## **OPINION EDITORIAL**

# Palliative care during the COVID-19 pandemic: An examination of gaps across global health systems

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#### **Background**

Due to the rapid spread of SARS-CoV-2 infection, the COVID-19 pandemic has resulted in hospital surges, strain on care systems, and increasing demand for health professionals. The overwhelming demand for care led to rationing practices among resources and personnel [1,2]. For emergency hospital admissions, patients were triaged based on the likelihood of their survival due to resource shortages [1,2]. The duration and scope of this pandemic exposed gaps within the global health system, notably in the field of palliative care [1,3]. During the COVID-19 pandemic, barriers for health professionals, ethics at the end of life, differential access to palliative care, and integration of culturally informed patient support have become apparent.

# Health professionals and palliative care

The COVID-19 pandemic has introduced barriers for health professionals supporting patients at the end of life. These include challenges due to work-related restrictions, staffing redeployments and workers' deteriorating mental health.

Prior to the pandemic, multi-disciplinary teams sought to reduce the fragmented care that patients experienced at the end of life [4,5]. Their goal was to clarify ambiguous definitions and integrate experiences at the end of life across diagnoses, age, and culture and improve fragmented care delivery between health providers [4,5]. By addressing these components, health professionals were taking steps to improve communication, to include families in

care delivery through the grieving process, and to prioritize spiritual, cultural, and psychosocial aspects at the end of life [4,5]. However, the COVID-19 pandemic compounded many existent issues in the palliative care system. Safety protocols, which aimed to limit transmission of the virus, had the consequence of restricting families and allied health from supporting loved ones and patients, respectively. Consequently, this impacted patient well-being, which reduced the quality of care delivered at the end of life.

Many health professionals who were re-deployed to support patients in critical condition lacked the education and skills fundamental to palliative care: knowledge of symptom management, experience communicating updates to family members, and insight to guide loved ones through the grieving process at the end of life [6]. In some instances, palliative care specialists were recruited to provide education symptom management and communication strategies to physicians and nurse practitioners [7]. Given the high volume of critical condition patients, palliative specialists who ought to be caring for patients were suddenly focusing their efforts on training other health professionals, who could not provide the same level of care as specialists [10].

Additionally, front-line workers experienced psychological ramifications from the lack of palliative specialists needed support departments and admitted patients [7,9]. Stressful conditions and traumatic experiences in the workplace led to deteriorating mental health among healthcare workers, including posttraumatic distress.

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depression, and anxiety [7,8]. Integrating palliative care knowledge across all hospital departments and disciplines has taken on a renewed urgency [7,10].

#### The ethics of palliative care

The COVID-19 pandemic has brought attention to the topic of ethical dying, and what is considered an acceptable death [11]. While the World Health Organization emphasizes the importance of incorporating palliative care in response to global humanitarian crises, reality differs from best practice [12,13]. Due to the pandemic, palliative care looks different than it did before.

Discussions regarding what constitutes acceptable death, and the ethics of dying are important when preparing and responding to pandemics. A variety of academics in bioethics argue that although maintaining population health is critical during pandemics, oversight of individuallevel care and of personal health must be avoided [14]. Specifically, Sheahan and Brennan (2020) argue that although utilitarianism is commonly used to make population health decisions based on costbenefit analyses, other ethical theories, like "virtue ethics". must be considered promote individualized care. If the virtue ethics model is integrated into palliative care, qualities like empathy and trust would then be central considerations for decision-makers and dying patients could be guaranteed an "ethical death" [14]. Due to strains on healthcare systems, the COVID-19 pandemic has exposed how the lack of access to appropriate palliative resources exacerbates grief for patients. families, and professionals [15]. Thus, it is imperative that ethics be considered by health policy makers to maintain quality end-of-life care during pandemics and to mitigate undue harm.

