

COMMENTARY

End of life care in Brazil: the long and winding road

Márcio Soares*^{1,2}

See related research by Fumis and Deheinzelin, <http://ccforum.com/content/14/6/R235>

Abstract

Disagreements between the perceptions of nurses and physicians regarding end-of-life (EOL) decisions are frequent. In a survey carried out in 13 Brazilian ICUs, Fumis and Deheinzelin reported that the majority of nurses, physicians and family members are in favor of limiting life-sustaining therapies in terminally ill patients and that such decisions should involve the ICU team, patients and family members. However, they also observed significant differences among the attitudes when faced with an incompetent patient. The present commentary evaluates the potential implications of the study results, contextualizing with the current scenario surrounding EOL care in Brazil.

In a recent issue of *Critical Care*, Fumis and Deheinzelin [1] evaluated the attitudes regarding end-of-life (EOL) decisions of physicians, nurses and family members in 13 Brazilian ICUs. Participants were asked whether mechanical ventilation should be withdrawn from two hypothetical terminally ill patients (one incompetent and another competent) and who should be involved in the decision-making process. The authors demonstrated that three-quarters of all groups of respondents agreed that withdrawal from mechanical ventilation should be considered for the competent patient. On the other hand, when faced with the clinical scenario of the incompetent patient, physicians were less likely to propose such a decision, in disagreement with nurses and family preferences. Additionally, most respondents shared the opinion that physicians, nurses, family members and patients themselves should necessarily be involved in the decision to withdraw life-sustaining therapies regardless of the scenario.

The results of the above mentioned study have potential implications, as disagreements between the perceptions of nurses and physicians regarding EOL decisions are common [2], and many ICU patients lack the capacity to participate in discussions and make decisions about their diagnosis, proposed treatments, and prognosis. When a patient is unable to make decisions, family members are automatically turned to as surrogates to decide and consent for advanced therapeutic interventions and for EOL decisions. However, family members are frequently unaware of patients' wishes and preferences in the case of critical illness. Gaps in communication, disregarding families' and patients' preferences, and disagreements in expectancies at the EOL are well-known sources of conflicts with devastating consequences for healthcare workers, patients and family members, such as burnout, depression, anxiety and post-traumatic stress disorders [3-6]. In addition, conflicts at the EOL are perceived as much more dangerous and severe in comparison to other conflicts [5]. Over the past years, we have learned that besides respectful, solidary and compassionate care of dying patients and their families, integration of palliative care and improvements in communication are key strategies to achieve and provide high-quality care at the EOL [5,7,8].

Although the debate surrounding EOL-related issues have progressed over the past decade, in Brazil the lack of legal regulation and consequently the concerns of prosecution still pose severe dilemmas and compromise the offering of appropriate care and management to dying patients. As acknowledged by the authors, caution is needed when interpreting the study results, as reported attitudes when faced with the two hypothetical scenarios may not reflect potential attitudes when managing patients in 'real life' in Brazilian ICUs. Firstly, reported rates of EOL decisions in Brazilian ICUs (up to 36% of dying patients) are much lower than those reported in Europe and the United States [9]. Second, do-not-resuscitate orders and withholding of organ support are more frequent than withdrawal. In addition, mechanical ventilation is very seldom removed [10]. Third, a paternalistic culture still prevails in Brazil (as in most Latin-American countries) and doctors are expected to choose 'the best option of care/treatment' for the patient.

*Correspondence: marciosaesms@yahoo.com.br

¹D'Or Institute for Research and Education, Rua Diniz Cordeiro, 30 - 3º andar; Rio de Janeiro - RJ; Brazil; CEP 22281-100

Full list of author information is available at the end of the article

Although informed consent is increasingly being adopted in Brazilian hospitals, advanced directives are not legally regulated in Brazil and registering of patients' preferences in medical charts is not a common practice, although it is now being more frequently performed. Finally, although a resolution of the Federal Council of Medicine (Resolução CFM N° 1805/2006. DOU, November 28, 2006) as well as the revised 2010 Brazilian Code of Medical Ethics determine that EOL decisions for incompetent terminally ill patients should necessarily be discussed with surrogates, family members are frequently still not involved in such decisions [11]. However, despite such limitations, the study of Fumis and Deheinzelin [1] provides valuable information to understand and improve decision-making processes at the EOL and to support the reformulation of competencies and skills expected to be achieved in training programs of intensivists to ensure that, in the near future, our ability to care for dying patients and their families will improve significantly in Brazil.

