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EDITORIAL

End-of-life care in Brazilian pediatric intensive care units: challenges and opportunities[☆]

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Pediatric Critical Care Medicine has evolved drastically as a specialty since its inception more than five decades ago.[1] Advances in technology and medical interventions have led to a substantial reduction in mortality rates, which are now in the single digits; an achievement once unfathomable in the early days of our specialty.[1,2] However, with the high survival rates currently seen in pediatric intensive care units (PICUs), the focus of care has shifted from life preservation "at all cost" to greater consideration given towards end-of-life care (EOLC), when appropriate. In fact, over 50% of deaths in the PICU represent the endpoint of a predetermined EOLC strategy within the scope of palliative care.[3,4] This shift has created a dilemma for pediatric intensivists, who must balance the benefits of technological interventions (what *can* be done) with the ethical and moral quandaries of providing quality care (what *should* be done) to terminally ill children. The use of technological equipment has become increasingly ordinary in patients with irreversible and chronic illnesses, leading to a reliance on artificial life-sustaining methods that can adversely affect the patient's quality of life, their loved ones, and the healthcare team. As counterpart to these contemporary care strategies, it is morally and ethically permissible – and most would reason that it is in fact one's responsibility – to recommend and facilitate discontinuation of life-sustaining measures when the distress brought about by treatment outweighs its benefit to the child.[5]

The objective of pediatric EOLC in the PICU is to facilitate a humane, comfortable, and respectful death for children, despite the high technological complexity that is emblematic of these units. The American College of Critical Care Medicine recommends a systematic approach to EOLC through family-centered care, which recognizes the importance of the social structure within which patients are rooted and focuses on the patient and their family at all stages of the process, including the frequent and early consideration of palliative care.[6] To ensure that terminally ill patients receive dignified and compassionate care, the entire multidisciplinary care team must have the necessary training and resources, coupled with support from colleagues, the organization, and, more broadly, from regulatory and governmental agencies, and the general population.

The care of a terminally ill child, even under optimal circumstances, can create ethical disagreements between families and care team members, resulting in significant emotional and moral distress to all involved parties. To navigate these challenges, physicians use a range of inputs, including the existing medical evidence, personal and clinical experiences, and consultation with other subspecialists in attempts to accurately prognosticate expected clinical outcomes and risk of death.[7–9] This is especially important for patients with degenerative or chronic conditions, such as progressive neuromuscular disorders, end-stage organ failure requiring transplantation, and sequelae from severe prematurity, whose survival rates and quality of life have been, at times, difficult to predict.

In this issue of *Jornal de Pediatria,* Sousa and colleagues[10] shed light on the important topic of pediatric EOLC in Brazil. Their study was designed to explore the viewpoints of Brazilian PICU professionals on various aspects of EOLC, including decision-making, bereavement, and family support. More specifically, they used a questionnaire to assess the self-perceived confidence of healthcare professionals around EOLC and their comfort levels in conducting goals of care meetings with family members. Ultimately, the

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[☆] See paper by Sousa et al. in pages 37–43.

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study aimed to facilitate a nationwide discussion on pediatric palliative care practices.

The study was conducted with a sample of subjects working as healthcare professionals in three tertiary/quaternary units in Southern and Southeastern regions of Brazil: two general PICUs comprising a total of 114 beds between them (46 and 68 beds) supporting pediatric cardiac surgical and extracorporeal membrane oxygenation (ECMO) programs, and a seven-bed PICU in an oncologic hospital. All three PICUs also supported pediatric organ transplant programs. One of the general PICUs and the oncologic PICU were part of the public hospital system, while the other general unit was in a private hospital. Between September 25, 2019, and December 15, 2019, a questionnaire was disseminated via e-mail to 626 professionals working in the three PICUs: 405 nurses and nursing technicians (65%), 156 physicians (25%), 40 physiotherapists (6%), and 25 allied healthcare professionals (4%). The questionnaire was composed of 37 questions, including 34 multiple-choice and 3 open-ended queries. The questions were divided into various sections covering training and personal experiences (6 questions), team perception of ideal practice (6 questions), comfort level with decision making (3 questions), existing EOLC models (6 questions), family communication (4 questions), care after support limitation/withdrawal and death (4 questions), and demographic information (8 questions). Out of the 626 surveys distributed, 144 (23%) were successfully returned and 136 were analyzed after appropriately excluding 9 surveys for incomplete data or insufficient professional class representation. The final cohort included 48 physicians, 41 nurses, 28 nurse technicians, and 19 physiotherapists.

Unsurprisingly, physician confidence in utilizing an EOLC approach in their practice increased gradually with experience. While physicians were more than 3 times more likely to feel comfortable with EOLC conversations than other HCP, most did not feel technically prepared for these types of conversations. This is also not unexpected, since less than half of the participants reported having received any EOLC training, and the vast majority of those considered their training to have been insufficient. Only 6% of physicians and 14% of other professionals reported having received adequate training. These findings highlight a vicious cycle where the lack of EOLC training leads to a lack of comfort and its inadequate incorporation into clinical practice, which in turn leads to subject avoidance, poor role modeling, and diminished enthusiasm to develop opportunities for formal EOLC training.

