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II Forum of the “End of Life Study Group of the Southern Cone of America”: palliative care definitions, recommendations and integrated actions for intensive care and pediatric intensive care units

II Fórum do “Grupo de Estudos do Fim da Vida do Cone Sul”: definições, recomendações e ações integradas para cuidados paliativos na unidade de terapia intensiva de adultos e pediátrica

ABSTRACT

Palliative care is aimed to improve the quality of life of both patients and their family members during the course of life-threatening diseases through the prevention, early identification and treatment of the symptoms of physical, psychological, spiritual and social suffering. Palliative care should be provided to every critically ill patient; this requirement renders the training of intensive care practitioners and education initiatives fundamental.

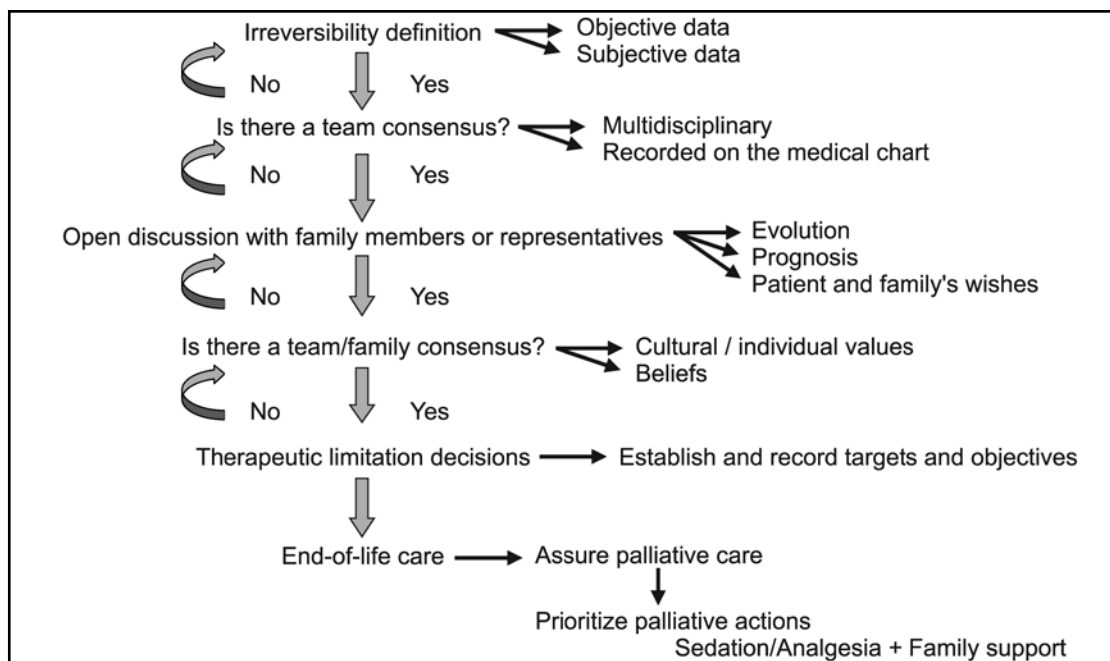
Continuing the Technical Council on End of Life and Palliative Care of the Brazilian Association of Intensive Medicine activities and considering previously established concepts, the II Forum of the End of Life Study Group of the Southern Cone of America was conducted in October 2010. The forum aimed to develop palliative care recommendations for critically ill patients.

Keywords: Hospice care; Intensive care units; Critical illness

INTRODUCTION

Although intensive care units (ICUs) are intended to manage potentially recoverable clinically unstable patients, many ICU patients eventually die from multiple organ failure. In addition, some patients with chronic-degenerative diseases are admitted to ICU due to acute intercurrents of their underlying diseases. This raises ethical issues related to both the appropriate care of terminal critically ill patients and to resource allocation policies. In 2009, aiming to optimize the care of terminal critically ill patients, members of the Argentinean, Uruguayan and Brazilian Intensive Care Associations developed an algorithm (Figure 1).⁽¹⁾

Although most patients and their family members say that interdisciplinary cooperation is essential for appropriate end-of-life care, treatment decisions are, mostly, made by physicians in a paternalist doctor-patient relationship model. Cultural aspects influence these decision-making processes.⁽²⁾ However, more debate on this subject is being stimulated, with growing importance attributed to the patient's autonomy, from a legal (Brazilian Civil Code, article 15), ethical⁽³⁾ or practical/cultural^(4,5) point of view; pre-established concepts therefore become dynamic. This statement is corroborated by the recent Brazilian



Are emphasized: ⇒ Support for the patient, their family members and the multidisciplinary team should be assured during the entire process
 ⇒ Any decision may be reevaluated at any time
 ⇒ The time required for patients and their family members to understand the process should be respected

Figure 1 – Suggestion of a decision-making process for critically ill patients with terminal disease.

