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Integration of Palliative Care Practices into the Ongoing Care of Children with Cancer: Individualized Care Planning and Coordination

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> To cure sometimes, to relieve often, to comfort always – this is our work.
> —Author unknown

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Suffering is nearly universal in pediatric cancer patients and their families. Addressing this suffering is an ethical imperative. High-quality palliative care is now an expected standard during the treatment of children with life-threatening illnesses. An American Academy of Pediatrics policy statement recommends that "all general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children" [1]. The goal of palliative care is the best quality of life for patients and their families that is consistent with their values and priorities. Pediatric palliative medicine may be further defined as "the art and science of patient- and family-centered care aimed at enhancing quality of life, promoting healing and attending to suffering" [2]. Inherent in these definitions is the need to integrate quality palliative care into the mainstream of medical treatment of all children suffering from chronic, life-threatening, and life-limiting illnesses, regardless of the curative intent of therapy.

Improving the quality of palliative and end-of-life care through individualized care planning and coordination

Most parents of children with cancer have dual primary goals: a primary cancer-directed goal of cure and a primary comfort-related goal of lessening suffering [3]. Early introduction of palliative care principles and practices into their child's treatment is respectful and supportive of these goals. The individualized care planning and coordination (ICPC) model (Fig. 1) is designed to facilitate this integration [4]. Individualized care planning emphasizes the value of subjective experiences in the context of meaningful personal relationships and uses a patient- and family-centered approach to information delivery, needs assessment, and understanding of the patient's and family's illness experience. It aims to enhance communication about difficult issues by discerning patient and family values and priorities before critical decision points are reached. Application of the ICPC model helps patients, families, and their clinicians negotiate care options in the presence of uncertainty by assessing the patient's and family's understanding of prognosis, elucidating their goals of care, and allowing them to choose from available goal-directed treatment alternatives. A comprehensive, individualized care plan that balances medical and personal goals, based on the relationship that has been established and the treatment options chosen, can then be generated.

Individualized care coordination, the process of implementing the individualized care plan, is detailed here. The authors' purpose is to address specific clinical gaps in the care of children with cancer. They highlight the deficiencies in the current provision of care, identify the national standards of care, recommend specific processes that should be integrated into pediatric oncology to fulfill the national standards, and identify research and education needs. The specific individualized care coordination processes that are the subject of palliative and end-of-life care quality improvement efforts