

ADDRESSING COMMUNICATION STRATEGIES, DECISION-MAKING FRAMEWORKS, AND PALLIATIVE CARE INTERVENTIONS FOR PATIENTS AND FAMILIES FACING END-OF-LIFE DECISIONS IN THE ICU

ABSTRACT

End-of-life care in the Intensive Care Unit (ICU) presents significant challenges due to the complexity of medical conditions, the intensity of treatments, and the profound emotional and ethical decisions required by patients, families, and healthcare providers. Effective communication strategies, robust decision-making frameworks, and targeted palliative care interventions are critical in managing these challenges. Effective communication is integral in end-of-life care settings, particularly in the ICU. There is always a need to emphasize on clear, compassionate, and timely communication between healthcare providers and family members. Decision-making in the ICU involves ethically complex and emotionally charged deliberations, often under conditions of uncertainty and time pressure. Palliative care, focused on providing relief from symptoms, pain, and stress, is crucial in the context of end-of-life care in the ICU. Studies have shown that early integration of palliative care teams in the ICU settings leads to better symptom management, higher quality of life, and more appropriate end-of-life care decisions. These teams work in conjunction with ICU staff to address not only physical symptoms but also the emotional, social, and spiritual needs of patients and their families. This literature review deals with the discussions that are carried out between the family members and the doctors to help the patients transition smoothly toward end-of-life care. A lot of psychological and emotional help is needed to succeed in this, and this review will prove to be a

guide that helps physicians and ICU doctors understand how things are done differently. This review will reflect on the current and updated protocols that are followed keeping in mind the end-of-life decisions of people admitted to the ICU.

Keywords: end-of-life care, emotional well-being, ICU patients, psychological support, family support and care, poor patient prognosis.

1. INTRODUCTION

Palliative care as a saving practice, often referred to as ‘end-of-life care’, is a medical specialty that is used to elevate the quality of illnesses of patients with life-threatening conditions and their families. (1)

The World Health Organization defines palliative care as an approach that involves all the measures to prevent and ease suffering through the early identification, proper assessment, as well as treatment of any type of problem whether physical, psychological, or spiritual. (2)

Presenting as early as the beginning of the 1990s, it has advanced up to now within the intensive care unit (ICU) settings, where 75% of patients are reported to have depressive symptoms as a result of their critical illnesses and painful treatments.(3)

The characteristics of illnesses dealt with in ICUs, the complexity of interventions, and the uncertain outcomes disrupt families in a great way, making many ICU experiences for patients and their families an extremely critical period. (4)

As a result, the adoption of palliative care principles in the ICU has been justifiably put forward and implemented year after year. Reports show that ICU has a strong impact on patient state at the physical level, establishing patient-centered care goals, and provision of moment’s care which is approximately 10%-30% of worldwide deaths in ICUs. (5)

Palliative care in the ICU is governed by core ethical principles: autonomy, beneficence, non-maleficence, justice, and fidelity which should be the underlying ethics that define patients' care and the effectiveness of the medical treatment.(6)

1.1 Autonomy

This principle protects decisions taken willfully concerning patient autonomy that includes refusal of LST and acceptance of them. Explicitly phrased at the core of this is advance care planning (ACP) which endows patients with the confidence to preplan intending that their treatment preferences are made known to help make decisions that correspond to their value system, mostly when they lose the capacity to make decisions.(7)

1.2 Beneficence

Beneficence is about actions that aim at a patient's advantage and include, for instance, treating a disease or providing healthcare for the patient's benefit and reducing their suffering. Thus, improvement objectives focusing particularly on the well-being of the patients while hospitalized in the intensive care unit (ICU) stand out.(8)

1.3 Non-maleficence

Non-maleficence, which means minimizing the possible harm, requires that the medical treatment and proceeding avoid taking to the patient's unnecessary harm and ensure that the former is more than the latter which might, as a result, be inevitable. This mandate sets monitoring and treatment options to be personalized to best help individual patients.(9)

1.4 Justice

By establishing a just allocation of the medical supplies justice affects fairly and equally the distribution process of the medical resources. It binds ICU staff to advance justice treatment and resource sufficiency, which is very crucial particularly during times of supply limitation such as pandemics or disasters, corroborating with the standards to ensure the best outcomes.(10)

1.5 Fidelity

Credibility constitutes the core of this aspect, meaning that patients and their families should be aware of the prognosis, every possible treatment option, and honest doctor's input. It saves patients from the stress of lacking information underpinning the outcomes they are likely to get after treatment and this, in turn, facilitates informed decision-making.(11)

