



Palliative Care Policy Implications for Children with Special Needs

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Children with chronic debilitating diseases are living longer and challenging the development of policies that recognize the need for an increased focus on holistic models of health including improved quality of life and prevention of other health problems rather than the emphasis on tertiary care and life saving treatment. The policy challenges are particularly critical as hospice models of funding care are not appropriate because treatments do substantially extend life and life with these conditions is all that these children will know. The concept of palliative care, where the emphasis on quality of life accompanies treatment rather than replaces treatment, requires policies that support concurrent treatment funding mechanisms accompanied by quality of life support funding mechanisms.

Results of a pilot outcome evaluation of a pediatric palliative care program have important implications for policies that support funding for concurrent palliative care and treatment care. In 2001, Community PedsCare was initiated through various alliances of healthcare organizations throughout Northeast Florida to address the need for holistic care coordinated services for children with chronic illnesses. The primary approach of the Community PedsCare palliative care program is a multiple disciplinary approach with psychosocial interventions, child life specialist care, home health care, spiritual support, pain and symptom management and volunteer interventions that complement specialized medical care. Results showed decreases in hospital costs and utilization and improved quality of life for families with children with special health care needs. The results provide important insights for program and policy development as well as evaluation research design.

Learning Objectives:

1. Distinguish palliative care from hospice care
2. Describe approaches to measuring palliative care outcomes
3. Discuss implications of palliative care evaluation results for program and policy development