Medical Ethics Code changes.⁽³⁾ Its last review states, as fundamental principle XXI, “*For professional decision-making processes, respecting his/her own dictates of conscience and legal injunctions, the physician shall accept the patient’s expressed diagnostic and therapeutic choices, since appropriate to the case and scientifically acknowledged,*” and principle XXII: “*In irreversible and terminal circumstances, the doctor should refrain from conducting unnecessary diagnostic and therapeutic measures, and provide every appropriate palliative care to his/her patients.*” Additionally, in chapter V, with respect to the medical relationship with patients and family members, Article 41 says that a doctor should not “*Abbreviate the patient’s life, even if requested by the patient him/herself or his/her legal representative,*” adding, “*In cases of incurable and terminal disease, the doctor should provide all available palliative care, and refrain from useless or obstinate diagnostic or therapeutic measures, always considering the expressed patient’s will or, if incapable, his/her legal representative’s.*”⁽³⁾ Article 15 of the new Brazilian Civil Code states that “*nobody can be constrained to undergo to life-threatening medical therapy or surgical intervention.*”

As a consequence, it is clear that physicians must inform their patients of treatment risks and of their disease course and consequences. Therefore, the patient is entitled to refuse a treatment, choosing the risk of dying from the disease instead of the risk of dying from the therapy.

There is evidence that the way in which family members are given information about ICU end-of-life conditions influences decision-making, satisfaction, conflict resolution, and family members’ health for up to 90 days after the patient’s death.⁽⁶⁻⁸⁾ For both ICS and non-ICU patients, communication about life-limiting diseases and therapy should not be associated with stress but with the reduction of the use of futile treatments and consequently improved quality of life and the conservation of health care resources.⁽⁹⁾

The World Health Organization describes palliative care as an approach aimed to improve the quality of life in patients with life-threatening conditions and for their family members through the early prevention and treatment of the symptoms of physical, psychological, spiritual and social suffering.⁽¹⁰⁾

The main treatment focus is the patient's quality of life. During the 1990s, palliative care focused only on end-of-life care. However, since 2002, this definition was extended, and the current trend is that all patients with life-threatening diseases receive early and integrated curative and palliative care, with its intensity customized according to the patients and family members' needs and wishes (Figure 2).⁽¹¹⁾ These modalities of care are not incompatible and may complement the patient and family members' care in life-threatening situations. The main question for the assisting team, the patient and family members is not "if" the patient is a candidate for palliative care but the treatment priority, either cure or comfort and quality of life. For this, both biological (disease severity, prognosis and available therapies) and ethical (e.g., autonomy and beneficence balance) issues, in addition to personal or cultural aspects (e.g., death-related values and preferences or willingness to participate in the decision-making process). In the ICU, the importance of the integration of palliative and curative care, starting from admission, is increasingly emphasized, aiming to provide better quality care.^(1,9-15) It should be emphasized that in outpatients, early palliative care integrated with disease-modifying therapies are associated both with better quality of life and higher survival rates.⁽¹⁶⁾

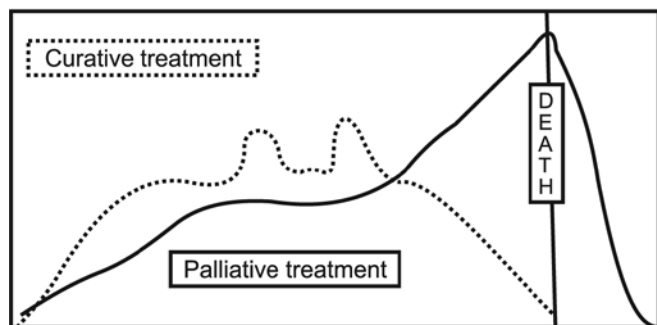


Figure 2 – Curative and palliative therapy phases.