2. INTEGRATING PALLIATIVE CARE INTO INTENSIVE CARE UNITS:

A REVIEW OF PRACTICES AND PRINCIPLES

Palliative care, formerly associated solely with the end-of-life care provided to seriously ill patients, has been included more and more within the concept of integrated care provided in intensive care units (ICUs), and the ultimate goal is to improve the quality of life for critically ill patients and their families.(12) Several key interventions form the backbone of palliative care integration into ICU settings:

2.1 EARLY FAMILY MEETINGS:

The ICU team, which is headed by nursing staff, shares information with family members in the support sessions, and the issues that are usually touched upon include the patient's condition,

prognosis, and care preferences.(13) The main goal of this intervention will be to have family members included in the process from the beginning of ICU care by explaining to them frequently, asking for their decisions, and providing professional support.(14)

2.2 ROUTINE PALLIATIVE CARE ASSESSMENT:

Regular scoring (ICU team) to spot the palliative requirements of patients. For example, this includes managing pain symptoms of other aspects and also touching on psychological spiritual, and social issues.(15)

2.3 INCLUSION OF TRAINED STAFF:

Placing palliative care staff in the ICU team reinforcement to improve the quality of care given by providing them with the necessary knowledge, and skills which gives them the power to offer a high-level approach.(16)

2.4 EDUCATION FOR ICU TEAM MEMBERS:

Improving the training of ICU professionals involving palliative care fundamentals such as symptoms management, communication issues, and the moral aspects of the last days of life.(17)

2.5 SUPPORT FOR FAMILIES:

Education and facilitation which is mostly preferable to have done for the families of ICU patients. This kind of support not only provides emotional comfort but aids family members in making well-rounded decisions and being able to cope with the stress that comes along with critical illness. This type of support is necessary for such a situation.(18)

3. END-OF-LIFE DECISION MAKING IN ICU ON BEHALF OF PATIENTS

Making healthcare decisions for a decisional impaired, critically ill patient is a profound responsibility that often falls to surrogate decision-makers (SDMs). (19)

This role can have long-lasting consequences not only for the patients but also for the SDMs, especially when their decisional needs are unmet. SDMs are tasked with making complex, preference-based healthcare decisions, a process that frequently evokes strong feelings of uncertainty, regret, stress, guilt, depression, and anxiety. (20)

These emotional impacts can linger for months following the patient's hospitalization or death, underscoring the psychological burden borne by SDMs.

3.1 TRANSITION TO FAMILY CAREGIVER ROLE

The transition of SDMs to a family caregiver role often results in significant physical and mental health challenges. This delineation as a family caregiver and its associated responsibilities demonstrate a profound burden, which can adversely affect the well-being of the SDM.(10)

Furthermore, when the emotional and decisional needs of SDMs are not sufficiently met, there is an increased likelihood of psychological morbidity. This state of compromised decision-making capacity can predispose patients and their SDMs to receive healthcare that is inconsistent with their values and preferences.(21)

3.2 DECISION SUPPORT INTERVENTIONS

To address these challenges, scientists and clinicians have spent the last two decades developing decision-support interventions aimed at facilitating shared decision-making and assisting SDMs with the formulation of complex healthcare decisions. (22)

Decision support is defined as a process that prepares individuals and promotes an environment that facilitates informed decision-making.(23)

These supports often manifest in the form of decision aids, which are interventions designed to help people make specific and deliberative choices among options (including the status quo) by providing, at a minimum, information on the options and outcomes relevant to a person's health status.(24)

3.3 EFFICACY OF DECISION AIDS

Decision aids can serve as a promising method to provide decision support to SDMs faced with making critical decisions related to life-sustaining preferences.

According to White, to optimize decision-making among SDMs, the clinical team must be effective communicators, accepting, supportive, and embedded in a system that promotes prompt and consistent multi-disciplinary communication. (25)

Moreover, an ideal SDM is described as an individual who can regulate their emotions and comprehend the medical situation appropriately to make decisions that align with the patient's values. (26)

However, despite the potential benefits of decision-support interventions, studies report mixed outcomes, indicating a failure to consistently provide benefits to patients and families. This suggests a need for further refinement of the approaches and methods used in decision support to enhance their effectiveness.(27)

NINR suggested that bio-behavioral explanatory paradigms should be adopted in the coming investigations which recognize emotions, behavior, and individual factors to be influential in decision-making. (28)

Additionally, to advance the art of decision support, especially in the context of end-of-life decisions, it is necessary to create standardized patient- and family-centered outcome

assessments that are appropriate for exploring the effects of the decision support interventions. (11)

Phrased scientific designs such as (MOST), and (SMART), in tandem with recruiting large and unique samples of patients and surrogate decision-makers, are indispensable. Through these efforts, the ICU will be able to progress in a directed fashion, for palliative care provision so that the needs and wishes of the patients and their family members will be met.(4)

