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TITOLO: *The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories*

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The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories

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Abstract

Background: With increasingly intensive treatments and population ageing, more people face complex treatment and care decisions. We explored patterns of the decision-making processes during critical care, and sources of conflict and resolution.

Methods: Ethnographic study in two Intensive Care Units (ICUs) in an inner city hospital comprising: non-participant observation of general care and decisions, followed by case studies where treatment limitation decisions, comfort care and/or end of life discussions were occurring. These involved: semi-structured interviews with consenting families, where possible, patients; direct observations of care; and review of medical records.

Results: Initial non-participant observation included daytime, evenings, nights and weekends. The cases were 16 patients with varied diagnoses, aged 19-87 years; 19 family members were interviewed, aged 30-73 years. Cases were observed for <1 to 156 days (median 22), depending on length of ICU admission. Decisions were made serially over the whole trajectory, usually several days or weeks. We identified four trajectories with distinct patterns: curative care from admission; oscillating curative and comfort care; shift to comfort care; comfort care from admission. Some families considered decision-making a negative concept and preferred uncertainty. Conflict occurred most commonly in the trajectories with oscillating curative and comfort care. Conflict also occurred inside clinical teams. Families were most often involved in decision-making regarding care outcomes and seemed to find it easier when patients switched definitively from curative to comfort care. We found eight categories of decision-making: three related to the care outcomes (aim, place, response to needs) and five to the care processes (resuscitation, decision support, medications/fluids, monitoring/interventions, other specialty involvement).

Conclusions: Decision-making in critical illness involves a web of discussions regarding the potential outcomes and processes of care, across the whole disease trajectory. When measures oscillate between curative and comfort there is greatest conflict. This suggests a need to support early communication, especially around values and preferred care outcomes, from which other decisions follow, including DNAR. Offering further support, possibly with expert palliative care, communication, and discussion of 'trial of treatment' may be beneficial at this time, rather than waiting until the 'end of life'.

Keywords: End-of-life care, Palliative care, Intensive care unit, Critical care, Decision-making, Uncertainty, Pathways, DNACPR

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