Progressively more targets are being identified to reduce the ethical tensions associated with terminal illnesses, with special emphasis on comfort-aimed therapy. Promotion of better communication and ICU palliative care knowledge may prevent conflicts and improve therapy for critically ill patients. The respect of the patients' and families' social-cultural values, the evaluation of the ethical and practical

consequences of the refusal or suspension of futile therapies and the administration of sedation/analgesia and non-pharmacological therapies are advised to reduce the suffering of all parties.^(9,10,14,17) The ability and the education and training of the ICU palliative care professionals to reduce the length of stay and improve the quality of provided care are not doubted.⁽⁹⁾ Different models were proposed to improve ICU palliative care. Two of them should be emphasized: integrative, aimed to incorporate palliative care and interventions into the daily practice of intensive care practitioners, and consulting, involving consultations with palliative care teams and including these practices in regular ICU care.⁽¹⁵⁾ Again, we emphasize that care should be provided to every single ICU patient and his/her family members.

METHODOLOGY AND OBJECTIVE

Proceeding with the Technical Council of End of Life and Palliative Care of the Brazilian Association of Intensive Medicine (AMIB) plans and considering the previously established concepts and the need for the palliative care of all critically ill patients, the II Forum of the End of Life Study Group of the Southern Cone of America was conducted. This forum aimed to develop recommendations for palliative care for critically ill patients.

The Forum was held during the XV Brazilian Intensive Care Medicine Congress, on October 15, 2010, in Brasilia, DF, Brazil. Members of the Intensive Care Medicine Societies of Brazil (AMIB), Uruguay (SUMI) and Argentina (SATI) were involved. Participated: Alberto Deicas (physician/SUMI), Daniel Neves Forte (physician/AMIB), Jairo Otero (physician/AMIB), Jefferson Piva (physician/AMIB), Mônica Capalbo (physician/SATI), Newton Brandão (physician/AMIB), Lara Patrícia Kretzer (physician/AMIB), Nara Azeredo (nurse/AMIB), Patrícia Lago (physician/AMIB), Rachel Duarte Moritz (physician/AMIB), Raphaella Ropelato (psychologist/AMIB) and Raquel Pusch (psychologist/AMIB).

Based on the literature, the Forum members made recommendations and suggested integrated actions to provide palliative care for critically ill patients (Charts 1, 2 and 3). In addition, an ICU palliative care flowchart was proposed (Figure 3).

Chart 1 – Palliative care definitions

Definitions	
Palliative care	An approach aimed to improve the quality of life in patients and their family members during life-threatening illnesses by means of early prevention and the treatment of the symptoms of physical, psychological, spiritual and social suffering. This care should be provided to every patient, concomitantly with curative care, and its intensity should be customized to the patient and family members' needs and wishes and the progression of individual illnesses.
Palliative care in the intensive care environment	Care to be provided to every patient with a life threatening illness with symptoms that impair the quality of life.

Chart 2 – Recommendations for the palliative care of critically ill patients

Recommendations
<p>1. Palliative care should be provided to every patient admitted to an intensive care unit (ICU).</p> <p>2. Intensive care phases should be clarified:</p> <p>First phase – a condition for which the team anticipates better outcomes (recovery versus death or irreversibility). It is judged, respecting beneficence and autonomy, that priority should be given to cure/recovery-focused measures. Palliative care will be provided to relieve the discomfort caused by the illness and the intensive therapy. (Death unlikely).</p> <p>Second phase – a condition for which the team perceives a lack of or an insufficient response to the interventions, with a growing trend to a fatal outcome or irreversibility. A consensus is established among the team, patient and family members, and priority is given to the best possible quality of life; disease-modifying interventions can be provided when considered by the team and the patient/family to be proportional (Death anticipated within days, weeks or months).</p> <p>Third phase – a condition for which the team acknowledges the disease irreversibility and imminent death, accepting the fatal outcome. Palliative care is now the exclusive type of care provided, and all measures are aimed to improve the quality of life and the patient/family members' comfort. (Death anticipated within hours or days).</p> <p>3. In all phases, customized care should be provided, sufficient to assure physical, psychological/ emotional, and social-cultural care for the patient and their family, respecting bioethical, deontological and legal perspectives.</p> <p>4. In all phases, previous guidelines should be verified, as well as interdisciplinary diagnosis, prognosis and therapy evaluations, family members' understanding and the identification of potential conflicts.</p> <p>5. During the first phase, the care emphasis is placed on the support of the patient's vital systems and on full recovery, but the psychological/emotional comfort of the patient/family should never be neglected.</p> <p>6. During the second phase, emphasis is shifted to offering and maintaining a set of measures aimed to ensure the physical and psychological/emotional comfort of the patient/family.</p> <p>7. During the third phase, the emphasis is focused on offering physical and psychological/emotional comfort measures to the patient/family. The importance of the avoidance of starting and/or maintaining unnecessary and futile actions should be emphasized, privileging communication and better conditions for the family to stay with the patient and get prepared for death.</p> <p>8. During palliative care, preferential emphasis should be focused on the patient's welfare, especially regarding symptom control (pain, discomfort, dyspnea, dry mouth, noisy breathing, etc.).</p> <p>9. When crossing from the second to the third phase, it is crucial to provide assistance with the decision-making process to the patient and/or family to establish a consensus. According to the severity of the condition and the patient/family's preferences and values. The model could be either more paternalist or more participative. The development of communication skills is fundamental to providing this assistance.</p>

