

## References

1. Social Justice Department, State of Kerala. Integrated Child Protection Scheme (60% CSS) Thiruvananthapuram: Government of Kerala. [cited 2021 Jun 30]. Available from: [http://swd.kerala.gov.in/scheme-info.php?scheme\\_id=IDQzc1Y4dXFSl3Z5#](http://swd.kerala.gov.in/scheme-info.php?scheme_id=IDQzc1Y4dXFSl3Z5#)
2. United Nations Children's Fund (UNICEF). Convention on the Rights of the Child. New York: UNICEF; 2002 [cited 2021 Jun 30]. Available from: <https://www.unicef.org/child-rights-convention/convention-text>
3. Sumitha TS. Individual and social-environmental level protective factors for institutionalized adolescents' mental health - a study among adolescents in childrens' homes under the Integrated Child Protection Scheme, Kerala. Thiruvananthapuram: Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum; 2016 [cited 2022 Nov 17]. Available from: <http://dspace.sctimst.ac.in/jspui/handle/123456789/10789>
4. Indian Council of Medical Research. National Ethical Guidelines for Biomedical Research Involving Children. New Delhi: Indian Council of Medical Research; 2017 [cited 2021 Jun 30]. Available from: [https://ethics.ncdirindia.org/asset/pdf/National\\_Ethical\\_Guidelines\\_for\\_BioMedical\\_Research\\_Involving\\_Children.pdf](https://ethics.ncdirindia.org/asset/pdf/National_Ethical_Guidelines_for_BioMedical_Research_Involving_Children.pdf)
5. Ministry of Law and Justice (Legislative Department). The Gazette of India Extraordinary Part II – Section I. The Juvenile Justice (Care and Protection of Children) Act. New Delhi: Ministry of Law and Justice; 2015 [cited 2021 Jun 30]. Available from: <http://cara.nic.in/PDF/JJ%20act%202015.pdf>
6. High Court of Allahabad. *Gauri Shanker And Ors. v. State Of U.P. And Ors.* 2005 (1) AWC 426. [cited 2021 Jun 30]. Available from: <https://indiankanoon.org/doc/1263825/>
7. Saleebey D. Vulnerability and strength—giving voice to the voiceless. *Bioethics Forum* 2001;17(3-4):31-8.
8. World Medical Association. WMA Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA.* 2013;310:2191-4. <https://doi.org/10.1001/jama.2013.281053>
9. Adashi EY, Walters LB, Menikoff JA. The Belmont Report at 40: Reckoning with time. *Am J Public Health.* 2018 oct;108(10):1345-1348. <https://doi.org/10.2105/AJPH.2018.304580>
10. Doyal L. Informed consent: moral necessity or illusion? *Qual Health Care.* 2001 Sep;10 (Suppl 1):i29-33. <https://dx.doi.org/10.1136%2Fqhc.0100029>
11. Ministry of Women and Child Development, Govt of India. The Gazette of India Part I – Section I. The National Policy for Children, 2013 New Delhi: Government of India 2013 [cited 2021 Jun 30]. Available from: <http://wcd-icps.nic.in/pdf/npc2013dtd29042013.pdf>
12. Council for International Organizations of Medical Sciences. International Ethical Guidelines for Health-related Research Involving Humans, 4th edition. Geneva: CIOMS; 2016 [cited 2021 Jun 30]. Available from: <https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf>
13. Sibley A, Pollard AJ, Fitzpatrick R, Sheehan M. Developing a new justification for assent. *BMC Med Ethics.* 2016 Jan 12;17:2. <https://doi.org/10.1186/s12910-015-0085-x>
14. European Data Protection Board. Guidelines 05/2020 on consent under Regulation 2016/679. Version 1.1. Adopted 2020 May 4 [cited 2022 Feb 7]. Available from: [https://edpb.europa.eu/sites/default/files/files/file1/edpb\\_guidelines\\_202005\\_consent\\_en.pdf](https://edpb.europa.eu/sites/default/files/files/file1/edpb_guidelines_202005_consent_en.pdf)
15. Tait AR, Geisser ME. Development of a consensus operational definition of child assent for research. *BMC Med Ethics.* 2017 Jun 9;18(1):41. <https://doi.org/10.1186/s12910-017-0199-4>
16. Nuffield Council on Bioethics. Children and clinical research: ethical issues. London: NCB; 2015. [cited 2021 Jun 30]. Available from: <https://www.nuffieldbioethics.org/assets/pdfs/Children-and-clinical-research.pdf>