4. THE SCOPE OF CARE IN EUTHANASIA, PHYSICIAN-ASSISTED SUICIDE (PAS), AND PALLIATIVE CARE

Ethical and legal dilemmas concerning euthanasia and doctor-assisted suicide (PAS) have over time become a focal area regarding which widespread debates take place in different parts of the world. (29)

Passive euthanasia is complying with unwillingly surrendering or depriving the treatment intended to save the patient's life, in the end, they die naturally due to the disorder. (30)

While this contradicts the former scenario termed as active euthanasia when a physician intentionally terminates the patient's life through a lethal treatment agent, hitherto it is those already dying who end their life with euthanasia and not those who are eased back to better health through palliative care. (31)

As PAS the procedure requires the doctor to provide the means for death at the patient's request. However, the patient is the one in control of themselves administering the lethal substance. (32)

Active euthanasia, passive euthanasia in medical institutions, and physician-assisted suicide are legal in 5, 12, and 7 countries. Some countries are more tolerant of different medical help methods euthanasia and PAS to bring pain-free death to terminally ill patients. (33)

Another matter here is that different ways usually imply great ethics and physician and patient autonomy, for instance, it is the physicians' right to refuse involvement in such rituals.

Within intensive care unit (ICU) settings, palliative care, which is beyond the common view that it is the treatment for the last days of a patient's life, takes the pivotal position. (34)

Palliative care is the model of approach to help the quality of the course of the disease by engaging in active symptom management and in-built social, psychological, and spiritual care. It can be carried out at any stage of a critical illness and is not limited to those who have little or no chance of survival to live. (3)

Hospice care or end-of-life care is indeed part of palliative care that specifies the patient with a life expectancy of fewer than six months who is considered to be terminally ill and futile to be cured of the disease.(4)

The aim of palliative care which goes in parallel with adult ICU and an ICU may lead to discomfort or confusion as it often gives rise to difficulties stemming from uncertainties about the patient's choices that may not have been expressed.(2)

Ensuring the dignity and rights of patients and their families is paramount, and the transition to comfort-oriented care must be handled with sensitivity and professionalism by all involved. Effective communication, collaboration, and competency in symptom management are essential skills for ICU and palliative care teams.(18) Research, including meta-analyses, supports the notion that high-quality end-of-life care not only improves the quality of life but can also extend life expectancy for patients with advanced diseases.(15)

CONCLUSION

At the core of palliative care is the provision of care to the patients and their families to enhance their quality of life, a fact many people fail to realize. It, the home of pain and stress relief, has a

philosophy that covers both the treatment of physical and emotional problems and especially patient-focused decisions. Good palliative health care cannot be made successful unless timely and effective communication related to goals of care, advance care planning (ACP), and transitioning from curative care to care with comfort is provided to the patients and their families. Such dialogue is needed to synchronize treatment with the patient's principles and views.

Nowadays, palliative care in the ICU is beyond society acceptance, with the case not yet generally recognized. Continual academic investigation becomes important for seeking ideal approaches under which palliative care, including ICU end-of-life care, can be delivered. This research has to focus on the treatment effectiveness-oriented clinical outcomes and the patient and family members' satisfaction.

REFERENCES

1. Pan H, Shi W, Zhou Q, Chen G, Pan P. Palliative Care in the Intensive Care Unit: Not Just End-of-life Care. *Intensive Care Res.* 2023 Mar 1;3(1):77–82.
2. Teoli D, Schoo C, Kalish VB. Palliative Care. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 [cited 2024 Apr 20]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK537113/>
3. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. *N Engl J Med.* 2015 Aug 20;373(8):747–55.
4. Roth AR, Canedo AR. Introduction to Hospice and Palliative Care. *Prim Care.* 2019 Sep;46(3):287–302.
5. Henson LA, Maddocks M, Evans C, Davidson M, Hicks S, Higginson IJ. Palliative Care and the Management of Common Distressing Symptoms in Advanced Cancer: Pain, Breathlessness, Nausea and Vomiting, and Fatigue. *J Clin Oncol Off J Am Soc Clin Oncol.* 2020 Mar 20;38(9):905–14.
6. Neukirchen M, Metaxa V, Schaefer MS. Palliative care in intensive care. *Intensive Care Med.* 2023;49(12):1538–40.
7. Liang Z, Xu M, Liu G, Zhou Y, Howard P. Patient-centred care and patient autonomy: doctors' views in Chinese hospitals. *BMC Med Ethics.* 2022 Apr 8;23:38.

