Decision-Making For Infants with Complex Life-Threatening Conditions

Abstract

Infants with life-threatening conditions who earlier would have died in the first months of life are now receiving highly complex treatments designed to cure the condition or prolong life. However, these treatments have uncertain outcomes, the infants are at high risk for death, and if they live face a life-span of significant morbidity. Infants with these conditions experience an uncertain illness trajectory that typically involves multiple health crises requiring parents and health care providers to make critical decisions about the type and level of treatment. Decisions span the continuum from whether to initiate treatment, how to alter the treatment to respond to a medical crisis, whether to shift from aggressive curative care to symptom-focused palliative care, to whether to withdraw treatment. This pilot study will use a longitudinal, case study design to examine the trajectory of decision making for infants undergoing life-sustaining treatment for complex life-threatening conditions (CLTC). Three groups of infants with CLTCs who are at particularly high risk for death and significant life-span morbidity are the focus of this study: extremely preterm infants (≤ 26 weeks gestation), infants with complex cardiac anomalies, and infants with genetic diagnoses requiring a hematopoietic stem cell transplant (HSCT). Six cases will be enrolled in the pilot and will include the infant, parents, providers and the physical context of caregiving. The pilot will be used to demonstrate the feasibility of the study procedures and identify modifications necessary to the protocol for a larger study.