## COMMENT

## Learning to switch gears — Steering palliative care into emergency medicine

RACHANA BHAT, AKSHAYA RAMASWAMI, PRAVEEN AGGARWAL

## Abstract

Emergency care is largely seen as synonymous with resuscitation and saving lives. In most of the developing world where Emergency Medicine (EM) is still evolving, the concept of EM

*palliative care is alien. Provision of palliative care in such settings poses its own challenges in terms of knowledge gaps, socio-cultural barriers, dismal doctor-to-patient ratio with limited time for communication with patients, and lack of established pathways to provide EM palliative care. Integrating the concept of palliative medicine is crucial for expanding the dimension of holistic, value-based, quality emergency care. However, glitches in decision-making processes, especially in high patient volume settings, may lead to inequalities in care provision, based on socio-financial disparities of patients or premature termination of challenging resuscitations. Pertinent, robust, validated screening tools and guides may assist physicians in tackling this ethical dilemma.*

**Keywords:** emergency medicine, palliative care

The term Emergency Department (ED) paints a picture of a fast-paced setting, with patients of varied but severe illness. Emergency care is largely linked with resuscitation. As Emergency Medicine (EM) physicians, years of our training are focused on how fast we can think and act to save lives and reduce morbidity.

Authors: **Rachana Bhat** (corresponding author — [rachana2806@gmail.com](mailto:rachana2806@gmail.com)), Department of Emergency Medicine, All India Institute of Medical Sciences, Ansari Nagar New Delhi, 110 029; Department of Emergency Medicine, Kasturba Medical College, Manipal, Manipal Academy of Higher Education, Manipal, INDIA; **Akshaya Ramaswami** ([1312ashura@gmail.com](mailto:1312ashura@gmail.com)), Department of Emergency Medicine, All India Institute of Medical Sciences, Ansari Nagar New Delhi, 110 029 INDIA; **Praveen Aggarwal** ([peekay\\_124@outlook.in](mailto:peekay_124@outlook.in)), Department of Emergency Medicine, All India Institute of Medical Sciences, Ansari Nagar New Delhi, 110 029 INDIA.

To cite: Bhat R, Ramaswami A, Aggarwal P. Learning to switch gears — Steering palliative care into emergency medicine. *Indian J Med Ethics.* 2023 Jul-Sep; 8(3) NS: 220-223. DOI: 10.20529/IJME.2023.007

Published online first on January 16, 2023.

Manuscript Editor: Vijayaprasad Gopichandran

## Copyright and license

©Indian Journal of Medical Ethics 2023: Open Access and Distributed under the Creative Commons license (CC BY-NC-ND 4.0), which permits only non-commercial and non-modified sharing in any medium, provided the original author(s) and source are credited.

Sharing the experience of a busy evening shift in the ED, a 56-year-old woman was brought in with severe abdominal pain. She was frail, pale and haemodynamically unstable. As the patient entered, the drill was activated; "Assess airway, breathing, circulation; get oxygen, IV and start stabilisation. Take history, perform examination, review labs and images. Is it haemorrhage, sepsis or perforation? Get consult and plan disposition." The patient's lab reports revealed metabolic acidosis, high lactate, deranged renal and liver function tests. Having adequately stabilised her with initial management, the plan was to proceed with a nephrology consult for haemodialysis and ICU admission. With the primary assessment and interventions completed, we began probing into her past medical history. We found in her records histopathology and imaging reports from the previous treating hospital, which were suggestive of metastatic cholangiocarcinoma, a cancer of the bile ducts. She had been well a few weeks earlier, when she was diagnosed to have gallstones and surgery was planned. The family was hopeful of complete recovery after the surgery. However, the post-operative histopathology report suggested otherwise. The relatives were keen to know about the further plan of care.

Our residency includes a fair share of teaching and experience in breaking bad news. However, choosing between resuscitation of an unstable patient and avoiding further escalation of care is a dilemma for which Emergency Physicians in most parts of the world lack training [1]. Such a decision involves various complexities — the moral distress of EM physicians on not utilising their best resuscitation skills, the dismay of patient or relatives for not choosing the right kind of care, or glitches in decision-making protocols, which may lead to inequitable care-provision based on the lack of financial resources of patients. Acceptance of the need for palliative care will mean preparing for death with dignity, providing holistic care with the inclusion of patient and caregiver, improving the quality of life in patients with life-limiting illness, though, it may mean limiting resuscitation.

