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

Comment [TW1]: See comments to Conclusion - will have to be rewritten accordingly

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)

Comment [TW2]: Since further decision making process is discussed, it is crucial to put there 3 basic models which pre-define how this process would run. For a standard patient transiting from ICU to PC, with the same disease and requiring the same symptoms management, those models will still affect process of decision making AND communciation to is family. The models are: (1) integrative model where ICU physicians possess tall main skills and provide palliative care(PC) themselves (2) consultative model when PC specialists as a separate team are invited to ICU on consultative basis (given that most hospices are located outside of inpatient multiprofile hospitals (3) integrative model when basic PC (e.g. pain, dyspnea management) is provided by ICU staff (anestesiologists, Critical Care doctors) and more advanced and specialized decisions (eg. on nutrition and hydration) - by specialized PC team. Depending on this, 3 situations are possible: A. Decision making: (1) Made by ICU staff who decide on a moment of transition from curative life sustaining therapy to PC (2) Made by specialized PC team who identifies patients who are at risk of death and require application of PC measures (3) joint decision with elements of PC to be integrated in ICU treatment from very beginning (e.g. advanced care planning based on disease trajectory - e.g. what measures and when to take in case of polyorgan failure in progressing renal insufficiency)
B. Communication strategies (1) ICU staff runs effective communication with the family with consideration that transition to PC means NOT only End of Life Care (2)PC team provides communication (3) as per roles within integrative team.

Reference: Edwards JD, Voigt LP, Nelson JE. Ten key points about ICU palliative care. Intensive Care Med. 2017;43:83–5.
1)

Ganz FD, Ben Nun M, Raanan O. Introducing palliative care into the intensive care unit: an interventional study. Heart Lung. 2020;49:915–21.

Neukirchen, M., Metaxa, V. & Schaefer, M.S. Palliative care in intensive care. *Intensive Care Med* **49**, 1538–1540 (2023). https://doi.org/10.1007/s00134-023-07260-z

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)

Comment [TW3]: Before the principles, the clear structure should be put as per objective of the article: A. Decision making process -(1) continuous monitoring of goals of care - how long curative care remains effective (2) the transition to End of Life care - the moment of withdrawal of curative treatments (3) symptoms management - incorporated from very beginning, however continuously adjusted to patient state (Frameworks will depend on model as above).B. Communication to the families -(1) establishing PoC (2) regular communciation of plans on patients state and state of play with goals of care reassessment (2) documenting feedback - patients and family preferences - care setting, treatment option, DNR, advance care planning (3) on transition to end of life phase - ascertaining as soon as possible patient wishes on place of death and transiting family to bereavement care plan.C Interventions - specific interventions should be named , namely pain and dyspnea management, cardiopulmonary resuscitation, nutrition and hydration, terminal sedation, specific life sustaining treatment (e.g. ECMO).Onlty after this, discussion on euthanasia can be led. The article clearly misses this very important structural parts.
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Pan, H., Shi, W., Zhou, Q. *et al.* Palliative Care in the Intensive Care Unit: Not Just End-of-life Care. *Intensive Care Res* **3**, 77–82 (2023). https://doi.org/10.1007/s44231-022-00009-0
National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care, 2018. Available online: https://www.nationalcoalitionhpc.org/ncp

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)

Comment [TW4]: What if patient is in the state when he is unable to express his preferences?The families/ surrogates/ authorised persons roles shoiuld be indicated - with consideration of earlier expressed patient preferences

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)

Comment [TW5]: Here the emphasis should be done that transition to End of Life care is exactly based on this principle - the moment when life sustaining treatment prevents patient from dying with dignity and does not bring any curative value, the compliance with this principle switches on end of life / PC phase.

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)

Comment [TW6]: Should also incorporate the opportunity for patient/family follow their own preferences - highly interceptible with autonomy principle. The role of physician is to inform of all options; the choice is of the patient.

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)

Comment [TW7]: Pp 2.1-2.4 are very well written but should be put into general framework on decision making depending on the model of PC in ICU. See above

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)

Comment [TW8]: It would be good to insert evidence based facts on quality indicators of such support -see National Consensus Domains on Palliative Care - physical, psychological, spiritual, social aspects, care in end of life, structure of care , communication

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)

Comment [TW9]: This part is also very well written, however should be logically incorporated in the structure. As mentioned, after decision paradigm and before switching to dilemmas surrounding euthanasia it is essential to discuss specific PC interventions=specific symptoms management as result of the decision making process (finally, this is within the title and objective of the article).see above what specific symptoms are to be discussed. Please consider that IAHPC official position is that no country or state should consider legalizing euthanasia or physician-assisted suicide until it ensures universal access to both PC services and appropriate medications!Therefore discussion of this topic is possible only after illustration of the measures taking as a result of decision making process.
Reference:'International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide,' Journal of Palliative Medicine, 2017;20(1):1-7.

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.

Comment [TW10]: Again, clear evidence base should be put to illustrate IAHPC concept - saying that normally, access to PC interventions at individual, system and multilevel, improving psychological spiritual and physical outcomes.
Reference:
Ito, K., George, N., Wilson, J. *et al.* Primary palliative care recommendations for critical care clinicians. *j intensive care* **10**, 20 (2022). https://doi.org/10.1186/s40560-022-00612-9

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

Comment [TW11]: Conclusion should be fully rewritten in lieu of the proposed (implied by the article title and objective) structure. It should touch the dicision making process illustrating in can be effective in all 3 models AND leading to effective PC interventions, both general and specific. The respective communication of goals of care to families strategy is chosen depending on the model/stage(key aspects to be always covered mentioned). In this way, the article will meet the initially stated objectives of the review.

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 acceptation, 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.

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