

DEVELOPMENT OF A MODEL OF INTEGRATED PEDIATRIC PALLIATIVE CARE

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Palliative care is defined as care given to minimize the physical and emotional distress that may be associated with intensive therapies for life threatening illnesses (IOM, 2003). Frequently palliative care is not offered in neonatal and pediatric acute care settings because it has been viewed as synonymous with end of life care which has a focus upon anticipated death. Physicians, nurses, families and other health care providers working with high risk neonates and acutely ill infants, children and adolescents do not want to give up intensive therapies and importantly they do not want to give up hope for a cure or recovery. A model that incorporates palliative care as an element of life sustaining therapies provided by the acute care health team will allow physicians, nurses and families to improve the care for children who survive as well as those that die. This model will conceptualize planning for palliative care needs as a natural component of health care delivery to infants or children with life threatening illness.

Despite the fact that 56% of child deaths occur in inpatient hospital settings (NCHS, 2001), there is paucity of research with a focus on the palliative care issues and needs of high risk neonates and acutely ill infants, children and adolescents. The aim of this study is to begin to develop a model of integrated pediatric palliative care through two pilot studies. The purpose of the first study is to identify characteristics of the population of infants and children who die in acute care settings. A five year, retrospective chart review of the decedent care data base at a large southeastern teaching hospital is currently underway. The results will include descriptive statistics regarding, age, diagnosis, length and number of hospital admissions, setting of death and infant, child and family demographic descriptors. The purpose of the second pilot study is to identify aids and barriers to the provision of palliative care in the pediatric acute care setting. A qualitative study using semi-structured interviews with physicians, nurses and social workers is being conducted to describe personal experiences with infants and children who have died.

The results of these pilot studies will inform a larger study regarding the trajectory of dying for acutely ill infants and children and the development of an integrated model of palliative care in the acute care setting.