Getting back to our patient, we sat down with the caregivers — the husband, son, daughter — to explain the possible further course of illness and available treatment options. The initial reaction was, understandably, devastation. What they thought was simple jaundice and gallstones ailing their patient supposedly curable with surgery, turned out to be something that had brought her to a near death state. Having limited experience in providing palliative and end-of-life care from the ED, one of us was fortunate to have worked at a tertiary centre with specialists in the field of palliative care. With the assistance of a colleague from their team, we decided on providing the option of palliative care within the ED. Meanwhile, supportive care was continued to prevent further deterioration of the patient. The caregivers had queries ranging from what could have been done in the past to how to stop her health from worsening in the present. We addressed their queries and gave them time to think over the decision. We explained to them not to solely consider the cost of treatment for further decision making and gave options of

other treatment centres for affordable continued care. The patient and her family deliberated and discussed. Neither the patient nor her family wanted her to be in pain or have her hooked to tubes and wires. All they wanted was to reduce her suffering and provide her some relief from the symptoms. Since it was a major decision, we gave them ample time to contemplate on their decision. Meanwhile, we had to be prepared ourselves to guide them further.

Palliative care in developing countries is in its fledgling state. Upon evaluation for overall availability and provision of quality palliative care, most middle- and low-income countries fare poorly [2]. This dearth of adequate services is multiplied at the level of EDs, where patients with life-limiting illnesses end up with an impending or present terminal event, without prior awareness or access to palliative or end-of-life care. Various questions arise on contemplating the provision of palliative care in our settings. Is it premature to initiate the palliative care pathway in the ED setting? The overcrowding in most EDs across the world and a dismal doctor-to-patient ratio in nearly all developing countries [3], limit the time for interaction between the treating EM physician and the patient or family. Would the brief rapport, perhaps the first interaction between the two teams, be adequate to have complex discussions about goals of patient care? Will EM palliative care be taking an easy way out of challenging resuscitations? Will the caregiver be left with guilt that decisions made in the ED were in haste? Would there be regret that the hope for better outcomes for the patient was abandoned by the choice made? These are only a few among many ethical issues that may arise in the pursuit of establishing ED palliative care. To address them, we need to observe and understand the pathway of such patients through our current healthcare system. Say a patient, goes to a clinic or nursing home for complaints that are unrelenting or distressing. The laboratory investigations and imaging suggest end-stage multisystem involvement and/or diagnosis of a terminal illness. In the primary and secondary care settings, symptomatic treatment is provided and the patient is referred to a tertiary care centre. The caregivers are only aware that treatment options are scarce in the small centres and expect curative care in the referred hospitals. This misconception, though preventable, is to be expected. Need for urgent referral to avoid further patient deterioration, inadequate knowledge or expertise regarding disease management, fear of litigation in case of patient deterioration, limited time for detailed interaction with the family may be some factors contributing to lack of adequate counselling of patient and relatives regarding the prognosis of the disease. Studies have shown that, in low- and middle-income countries, based on the time or distance it takes to reach a centre capable of addressing the disease and the delay from symptom to diagnosis and treatment can range anywhere between 4 to 6 months [4,5]. Such a lag can alter the treatment plan for the patient from curative to palliative care.

On arrival in an ED, resuscitative strategies employed may include countless resources ranging from oxygen therapy to mechanical ventilation, blood products, antibiotics, inotropic support to stabilise circulation, or renal replacement therapy owing to the patient's likely debilitated condition. Apart from these tangible ED resources utilised for a patient, there are multiple services that cost money but are not evident such as laboratory, imaging services, manpower and critical care bed occupancy [6]. Based on whether they reach a centre with government subsidies or in the private sector, these significant costs are borne by the hospital or the family members, respectively.

However, monetary concerns are not the major factor if patient outcome is potentially favourable. The question is "Will all these measures ensure the cure for illness?" Most of the time in scenarios such as the above, at no point during the harrowing journey from symptom onset to ED arrival will the family have been adequately counselled about the likely outcome, with or without rigorous management. The only goal of the relatives is to see their patient get better; hence, they would never have considered or been made aware of the alternative of palliative care. Owing to such a disease course and poor chances of cure, the likely outcome is that the patient cannot be weaned off the medical equipment and ultimately succumbs, without meaningful interaction with the caregivers prior to passing. Are such outcomes actually favourable?

