

28th International Conference on

PEDIATRIC NURSING & HEALTHCARE

September 04-05, 2017 | Edinburgh, Scotland

Relational practice, innovation and the ethics of hope: End of life care in the PICU/NICU

Philip Crowell^{1, 2}¹British Columbia Children's Hospital, Canada²University of British Columbia, Canada

Statement of the Problem: Where there is medical uncertainty, Pediatric Intensive Care Unit (PICU)/Neonatal Intensive Care Unit (NICU) have the capacity to send mixed messages regarding continuing intensive care or discontinuing that care. The capacity to innovate to deal with uncertainty within the pediatric and neonatal ICU has been a hallmark of the extraordinary care provided in these contexts. It has pushed the limits as to what is considered the norm, innovative and experimental. Key terms as futility which defines limits and innovative therapy expanding limits has caused a paradigm shift in an already fast changing clinical environment. The challenge is dealing with these two antithetical dynamics of setting limits and expanding them. Parental decision making may be pushing for everything to be done. The team may be asking why don't they get it and why are we continuing this care?

Methodology & Theoretical Orientation: Using an ethics and hermeneutical lens, we examine the nature of care at the edge of the beginning of the end of life care and the pre-eminent question what is in the best interests of the infant/child. Using in-depth interviews and surveys, we examine the context and conditions for these often conflictual encounters.

Findings: Deciphering parent's values, beliefs and even their spirituality is a means to balance the demands for maximizing the resources versus maximizing the quality of life and care. Utilizing our own qualitative studies and moral distress research the evidence points to a more nuanced approach.

Conclusion & Significance: The goal of the presentation is to understand the enactment of relational practice through communication utilizing the patient's and family's self-understanding and personal resources to navigate many of these uncertainties. The ethics of hope depicts hope as more than a coping mechanism; there are different modalities of hope which can be communicated without compromising truth.

pcrowell@cw.bc.ca

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