## Differential accesses to palliative care

There are several institutions that facilitate and provide palliative care options, including hospitals and community-based hospices [16]. Current approaches to palliative care emphasize quality of life, with practitioners aiming to address physical, psychosocial, familial, spiritual, and prospective

dimensions of end-of-life care [17]. At a global scale, individuals residing in low- and middle-income countries, however, are more likely to face barriers that hinder their access to end-of-life care, such as a scarcity of palliative care resources. At national and sub-national levels, individuals from marginalized groups-including those experiencing homelessness, displacement, and adverse mental health outcomes -often face poor access to quality palliative care [18]. Globally, many healthcare systems were illequipped to manage rapid influxes of COVID-19 patients requiring end-of-life care, due to the already strained staffing [20]. As a result, many patients experienced solitary deaths or did not receive symptomatic care [18]. Overall, it is evident that some populations were afforded better access to quality palliative care than others, especially those in marginalised groups.

## **Culturally competent palliative care**

During the COVID-19 pandemic, the need for palliative care increased while its delivery and the ethics of dying were seemingly overlooked. Understanding and acknowledging a patient's wishes in relation to their cultural beliefs and traditions has generally played an important role during the provision of palliative care. However, cultural aspects of care have not been adequately incorporated throughout the pandemic [21]. Safety protocols such as visitation restrictions resulted in isolated end-of-life care, which perpetuated distress for both patients and families, who were unable to perform cultural and traditional rituals associated with death, promoting feelings of anguish [22].

Moreover, studies have indicated that patients from culturally diverse communities, such as New York City, generally face barriers and disproportionate health outcomes in end-of-life care, further exacerbated by the COVID-19 pandemic [23]. This includes challenges such as limited English proficiency and or the lack of cultural mediators between patients and the healthcare system. As such, systemic gaps in healthcare need to be reexamined to improve access to culturally competent palliative care.

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# **Future implications**

There is an urgent need to address the gaps and weaknesses in the palliative care system that have been compounded by the COVID-19 pandemic to strengthen the quality and accessibility of our global health systems. As outlined, it is important to address the gaps that limit care delivery, in addition to those that cause undue harm among health professionals, patients, and their families. Globally, differential access to care is evident and the provision of care across the world has often disregarded cultural considerations within palliative care, despite its vitality and necessity. Although efforts have been made within the public health realm to address the physical, biological, and social aspects of illness, end-of-life care has frequently been disregarded [19]. Integrated efforts across public health domains that include specialists, those with lived experience, and culturally diverse voices would be highly beneficial for health systems in addition to patient and family quality of life and satisfaction [24].

#### **REFERENCES**

- 1. Haseltine, W. America's New Triage: Covid Crisis Standards of Care. Forbes. 2021. Retrieved on March 13th, 2022 from:
- https://www.forbes.com/sites/williamhaseltine/2021/10/06/the-crisis-around-crisis-standards-of-care/?sh=31851cf42fda
- Lancet, T. Palliative care and the COVID-19 pandemic. Lancet (London, England). 2020. 395(10231), 1168. Available from: https://doi.org/10.1016/S0140-6736(20)30822-9
- 3. OECD. The impact of COVID-19 on health and health systems. N.d. Retrieved on March 13th, 2022 from: https://www.oecd.org/health/covid-19.html
- 4. National Institutes of Health State-of-the-Science Conference Statement on improving end-of-life care. NIH consensus and state-of-the-science statements. 2004; 21(3): 1-28.
- 5. Csikai, E.L. Developing the Science of End-of-Life and Palliative Care Research: National Institute of Nursing Research Summit, . Soc. Work End-of-Life Palliat. Care. 2020; 7:4, 291-299, doi: 10.1080/15524256.2011.623457
- 6. Arya, A., Buchman, S., Gagnon, B., & Downar, J. Pandemic palliative care: beyond ventilators and saving lives. Can. Med. Assoc. J.
- 7. Connolly, M., Bell, M., Lawler, F., Timmins, F., & Ryder, M. Hospital-Based Palliative and End-of-Life Care in the COVID-19 Pandemic: A Scoping Review. Am. J. Hosp. Palliat. Med. 2021. Available from: https://doi.org/10.1177/10499091211057049

