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An Ethical Pathway to Quality of Life in Critically Ill Newborns

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Abstract

Advances in perinatology have permitted the survival of fragile neonates. Quality of life (QoL) has been considered a key element in medical decision-making. In this review we analyse the role of QoL regarding the decision of withholding or withdrawing of life-sustaining treatment (LST). The role of QoL is debated because of the conceptual difficulties it raises. The lack of consensus on its definition and the difficulties in measuring it objectively, mean that basing clinical decisions solely on QoL has some risks. To avoid a purely subjective assessment, the principle of totality, and the principle of therapeutic adequacy should be considered. In case of uncertain prognosis, some therapeutic persistence seems reasonable. If this does not benefit the clinical condition of the child, then it may be no longer appropriate to continue the LST in case of severe disabilities. QoL is essential in medical decision-making, but is insufficient as the only criterion.

Keywords: Quality of life; critically ill newborn; decision-making; ethics.

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