This decisively highlights the point that the ED setting is not too soon to initiate the palliative care option. While the rapport developed in the ED may be brief, in appropriate patients, it would be better to discuss goals of patient care at the outset rather than when it is too late to alter the treatment course. EM palliative care would not be an excuse to avoid resuscitation, but rather an option provided to the patient and family to choose a peaceful passing. It is important to offer this choice for caregivers to come to an informed decision and not regret failing to explore all possible treatment pathways.

The principles of palliative care rest on the pillars of ethics in medicine, ie autonomy, beneficence, non-maleficence and justice. It should be the patient's and family's decision to choose either palliative care or an alternate treatment pathway. In the context of EM palliative care, as mentioned above, the brief patient-physician rapport or time constraints for decision-making may become a barrier in a patient's complete understanding of the disease and hence, may impact the decision taken. Treatment decisions should be taken in the best interest of the patient considering risk vs benefit, suffering vs better quality of life or painful vs dignified death. The concepts of non-maleficence and justice get intertwined with complexities such as the patient's and family's understanding of the disease or their perspectives on the outcome. Will the death of the patient be considered non-maleficent or just in comparison with continued life? The scientific knowledge of the physician regarding the disease

may provide him or her with the clarity to differentiate between the two. However, imparting the same knowledge and understanding of the disease to the patient and family sensitively is crucial to provide them the lucidity to make informed decisions, going beyond the emotional, social and financial barriers they face.

EM palliative care has been an area of interest and growth in several developed countries [1,6,7]. Even in the best of institutions, there is a perceived gap in the skill level among physicians. Among developing countries, the barriers to palliative care in ED are manifold. Lack of professional knowledge and public awareness are the foremost reasons that are compounded by the absence of strong government and institutional policies on palliative, hospice care and distribution of pain medication. The ageing population, especially those with comorbid conditions in many of these countries, is on the rise without a plan for tackling the healthcare burden this represents. Financial limitations and cultural beliefs are also obstacles to the provision and acceptance of palliative care [8].

The Covid-19 pandemic has destabilised healthcare systems, which are gradually coming back to normalcy in new ways. The interrupted outpatient services during the pandemic have forced healthcare naive patients to approach an ED as their first interface for medical care. This has produced a surge in ED visits of patients with advanced malignancy and end-stage organ failure for acute care with no exit plan for definitive treatment or follow up. Furthermore, a substantial cohort of critically ill Covid-19 and post-Covid patients has been added to this pool, with ED as the easiest interface for availing therapy. Not only overburdened healthcare systems, scarcity of critical care beds, mounting healthcare costs but also rising numbers of psychologically, financially and emotionally stricken caregivers is the challenge to be addressed [9]. Thus, early integration of palliative care into ED is of utmost importance, which is lacking in most developing countries [10]. Post-Covid remodelling and restructuring of healthcare systems provide an avenue for this process.

Palliative care comprises symptom management, advance care planning, support to patients, caregivers and addressing psychological and spiritual wellbeing. In our part of the world, where the concept of hospices is yet to percolate into the healthcare system, it is either hospital or home-based care. Hence, educating the caregivers regarding home-based care becomes a crucial component. Our patient and her family had confirmed their decision on palliation. We sat with them again and explained regarding the possible course of illness. We prescribed medicines for symptomatic relief, advised for nutrition and explained home-based treatment for simple symptoms to prevent frequent hospital visits. We referred them to seek consultation and further guidance from a palliative care specialist. As We ended the conversation, We could observe

a sense of peace amidst the prevailing despair within the patient and her family. As physicians, we could find meaning to the care and guidance provided to the patient.

It is time to "Re-SET" the stage for palliative care in the ED, ie: **Reference** — involve palliative care team early when appropriate; **Screen & Substantiate** — Screen for the need for palliative care, substantiate the decision to provide palliative care as a treatment option; **Engage and Elucidate** — engage the patient and caregivers, explain about the nature and course of illness and provide adequate knowledge for them to make an informed decision. Give **Time to deliberate** and if they choose palliative care, **Teach and rehabilitate** the patient and caregiver to care for self and manage simple symptoms.

Sometimes it's not adrenaline to pump the heart but serotonin to soothe the soul that needs to be provided in the ED. Although it is a tough call, knowing when to choose the path to palliation, and how to deliver the same will be important skills in the armoury of an EM physician. Designing robust, validated and globally pertinent screening tools to assist in this practice is the need of the hour.