Abbreviations

EOL, end-of-life.

Competing interests

The author declares that they have no competing interests.

Acknowledgements

MS is supported in part by individual research grants from Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq).

Author details

¹D'Or Institute for Research and Education, Rua Diniz Cordeiro, 30 - 3° andar; Rio de Janeiro - RJ; Brazil; CEP 22281-100. ²Postgraduate Program, Instituto Nacional de Câncer, Rio de Janeiro, Brazil.

Published: 26 January 2011

References

1. Fumis RR, Deheinzelin D: **Respiratory support withdrawal in intensive care units: families, physicians and nurses views on two hypothetical clinical scenarios.** *Crit Care* 2010, **14**:R235.
2. Ferrand E, Lemaire F, Regnier B, Kuteifan K, Badet M, Asfar P, Jaber S, Chagnon JL, Renault A, Robert R, Pochard F, Herve C, Brun-Buisson C, Duvaldestin P;

- French RESENTI Group: **Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions.** *Am J Respir Crit Care Med* 2003, **167**:1310-1315.
3. Embríaco N, Azoulay E, Barrau K, Kentish N, Pochard F, Loundou A, Papazian L: **High level of burnout in intensivists: prevalence and associated factors.** *Am J Respir Crit Care Med* 2007, **175**:686-692.
 4. Poncet MC, Toullic P, Papazian L, Kentish-Barnes N, Timsit JF, Pochard F, Chevret S, Schlemmer B, Azoulay E: **Burnout syndrome in critical care nursing staff.** *Am J Respir Crit Care Med* 2007, **175**:698-704.
 5. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, Barnoud D, Bleichner G, Bruel C, Choukroun G, Curtis JR, Fieux F, Galliot R, Garrouste-Orgeas M, Georges H, Goldgran-Toledano D, Jourdain M, Loubert G, Reignier J, Sauti F, Souweine B, Vincent F, Barnes NK, Pochard F, Schlemmer B, Azoulay E: **A communication strategy and brochure for relatives of patients dying in the ICU.** *N Engl J Med* 2007, **356**:469-478.
 6. Azoulay E, Timsit JF, Sprung CL, Soares M, Rusinová K, Lafabrie A, Abizanda R, Svantesson M, Rubulotta F, Ricou B, Benoit D, Heyland D, Joynt G, François A, Azevedo-Maia P, Owczuk R, Benbenishty J, de Vita M, Valentin A, Ksomas A, Cohen S, Kompan L, Ho K, Abroug F, Kaarilola A, Gerlach H, Kyprianou T, Michalsen A, Chevret S, Schlemmer B; Conflicus Study Investigators and for the Ethics Section of the European Society of Intensive Care Medicine: **Prevalence and factors of intensive care unit conflicts: the conflicus study.** *Am J Respir Crit Care Med* 2009, **180**:853-860.
 7. Nelson JE, Bassett R, Boss RD, Brasel KJ, Campbell ML, Cortez TB, Curtis JR, Lustbader DR, Mulkerin C, Puntillo KA, Ray DE, Weissman DE; Improve Palliative Care in the Intensive Care Unit Project: **Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: a report from the IPAL-ICU Project (Improving Palliative Care in the ICU).** *Crit Care Med* 2010, **38**:1765-1772.
 8. Truog RD, Campbell ML, Curtis JR, Haas CE, Luce JM, Rubenfeld GD, Rushton CH, Kaufman DC; American Academy of Critical Care Medicine: **Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine.** *Crit Care Med* 2008, **36**:953-963.
 9. Soares M, Terzi RG, Piva JP: **End-of-life care in Brazil.** *Intensive Care Med* 2007, **33**:1014-1017.
 10. Lisboa T, Friedman G: **Forgoing life support in Intensive care units of South Brazil: the results of an ethical questionnaire.** *Rev Bras Ter Intens* 2005, **17**:15-22.
 11. Kipper DJ, Piva JP, Garcia PC, Einloft PR, Bruno F, Lago P, Rocha T, Schein AE, Fontela PS, Gava DH, Guerra L, Chemello K, Bittencourt R, Sudbrack S, Mulinari EF, Morais JF: **Evolution of the medical practices and modes of death on pediatric intensive care units in southern Brazil.** *Pediatr Crit Care Med* 2005, **6**:258-263.

doi:10.1186/cc9962

Cite this article as: Soares M: End of life care in Brazil: the long and winding road. *Critical Care* 2011, **15**:110.