8. Olejarczyk JP, Young M. Patient Rights and Ethics. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 [cited 2024 Apr 20]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK538279/>
9. Girdler SJ, Girdler JE, Tarpada SP, Morris MT. Nonmaleficence in medical training: Balancing patient care and efficient education. *Indian J Med Ethics*. 2019;4(2):129–33.
10. Pratt B, Wild V, Barasa E, Kamuya D, Gilson L, Hendl T, et al. Justice: a key consideration in health policy and systems research ethics. *BMJ Glob Health*. 2020 Apr 8;5(4):e001942.
11. Bonar JRM, Wright S, Yadrich DM, Werkowitch M, Ridder L, Spaulding R, et al. Maintaining Intervention Fidelity When Using Technology Delivery Across Studies. *Comput Inform Nurs CIN*. 2020 Aug;38(8):393–401.
12. Mercadante S, Gregoretti C, Cortegiani A. Palliative care in intensive care units: why, where, what, who, when, how. *BMC Anesthesiol*. 2018 Aug 16;18:106.
13. Vuong C, Kittelson S, McCullough L, Yingwei Y, Hartjes T. Implementing primary palliative care best practices in critical care with the Care and Communication Bundle. *BMJ Open Qual*. 2019;8(3):e000513.
14. Edwards JD, Voigt LP, Nelson JE. Ten Key Points About ICU Palliative Care. *Intensive Care Med*. 2017 Jan;43(1):83–5.
15. Ganz F, Ben-Nun M, Raanan O. Introducing palliative care into the intensive care unit: An interventional study. *Heart Lung*. 2020 Jul 1;49.
16. Catalisano G, Ippolito M, Marino C, Giarratano A, Cortegiani A. Palliative Care Principles and Anesthesiology Clinical Practice: Current Perspectives. *J Multidiscip Healthc*. 2021;14:2719–30.
17. Metaxa V, Anagnostou D, Vlachos S, Arulkumaran N, Bensemmane S, van Dusseldorp I, et al. Palliative care interventions in intensive care unit patients. *Intensive Care Med*. 2021 Dec;47(12):1415–25.
18. Glajchen M, Goehring A, Johns H, Portenoy RK. Family Meetings in Palliative Care: Benefits and Barriers. *Curr Treat Options Oncol*. 2022;23(5):658–67.
19. Grignoli N, Di Bernardo V, Malacrida R. New perspectives on substituted relational autonomy for shared decision-making in critical care. *Crit Care Lond Engl*. 2018 Oct 1;22(1):260.
20. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010 Apr 1;362(13):1211–8.
21. Braun UK, Beyth RJ, Ford ME, McCullough LB. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *J Gen Intern Med*. 2008 Mar;23(3):267–74.

22. Nelson JE, Kinjo K, Meier DE, Ahmad K, Morrison RS. When critical illness becomes chronic: informational needs of patients and families. *J Crit Care*. 2005 Mar;20(1):79–89.
23. Pignatiello G, Hickman RL, Hetland B. End of life decision support in the ICU: Where are we now? *West J Nurs Res*. 2018 Jan;40(1):84–120.
24. Jacob M, Horton C, Rance-Ashley S, Field T, Patterson R, Johnson C, et al. Needs of Patients' Family Members in an Intensive Care Unit With Continuous Visitation. *Am J Crit Care Off Publ Am Assoc Crit-Care Nurses*. 2016 Mar;25(2):118–25.
25. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. *Am J Crit Care Off Publ Am Assoc Crit-Care Nurses*. 2012 Nov;21(6):386–93; quiz 394.
26. Obringer K, Hilgenberg C, Booker K. Needs of adult family members of intensive care unit patients. *J Clin Nurs*. 2012 Jun;21(11–12):1651–8.
27. Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Caregiving. *Am J Nurs*. 2008 Sep;108(9 Suppl):23–7.
28. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med*. 2011 Mar 1;154(5):336–46.
29. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns*. 1998 Mar;33(3):267–79.
30. Brassington I. What passive euthanasia is. *BMC Med Ethics*. 2020 May 14;21:41.
31. Brassington I. What passive euthanasia is. *BMC Med Ethics*. 2020 May 14;21(1):41.
32. Annadurai K, Danasekaran R, Mani G. 'Euthanasia: Right to Die with Dignity.' *J Fam Med Prim Care*. 2014;3(4):477–8.
33. Fontalis A, Prousalis E, Kulkarni K. Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate? *J R Soc Med*. 2018 Nov;111(11):407–13.
34. Math SB, Chaturvedi SK. Euthanasia: Right to life vs right to die. *Indian J Med Res*. 2012 Dec;136(6):899–902.