**Conflict of interest and funding:** None to declare.

#### References

1. Grudzen CR, Stone SC, Morrison RS. The Palliative Care Model for Emergency Department Patients with Advanced Illness. *J Palliat Med.* 2011 Aug;14(8):945-950. <https://doi.org/10.1089%2Fjpm.2011.0011>
2. The Economist Group. 2015 Quality of Death Index. Perspectives. The Economist Intelligence Unit. 2015 Oct 6 [Cited 2021 Jul 26]. Available from: <https://eiuperspectives.economist.com/healthcare/2015-quality-death-index>
3. Pines JM, Hilton JA, Weber EJ, Alkemade AJ, Shabanah HA, Anderson PD, et al. International perspectives on emergency department crowding. *Acad Emerg Med.* 2011 Dec;18(12):1358-1370. <https://doi.org/10.1111/j.1553-2712.2011.01235.x>
4. Varma S. Cancer treatment starts in India at least after 4 months' delay, finds study. *Times of India.* 2016 Dec 7 [Cited 2022 Jul 1]. Available from: <https://timesofindia.indiatimes.com/home/science/cancer-treatment-starts-in-india-at-least-after-4-months-delay-finds-study/articleshow/55857759.cms>
5. Tiwari V, Yogi V, Ghori HU, Singh OP, Peepre K, Yadav S, Mohare C. Identifying the factors causing delayed presentation of cancer patients to a government medical college of central India. *J Clin Diagn Res.* 2015 Sep;9(9):XC09-XC12. <https://doi.org/10.7860%2FJCDR%2F2015%2F15104.6512>
6. Cooper E, Hutchinson A, Sheikh Z, Taylor P, Townend W, Johnson MJ. Palliative care in the emergency department: A systematic literature qualitative review and thematic synthesis. *Palliat Med.* 2018 Oct;32(9):1443-1454. <https://doi.org/10.1177/0269216318783920>
7. Bailey CJ, Murphy R, Porock D. Dying cases in emergency places: caring for the dying in emergency departments. *Soc Sci Med.* 2011 Nov;73(9):1371-1377. <https://doi.org/10.1016/j.socscimed.2011.07.036>
8. Wilson W. The case for palliative medicine in the emergency medicine department – the time is now! *Indian J Palliat Care.* 2020 Jul-Sep;26(3):395-396. [https://doi.org/10.4103/ijpc.ijpc\\_49\\_20](https://doi.org/10.4103/ijpc.ijpc_49_20)
9. Kraus CK, Greenberg MR, Ray DE, Dy SM. Palliative Care Education in Emergency Medicine Residency Training: A Survey of Program Directors, Associate Program Directors, and Assistant Program Directors. *J Pain Symptom Manage.* 2016 May;51(5):898-906. <https://doi.org/10.1016/j.jpainsymman.2015.12.334>
10. World Health Organization. Palliative Care. Geneva: WHO; 2020 Aug 5 [Cited 2021 Feb 17]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

**The FMES is supported by occasional grants from philanthropists and subscriptions to the journal.**

### APPEAL FOR DONATIONS TO THE FORUM FOR MEDICAL ETHICS SOCIETY

**The Indian Journal of Medical Ethics (IJME)** has been published for over 30 years by the **Forum for Medical Ethics Society (FMES)** since 1993. IJME is a multi-disciplinary academic journal providing a platform for original content and discussion on all aspects of healthcare ethics, as well as law, history, literature, philosophy and the humanities where they intersect with health and healthcare. We are committed to maintaining our editorial independence which is critical to safeguarding the scientific integrity of what we publish. Therefore, wider support from all those who are committed to social justice in health is essential.

FMES is registered under the Societies Registration Act, 1860 and the Bombay Public Trusts Act, 1950. Donations are eligible for tax exemption under Section 80G of the Income Tax Act, 1961. Donations are solicited only from Indian individuals and entities, as donations from foreign individual/entities are not permitted under Indian law. However, foreign readers/authors may wish to support the journal by:

- Gifting subscriptions to the print or soft PDF copies of the journal;
- Voluntarily paying any amount for full text views of individual online articles or PDF downloads;
- Or paying a fee for article processing when submitting an article to be considered for publication
- For more details on how to support us, write to [admin@ijme.in](mailto:admin@ijme.in) or visit our website <https://ijme.in/subscribe/>

**SUPPORT OPEN ACCESS ACADEMIC PUBLICATIONS, DONATE TO THE FMES CORPUS FOR THE PUBLICATION OF IJME!**