- 8. Hospice Palliative Care Ontario. Canadian report explores the impact of COVID-19 on Community-Based Palliative Care. 2022. Retrieved on March 13th, 2022 from: https://www.hpco.ca/canadian-report-explores-the-impact-of-covid-19-on-community-based-palliative-care/
- 9. Johns Hopkins University & Medicine Coronavirus Resource Center. COVID-19 Dashboard by the Center for Systems Science and Engineering at Johns Hopkins University. 2022. Retrieved on March 13th, 2022 from: https://coronavirus.jhu.edu/map.html
- 10. Rosa, W. E., Gray, T. F., Chow, K., Davidson, P. M., Dionne-Odom, J. N., Karanja, V., et al. Recommendations to Leverage the Palliative Nursing Role During COVID-19 and Future Public Health Crises. J Hosp Palliat Nurs. 2020. 22(4), 260-269. Available from: https://doi.org/10.1097/NJH.000000000000665
- 11. Parks JA, Howard M. Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic. Bioethics. 2021 Jul;35(6):589-95. doi: 10.1111/bioe.12881
- 12. Davies A, Hayes J. Palliative care in the context of a pandemic: similar but different. Clin Med. 2020 May;20(3):274. doi: 10.7861/clinmed.2020-0157
- 13. Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. Lancet. 2020 May 9;395(10235):1467-9. https://doi.org/10.1016/S0140-6736(20)30964-8
- 14. Sheahan L, Brennan F. What matters? Palliative care, ethics, and the COVID-19 pandemic. J Bioethical Inq. 2020 Dec;17(4):793-6. doi: 10.1007/s11673-020-10046-3
- 15. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 pandemic: considerations for palliative care providers. J Pain Symptom Manage. 2020 Jul 1;60(1):e70-6. doi: 10.1016/j.jpainsymman.2020.04.012
- 16. On racism: A new standard for publishing on Racial Health Inequities. Forefront Group. 2020
- 17. Connolly M, Bell M, Lawler F, Timmins F, Ryder M. Hospital-based palliative and end-of-life care in the COVID-19 pandemic: A scoping review. Am J Hosp Palliat Care. 2021; doi: 104990912110570.
- 18. Dy SM, Isenberg SR, Al Hamayel NA. Palliative Care for Cancer Survivors. Med. Clin. N. Am. 2017;101(6):1181-96. doi: 10.1016/j.mcna.2017.06.009
- 19. Abu-Odah, H., Molassiotis, A., & Liu, J. (2020). Challenges on the provision of palliative care for patients with cancer in low- and middle-income countries: A systematic review of reviews. BMC Palliat. Care, 19(1). Available from: https://doi.org/10.1186/s12904-020-00558-5
- 20. Rodin G, Zimmermann C, Rodin D, al-Awamer A, Sullivan R, Chamberlain C. Covid-19, palliative care and public health. Eur. J. Cancer. 2020;136:95–8. doi: 10.1016/j.ejca.2020.05.023
- 21. Patneaude A, Kett J. Cultural responsiveness and palliative care during the COVID-19 pandemic. PMR. 2020;1(1):171–3. doi: https://doi.org/10.1089/pmr.2020.0049
- 22. LeRoy AS, Robles B, Kilpela LS, Garcini LM. Dying in the face of the COVID-19 pandemic: Contextual Considerations and clinical recommendations. Psychol. Trauma: Theory Res. Pract. Policy.10.1037/tra0000818
- 23. Ross J, Diaz CM, Starrels JL. The disproportionate burden of covid-19 for immigrants in the Bronx, New York. JAMA Intern Med. 2020;180(8):1043. doi: 10.1001/jamainternmed.2020.2131
- 24. Payne, S., Hughes, S., Wilkinson, J., Hasselaar, J., & Preston, N. (2019). Recommendations on priorities for integrated palliative care: Transparent expert consultation with international leaders for the INSUP-C project. BMC Palliat. Care, 18(1). Available from: https://doi.org/10.1186/s12904-019-0418-5

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