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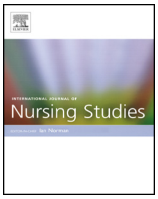

Review

Parental decision-making for medically complex infants and children: An integrated literature review

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ABSTRACT

Background: Many children with life-threatening conditions who would have died at birth are now surviving months to years longer than previously expected. Understanding how parents make decisions is necessary to prevent parental regret about decision-making, which can lead to psychological distress, decreased physical health, and decreased quality of life for the parents.

Objective: The aim of this integrated literature review was to describe possible factors that affect parental decision-making for medically complex children. The critical decisions included continuation or termination of a high-risk pregnancy, initiation of life-sustaining treatments such as resuscitation, complex cardiothoracic surgery, use of experimental treatments, end-of-life care, and limitation of care or withdrawal of support.

Design: PubMed, Cumulative Index of Nursing and Allied Health Literature, and PsycINFO were searched using the combined key terms ‘parents and decision-making’ to obtain English language publications from 2000 to June 2013.

Results: The findings from each of the 31 articles retained were recorded. The strengths of the empirical research reviewed are that decisions about initiating life support and withdrawing life support have received significant attention. Researchers have explored how many different factors impact decision-making and have used multiple different research designs and data collection methods to explore the decision-making process. These initial studies lay the foundation for future research and have provided insight into parental decision-making during times of crisis.

Conclusions: Studies must begin to include both parents and providers so that researchers can evaluate how decisions are made for individual children with complex chronic conditions to understand the dynamics between parents and parent–provider relationships. The majority of studies focused on one homogenous diagnostic group of premature infants and children with complex congenital heart disease. Thus comparisons across other child illness categories cannot be made. Most studies also used cross-sectional and/or retrospective research designs, which led to researchers and clinicians having limited understanding of how factors change over time for parents.

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What is already known about the topic?

- The parental role in decision-making has changed over the past decade giving parents more autonomy about how they personally believe their child should be treated.

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- Parental participation in medical decisions may lead to additional anxiety and stress, when the parents are already enduring physical and emotional stress watching their child battle a life-threatening condition and complications associated with the disease.
- The importance of understanding how and why parents choose specific treatments is increasingly relevant given the advances in technology and experimental therapies. How making decisions effects parental outcomes in the long-term remains unknown.

What this paper adds

- The results of the integrated review suggest that parental decision-making for children with medically complex conditions is impacted by a range of factors including the type and content of information provided to them as well as the information they sought, the seriousness of the child's illness, whether other treatment options exist, what is best for the child, religiosity and spirituality, parental factors, and support.
- This study identifies gaps within our understanding of factors that effect parental decision-making and suggest the next steps that need to be undertaken by researchers.
- Future research needs to focus on how to understand parental decision-making over the entire course of life, not only at points where parents are choosing between life or death of their child.

1. Introduction

Many children with medically complex conditions who would have died at birth are now surviving months to years longer than previously expected. The initial life-threatening condition (e.g., extreme prematurity, metabolic disease, hypoxic–ischemic encephalopathy, cardiac defect) and the therapies usually lead to a medically complex child (Simon et al., 2010). Medically complex children have chronic complex conditions (e.g., cardiovascular disease, congenital abnormalities), potential dependence on technology (e.g., tracheostomy, cerebral spinal fluid shunts), frequent inpatient admissions, parental administration of multiple medications, multiple specialists involved in care (Srivastava et al., 2005), and potentially an early death (Morris, 2009; Ortenstrand et al., 2010). Decision-making for medically complex children begins at diagnosis and continues throughout the child's life with each prior decision effecting the next decision (Toebbe et al., 2012).

Decision-making for medically complex children may begin prenatally when fetal diagnostic and imaging studies provide information about a possible life-threatening condition that may elicit making a choice between whether to terminate or continue a pregnancy (Rempel et al., 2004). For others, the decision-making process does not begin until birth or at the time of a later diagnosis when it must be decided whether to once again initiate care that is life-sustaining and curative or opt for therapies that focus on alleviating distressing symptoms that are designated as palliative care (Grobman et al., 2010). Parents and healthcare providers (HCPs) of medically complex children also need to determine how aggressively to pursue potential therapies including both standard and experimental therapies. All decisions are complex and challenging for parents because some of the therapies inflict pain and shorten the duration of the child's life (Sharman et al., 2005), all of which can profoundly impact parents and health care system resources (Michelson et al., 2009). In essence, the main decisions for medically complex children are often a matter of life or death, depending on which option is chosen.

Regardless of the type of decision, parents work with HCPs to determine the optimal choice for the child. HCPs generally are the first to tell the parents that their child has a life-threatening illness. Parental interactions with HCPs can range from limited information exchange to heavy reliance on HCPs information and advice in the decision-making process. Parents are reluctant for many reasons to accept a diagnosis or complication resulting from a life-threatening illness for their child (Giannini et al., 2008), but when parents and HCPs have an incongruent evaluation of the 'best treatment' for the child (usually in the case of neurological injury) (Verhagen et al., 2009), current customs, personal preferences and resources, and legal precedence may become central to decision-making about initiating life-support or withdrawing life-support measures.

Whether parents or HCPs are primarily responsible for initiating life-support or withdrawal of life-support measures in a critical care setting varies significantly. For example in many of the Pacific Rim countries (e.g., Hong Kong, Singapore, Malaysia, Japan, and Australia) the final decision-makers when parents and HCPs do not agree on the appropriate medical interventions for a child, the physicians report they have the final say in treatment decisions (Martinez et al., 2005). In Northern/Western European countries, it is also custom to rely heavily on physicians to be the decision-makers when children are critically ill or have cancer; parents are informed of the decision and generally agreeing with the decision (Devictor and Latour, 2011). In Turkey, physicians often determine the type of treatments, where the treatments are delivered, and the healthcare team for children undergoing cancer treatment (Kilicarslan-Toruner and Akgun-Citak, 2013). For the most part, medical judgment of long-term outcomes impacts these difficult decisions, but physicians in some countries (e.g., Malaysia, Singapore) must also consider the financial burden that will be assumed by the parents because of the medical care (Martinez et al., 2005). In other countries, the medical cost is deferred to government agencies, insurances companies, or other entities. The predominate decision maker and financial constraints can effect the decisions made for critically ill children.

A current legal case in the United States illustrates some of the complexities of decision-making for children. The mother of a child declared brain dead has taken legal action (Winkfield vs. Children's Hospital Oakland) against the hospital caring for her child prohibiting the physicians from removing the child from the ventilator. The child was originally admitted to the hospital to undergo a complex adenotonsillectomy, uvulopalatopharyngoplasty

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