Chart 3 – Suggested actions for the implementation of palliative care in critical environments

Integrated palliative action suggestions
<ul style="list-style-type: none"> • Provide communication skills training • Differentiate between planned conferences (information and verification of the understanding of the diagnosis, prognosis and therapy; evaluation of potential conflicts/satisfaction/trust) and medical reports (daily information on the patient's development) • Verify and promote Previous Guidelines documentation • Check the parties' wishes regarding decision-making participation • Provide multidisciplinary meetings • Schedule reevaluation meetings for difficult cases • Develop protocols to handle conflicts • Establish protocols for quality assurance and compliance with palliative actions

Intensive care unit palliative care flowchart	
<p>For all phases, Prioritize</p> <ul style="list-style-type: none"> • Individual decision-making • Symptoms control (pain, discomfort, dyspnea, dry mouth, noisy breathing, etc.) 	<p>In all phases: Provide psychological and spiritual support</p> <ul style="list-style-type: none"> • Respect the existing beliefs/disbeliefs • Allow farewell ceremonies (appropriate to the environment) • Provide psychological support for: <ul style="list-style-type: none"> • Patient/family/team
<p>Phase II Death anticipated within days, weeks or months Associated with the pathophysiological condition, chronic technological and/or therapeutic dependence</p> <ul style="list-style-type: none"> • Stimulate empathic communication measures • Stimulate solidarity attitudes • Ease family members' presence • Evaluate the best site for providing palliative care • Allow ICU discharge • Establish priorities between palliative and/or curative cares • Prioritize the patient's comfort • Avoid futile interventions • Appropriate sedation-analgesia, ventilation support and nutrition measures • Appropriate monitoring and multi-professional care 	<p>Phase III Death anticipated within hours or days</p> <ul style="list-style-type: none"> • Intensify empathic communication measures • Intensify solidarity measures • Permanently ease family members' presence • Prioritize the patient's comfort • Remove futile therapies (nutrition, vasoactive drugs, dialysis methods, etc.) • Appropriate measures (sedation-analgesia, ventilation support, etc.) • Appropriate monitoring and multi-professional care

ICU – intensive care unit.

Figure 3 – Intensive care unit palliative care flowchart.

CONCLUSION

Palliative care should be included in good ICU practices, both for adults and for children. Aiming to improve the care of critically ill patients, recommendations focused on the qualifications of medical and multidisciplinary teams were developed.

RESUMO

Cuidado paliativo é uma forma de abordagem que visa a melhoria da qualidade de vida de pacientes e seus familiares que enfrentam doenças ameaçadoras à vida, através da prevenção, da identificação e do tratamento precoces dos sintomas de sofrimen-

to físico, psíquico, espiritual e social. Todo paciente criticamente enfermo deve receber cuidados paliativos desde a internação, o que torna de primordial importância a educação e o treinamento dos intensivistas para a implantação destes cuidados nas unidades de terapia intensiva, tanto para atendimento de adultos como pediátrico. Em continuidade aos planos da Câmara Técnica de Terminalidade e Cuidados Paliativos da Associação de Medicina Intensiva Brasileira e, levando em consideração o conceito previamente apontado, foi realizado em outubro de 2010, durante o Congresso Brasileiro de Terapia Intensiva, o IIº Fórum do “Grupo de Estudos do Fim da Vida do Cone Sul”, com o objetivo de elaborar recomendações pertinentes aos cuidados paliativos a serem prestados aos pacientes criticamente enfermos.

Descritores: Cuidados paliativos; Unidades de terapia intensiva; Estado terminal

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