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## End-of-life care in Brazilian ICUs is not just a legal issue. Adequate training and knowledge are essential to improve care

*Cuidados de final de vida nas UTIs brasileiras, certamente não é apenas uma questão legal. Treinamento e conhecimento adequados são essenciais para melhorar estes cuidados*

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Over the last three decades, end-of-life (EOL) decisions have become a frequent and challenging issue in intensive care units (ICUs) worldwide. Patients with severe, progressive and terminal diseases frequently require ICU admission. In these cases, the ICU staff is faced with medical, moral and ethical decisions involving (sometimes) opposed strategies, such as (a) pursuing an improbable cure that might just prolong the process of dying or (b) recognizing that the patient's condition is terminal and electing to provide palliative care while avoiding aggressive treatment. The EOL decision-making process and the consequent choice of strategy vary around the world, depending on several factors: cultural aspects, religious beliefs, legal burdens, ethical and moral values and medical knowledge regarding terminal diseases and palliative care.<sup>(1-5)</sup>

There are two common models for EOL decisions. The first is the shared model, in which the physicians (ICU staff) and patients (along with their families) achieve a consensus regarding the diagnosis, prognosis (whether the condition is terminal) and treatment to be delivered. In this model, the medical perspective (centered on principles of beneficence and non-maleficence) is counterbalanced with the desires and autonomy of the patient (or the family). Sometimes physicians express their concern regarding the final decision in this process because they feel obligated to deliver a treatment that they do not completely support, but even in this case, they provide the chosen treatment out of respect for the decision of the patient. A second model is the paternalistic model, in which the physicians (ICU staff) use their medical perspective to guide the patients (and family) toward the final decision. Obviously, this model carries an intrinsic and strong bias because the perspective of the physician might be influenced by factors that go beyond medical issues, such as cultural and moral values that might diverge from the values of the patient. In these situations, it is highly recommended that the medical perspective be shared with other members of the ICU staff, and in particular, the nurses should be included in the decision-making process.<sup>(1-3,6)</sup>

As a result of the cultural characteristics of certain countries (e.g., France, Italy, Brazil and India), the paternalistic approach has been the preferred model for EOL decisions.<sup>(1-3)</sup> The paternalistic model assumes that the physician will propose a decision considering the best interests of the patient.<sup>(6)</sup> However, Brazilian studies have demonstrated that this model, centered on the medical perspective, is far from what the paternalistic model actually entails. Because of legal fears, a lack of knowledge and a lack of training on the ethical aspects of EOL care, Brazilian physicians frequently provide full curative treatment to terminally ill patients up to the last moments of life, with do not resuscitate

orders (DNR) being the most frequent LSLT.<sup>(7-10)</sup> The patient's participation (or that of the family) and nurse's involvement in the Brazilian ICU EOL decision-making process are scarce, even in cases involving children with terminal diseases.<sup>(7-11)</sup> Legal fear has been cited as the most important reason for this peculiar Brazilian medical behavior regarding EOL decisions.<sup>(9,12)</sup>

Recently, Forte et al. published the results of a questionnaire submitted to 105 Brazilian ICU physicians selected from 11 university-affiliated ICUs, evaluating EOL decisions involving a fictitious, severely brain damaged patient.<sup>(13)</sup> The results reinforce two important points: a) legal fears still impact the EOL decisions of Brazilian physicians and b) ethical knowledge has a positive effect on the EOL decision-making process. Moreover, ICU physicians who regularly read about ethical issues were more likely to involve family and nurses in the EOL process, as well as assume pro-active decisions.<sup>(13)</sup> Additionally, many interventions, including ethics and palliative care consultations, intensive communication strategies, formal family conferences combined with the bereavement brochure were able to improve the quality of EOL care by reducing the length of stay and the use of inappropriate ICU resources, preventing conflicts and minimizing the psychological burden on family members.<sup>(14-17)</sup>

In this issue of RBTI an article by Santos and Bassit describes the expectations of families of patients staying for a long time in a hospital (+ 30 days), 17% of this time in the ICU. Although 53% of the patients had discussed with their families the possibility of limitation of life support, 76% of them had never discussed this issue with their physicians!<sup>(18)</sup> Even when patients and families are prone to discuss of limitation of life support in terminal and irreversible diseases, medical teams are failing to create appropriate conditions for a consensual decision.

Lawyers, judges, prosecutors and the Brazilian Medical Council have been involved in a long discussion regarding

the legal aspects of EOL decisions. Finally in 2010, two issues were finalized (at least for a while) regarding this discussion. First, a new Medical Ethics Code was created; this code repeatedly mentions the need and ethical duty of the physician to provide palliative care to patients suffering from incurable and terminal illness and to avoid therapeutic obstinacy by always taking into consideration the wishes of the patient or, failing that, his legal representative. Moreover, any breach of these guidelines represents a violation of the Brazilian Medical Ethics Code.<sup>(19)</sup> Second, in August 2010, the Brazilian Court rejected a motion proposing that physicians should not be allowed to provide life support limitations to terminally ill patient. The court decided that EOL decisions involving terminal ill patients are a medical matter and should not be treated as violations of the Brazilian Civil Code.

Abstracting the legal aspects of this complicated scenario, physicians are now able to concentrate their attention on providing the best care to their patients. There is no doubt that palliative care should be prioritized for the terminal ill patient above curative measures. However, Forte, Santos and Bassit, and from other groups have demonstrated that an emphasis should be made on medical education.<sup>(13-18)</sup> Physicians who have more extensive knowledge of ethical issues and who are well trained on the various aspects of EOL care are more likely to involve nurses and families in the EOL decision-making process; in addition, their decisions are more frequently in agreement with what they believe is in the best interest of their patients.<sup>(13)</sup> In other words, the lack of knowledge and training impairs the ability of physicians to provide the best care to ICU patients.

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