

A Meta-Ethnography and Theory of Parental Ethical Decision Making in the Neonatal Intensive Care Unit

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ABSTRACT

Objective: To synthesize the existing qualitative literature about parent ethical decision making in the neonatal intensive care unit (NICU) and to investigate the potential impact of culture on parents' decision making experiences.

Data Sources: PubMed, CINAHL plus, and PsychInfo using the search terms *parental decision making, culture, race, decision making, and parental decisions*.

Study Selection: Qualitative research studies investigating decision making for infants in the NICU from the parents' perspective were included. Studies involving older pediatric populations were excluded.

Data Extraction: Ten primary qualitative research articles were included. The primary author read all manuscripts and tabulated themes related to parents' ethical decision making.

Data Synthesis: Study findings were synthesized using meta-ethnography involving translating concepts of separate studies into one another, exploring contradictions, and organizing these concepts into new theories. Key themes included parent involvement in decision making, parental role, necessity of good information, need for communication, desire for hope and compassion conveyed by providers, decision making satisfaction, and trust in caregiving team. A preliminary theoretical framework of ethical parent decision making was modeled based on the proposed relationships between the themes.

Conclusions: Parent preferences for their involvement in decision making, their perceptions of communication with providers, and their relationships with providers are all important factors in the experience of making decisions for their infants. Needs of parents were the same regardless the ethnic or racial diversity of study participants.

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Approximately 12% of all births in the United States are preterm, occurring before 37 weeks of completed gestation (Martin et al., 2010). Prematurity is one of the leading causes of childhood death in the United States, and a significant cause of morbidity and poor neurodevelopmental outcomes in those who survive (Behrman & Butler, 2007; Field & Behrman, 2003; Martin et al.). Because parents are viewed as moral surrogates for their infants and because they and their infants must deal with the lifelong consequences of preterm birth, it is important for parents to be involved in ethical treatment decisions that are made for their critically ill neonates.

The American Academy of Pediatrics has emphasized the need for shared parent-physician decision making when considering initiation or withdrawal of intensive care for high risk newborns

(American Academy of Pediatrics Committee on Newborn and Fetus, 2007). Yet physicians who specialize in care of newborns in the neonatal intensive care unit (NICU) are often unprepared to engage parents in end-of-life decision making (Boss, Hutton, Donohue, & Arnold, 2009). Adding to the complexity of these discussions, it is not always clear what level of involvement parents wish to have in treatment decisions regarding their critically ill newborns. Many factors could potentially influence parents' desired participation as well as their satisfaction with decisions made for their infants.

Qualitative research approaches are often ideal for examining understudied phenomena in health care because they allow full exploration of the patients' experience of health care services. Synthesis of qualitative research is viewed as particularly

valuable in examining health care decisions, the decision making process, and the context in which patients view decision making (Hansen, Draborg, & Kristensen, 2011). Therefore, the purpose of this paper is to synthesize the existing qualitative literature about parental involvement in ethical decision making for critically ill neonates. Synthesis of qualitative findings can also be used for theory development by identifying common domains of interest across studies (Hansen et al.). The resulting theory can then suggest hypotheses for further testing. A secondary aim of this study is the development of a preliminary theoretical framework of parent ethical decision making.

Method

Search Strategy

A literature search was performed using the PubMed, CINAHL plus, and PsychInfo databases. The search terms utilized were *parental decision making, culture, race, decision making, and parental decisions*. Limits were set to include only research articles published from 1998 to 2011. Additional limits were English language publications and research involving human neonates (birth to 28 days).

Inclusion and Exclusion Criteria

Primary qualitative research articles were included in this synthesis if they addressed decision making for critically ill neonates from the parents' perspective. Articles involved decisions for infants who were being treated in a NICU or whose preterm birth was imminent and for whom resuscitation and treatment decisions were made at birth. Studies in which researchers investigated decision making in older pediatric populations or decisions of a less critical and non-ethical nature, such as immunization decisions, were excluded. Studies were excluded if they focused primarily on decision making from the health provider's perspective.

A table describing the sample, purpose, method, and study outcomes was created to summarize the studies (see Table 1). Each study was given a number. Meta-ethnography synthesis was used that involved translating concepts of separate studies into one another, exploring contradictions, and organizing these concepts into new theories (Barnett-Page & Thomas, 2009).

Quality Evaluation

An evaluation of the quality of the literature is a common step in synthesizing quantitative study

findings. However, Sandelowski, Docherty, and Emden (1997) in their seminal work on qualitative metasynthesis concluded that studies should not be excluded from a review based on quality, but that those individuals synthesizing the literature should use quality criteria general enough to be applied to any qualitative study. Therefore, seven criteria suggested by Kitto, Chesters, and Grbich (2008) were used for assessing qualitative research in this synthesis: (a) clarification refers to a statement about the aims or research question; (b) justification is an explanation of why qualitative approach was the best for addressing the study aims/question; (c) procedural rigor is a statement about data collection and analysis methods; (d) representativeness refers to the sampling techniques used to address the question; (e) interpretation is a conceptual discussion about the results and their linkage to existing or new theory; (f) reflexivity is a statement of the effect of the data on the investigator's views; and (g) transferability is the evaluation of the extent to which findings can be applied to similar contexts or to policy or practice. Two authors reviewed the selected articles independently regarding these criteria and then discussed any conflicts to reach consensus on whether the criterion was present in a particular article.

Method of Synthesis

Meta-ethnography was the method of synthesis used in this review. This method involves the translation of concepts of separate studies into one another, exploring contradictions, and organizing this into new theories (Barnett-Page & Thomas, 2009). The selected articles were reviewed in detail for themes that related to parents' experiences and thoughts on treatment decision making for their critically ill newborn. Decision making themes from each article were entered into a chart, and similar themes collapsed for brevity and simplicity. Quotes from the original publications are provided to illustrate the various aspects of these themes in the following sections. One author created the initial themes that were refined after discussion with a second author who reviewed all articles and the initial themes.

Findings

The searches returned 776 citations, and after a review of their abstracts, only 21 articles potentially met the inclusion criteria. These articles were reviewed in detail and 11 additional studies were excluded. A total of 10 qualitative articles met the inclusion criteria of this study. Tables 1 and 2

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