Cultural and social constructs appear to be the most important barriers to the discussion and implementation of EOLC in Brazil. Family resistance was cited by 65% of subjects as the biggest obstacle to addressing EOLC, followed by resistance from other specialists (38%) which was particularly pervasive in the oncologic PICU (73%). From the available data, it is impossible to determine whether this perceived family resistance was the result of a well-thought decision on their part as opposed to a poorly informed choice from an inadequate approach by the care team, or worse, projection. Interestingly, 23% of the participants reported that "religious reasons" posed a barrier for EOLC. It is unfortunate here that the authors did not specify the proportion of religious objections on the part of the patient versus the provider, as the former might be worthy of consideration, yet the latter should have no place in the practice of pediatric critical care medicine. Importantly, 36% of physicians reported fear of legal consequences as a barrier to implementing EOLC, despite the fact that the Brazilian Federal Medical Council (CFM) and Brazilian legislation support the implementation of palliative care for irreversible life-threatening conditions and terminally ill patients, including withholding and withdrawal of life-sustaining treatments, when there is alignment between the family and the care team.[5,11] Fear of litigation and its legal consequences are likely also factors in the passive posture assumed by the physicians involved in elective discontinuation of life support. It is striking to note that, while more than half of physicians were agreeable to withholding initiation of mechanical ventilation, none would consider active withdrawal of respiratory support (palliative extubation). It should be noted that, from an ethical or legal perspective, there is no difference between withholding and withdrawing life support in the context of well-planned EOLC. Therefore, it is vital for healthcare professionals to acknowledge and address any personal biases or discomfort that could impact their decision-making process regarding EOLC, since, above all, compassionate care must be provided to prioritize the child's comfort and dignity.[12−14]

The study by Sousa and colleagues[10] has many strengths, including its relevant focus and multidisciplinary sample, but it also has important limitations that warrant further consideration. First, only less than one-quarter of the surveys submitted received a response. This resulted in a relatively small sample size that makes more sophisticated subgroup analyses prohibitive. In addition, there is concern that the very low response rate could have introduced selection bias since it is possible that subjects who are more comfortable discussing EOLC might have been more likely to respond. Second, the three PICUs that were part of the study have vastly different characteristics (i.e., large vs small, public vs private, general vs oncological). While heterogeneity within a representative sample generally is welcomed, the small number of PICUs in the study is insufficient to ensure diversity and limits the generalizability of their findings. Third, all PICUs in the study were located in the Southern and Southeastern regions of the country. Brazil is a large and culturally diverse nation with strong regional characteristics. Therefore, it should be understood that their findings are unlikely to represent the state of EOLC for the entire country. Fourth, by grouping the small oncological PICU with the two large general medical/surgical PICUs, the study obliterates any signal that could have been specific to the very peculiar ecosystem of a PICU dedicate to the care of children with cancer. As an example, the fact "resistance from the teams or specialists involved in the case" was noted as a barrier to EOLC by 76% of subjects working in the oncologic PICU but only in 43% and 26% of those working in the general PICUs leaves the reader wondering how many more striking differences between the two types of units are buried within their results. Lastly, as is customary in cross-sectional survey studies, the authors had to navigate the fine line between risking subject indifference and striving to obtain robust, detailed, and complete data from uncompensated volunteer subjects. It is understood that survey-based studies often cannot tell the whole story due to the practical limitations of this balance between questionnaire detail and subject engagement. However, in the current study, it appears that this limitation might have been self-inflicted since the authors indicate that this is only “a portion of the data obtained, to be complemented by future publications.” Assuming the remaining data is thematically related to EOLC practices among PICU professionals, we believe that a more definitive article covering the entire dataset would have been preferred.

Attitudes towards end-of-life in Brazilian PICUs appear to have evolved over the last several years, and most certainly since 2005 when we commented on the courageous reports by Lago and colleagues,[9] and Tonelli and colleagues,[15] and advanced that EOLC in Pediatrics was much more than a mere fight against entropy.[5] The *Journal de Pediatria* has recently published pioneering reports on pediatric palliative extubation practices in a Brazilian pediatric hospital[16] and on more comprehensive approaches to EOLC.[17] These articles may signal a welcome change in the ethical and moral zeitgeist surrounding end-of-life care in Brazil. However, despite progress in recent years, there is still much work to be done, as demonstrated by the significant gap between the level of comfort that Brazilian PICU professionals have with end-of-life issues and the delivery of optimal pediatric EOLC.

Effecting change toward optimal EOLC will require a multifaceted approach that involves all stakeholders. These include: a) compulsory education and training on the moral and ethical determinants of EOLC for children; b) alignment of PICU professionals and supporting specialists towards the common goal of optimal care; c), frequent team training through simulation and sessions dedicated to the art of leading difficult conversations and conflict resolution; d) development of clear institutional protocols for the conduct of EOLC; e) investment in the development of a dedicated palliative care service in every pediatric hospital to provide sustainable high-level support to PICU professionals involved in EOLC; f) the backing of key medical societies (e.g., Sociedade Brasileira de Pediatria, Associação de Medicina Intensiva Brasileira) in advancing the national standard of care; g) obtaining legislative clarity from governmental agencies and the federal medical council to assuage the palpable apprehension of PICU professionals regarding legal exposure during EOLC; and h) work towards shifting public perception and mistrust of healthcare practices surrounding EOLC.

The authors congratulate Sousa and colleagues[10] for this latest contribution to the Brazilian EOLC literature and thank them for stoking the fire on this important conversation.

Conflicts of interest

Dr. Rotta has received honoraria from Breas US for participating in its clinical advisory board, and royalties from Elsevier for editorial work. Dr. Alibrahim has nothing to declare.

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