

Free papers 19–21 – Paediatrics

019 PARENTAL PERCEPTIONS OF END-OF-LIFE CARE ON PAEDIATRIC INTENSIVE CARE UNITS IN BRAZIL

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Objective Assess the perception of parents of patients who died in a Pediatric Intensive Care Unit (PICU) about the care given by health staff in the moments preceding death.

Methods Exploratory-descriptive study with a qualitative approach.

Settings Two PICU (Hospital Sao Lucas, and Hospital de Clinicas de Porto Alegre).

Subjects 15 parents of children who died from April to September 2008. Data collection was performed through three steps: (A) The researchers contacted the parents through a phone call, (B) At the hospital, the doctors who assisted the children clarified doubts about the therapy offered, results of exams and decisions regarding end of life, (C) Semistructured interview, recorded in audio, was carried out by researchers (not participated of the care of children). Data analysis was performed using the technique of thematic content analysis.

Results The analysis resulted in four categories: (A) the moment of death in the PICU; (B) talking with the attending physicians – possibility of understanding; (C) parental involvement in decision making in the PICU; (D) parental participation in research – moments of unburdening and the possibility of satisfaction. The results show that parents lack a peaceful environment where they can adequately carry out the good-byes at the time of death of their children. They emphasised the solidarity provided by the nursing staff at this point and the poor involvement of the medical team. The opportunity to revisit the process of their children's death was considered positive. Parents felt that they did not have an effective participation in the end of life decisions.

Conclusion Research shows that the difficulty of communication between health staff and parents is a factor that impacts negatively on the decision taking and grieving processes. Moreover, it stresses the importance for the parents to reassess the moment of the children's death with health professionals.