomopathological fact that can be physically located and characterised as a pathophysiological process, and where the disease is a specimen of a given type. On the other hand, for patients, in phenomenological terms, the disease and their suffering are unique and deeply personal and cannot be classified only within the framework of one or another disease entity (Bieńkowska, 2015).

The work of carers, volunteers, and social workers who are referred to as *caregivers* in the literature on the subject is invaluable in this respect (Herring, 2008). According to the author, so far, their work has been largely ignored. Nevertheless, it has been argued in the political field in favour of interpolating this type of work into medical domain. This was justified by presenting the immense societal benefits of

this work, not only in economic terms but also for the sake of ethical and moral facets of wellbeing (Fineman, 2004).

## **References:**

- Bieńkowska, D. 2015. Bureaucratization of death. Legal and ethical aspect in the light of Belgian Act on Euthanasia. *Sztuka Leczenia*, Vol. 1-2, 13-24.
- Brennan, F., Gwyther, L., Harding, R. 2008. *Palliative Care as a Human Right*. Open Society Institute, Public Health Program, USA, New York.
- Doyle, D., Woodruff, R. 2013. *The IAHPC Manual of Palliative Care 3rd Edition*.
- Elbe, S. 2011. Should health professionals play the global health security card? *The Lancet*, 378, 220-221.
- Ferrell, B.R., Handzo, G., Picchi, T., Puchalski, C., Rosa, W.E. 2020. The Urgency of Spiritual Care: COVID-19 and the Critical Need for Whole-Person Palliation. *Journal of Pain and Symptom Management*, 60, 7-11.
- Fineman, M.A. 2004. *The Autonomy Myth: A Theory of Dependency*. New York.
- Herring, J. 2008. Caregivers in Medical Law and Ethics. *Journal of Contemporary Health Law & Policy*, 25/1, Article 3, 1985-2015.
- Jackson, T., Hobson, T. Clare, H., Weegmann, D., Moloughney, C., McManus, S. 2020. End-of-life care in COVID-19: An audit of pharmacological management in hospital inpatients. *Palliative Medicine*, 34/9, 1235-1240.
- Łuczak, M.J. 2014. Palliative and hospice care as factors in the prevention of marginalization and social exclusion of people with illnesses and their families. The social roles of hospice patients. In *Życie na skraju. Marginesy społeczne wielkiego miasta*. Z. Galor, B. Goryńska-Bittner, S. Kalinowski (Eds.), Bielefeld.
- Łuczak, M.J. 2019. Opieka u kresu życia (end-of-life care) jako wyraz troski o bezpieczeństwo zdrowotne w kontekście praw człowieka. In *Prawa człowieka i ludzkie bezpieczeństwo. Osiągnięcia i wyzwania w 70 Rocznicę Ogłoszenia Powszechnej Deklaracji Praw Człowieka*, D. Bieńkowska, R. Kozłowski (Eds.) Warszawa.
- Munn, J.C., Zimmerman, S. 2006. A Good Death for Residents of Long-Term Care. *Journal of Social Work in End-of-Life & Palliative Care*, 2(3), 45-59.
- Rome, R., Luminais, H., Bourgeois, D., Blais, C. 2011. The Role of Palliative Care at the End of Life. *The Ochsner Journal*, 11(4), 348-352.
- Rosa, W.E., Ferrell, B.R., Applebaum, A.J. 2020. The alleviation of suffering during the COVID-19 pandemic. *Palliative and Supportive Care*, 1-3. <https://doi.org/10.1017/S1478951520000462>.
- Steinhauser, K.E., Tulsky, J.A. 2015. Defining a 'good' death. In *Oxford Textbook of Palliative Medicine 5<sup>th</sup> ed.*, N. Cherny, M. Fallon, S. Kaasa, R.K. Portenoy and D.C. Currow (eds.), Oxford University Press.
- Wang, S.S.Y., Teo, W.Z.W., Woon Chai, Y. 2020. Virtual Reality as a Bridge in Palliative Care during COVID-19. *Journal of Palliative Medicine*, 23/6, published online: 29 May 2020: <https://doi.org/10.1089/jpm.2020.0212>.
- WHO. 2002. *National Cancer Control Programs: Policies and Managerial Guidelines*, 2nd Ed., Geneva.